

## DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES

### COPR Alumni

#### CLASS OF 2011

- [Micah Berman](#) (Massachusetts)
- [Naomi Cottoms](#) (Arkansas)
- [Elmer R. Freeman](#) (Massachusetts)
- [Beth Furlong](#) (Nebraska)
- [Brent Jaquet](#) (Washington, DC)
- [Matthew Margo](#) (New York)
- [Anne Muñoz-Furlong](#) (Virginia)

#### Micah Berman

Term: 2008-2011



Mr. Micah Berman is an Assistant Professor at New England School of Law in Boston, where he teaches health law and related courses. He was previously the Executive Director of the Tobacco Public Policy Center (TPPC) at Capital University Law School in Columbus, Ohio, which provided technical and legal support to tobacco control advocates. Under Mr. Berman's leadership, the TPPC pursued innovative approaches to reducing tobacco-related disease, such as drafting tobacco-free policies for school districts, helping businesses implement the Ohio Smoke-Free Workplace Act, and collaborating with apartment associations to address drifting secondhand smoke in multi-unit housing.

As a law professor, Mr. Berman's research focuses on public health policy and health-related litigation, and he developed and taught a public health law course addressing tobacco, infectious diseases, bioterrorism, alcohol and drugs, medical trials, and nutrition.

Mr. Berman received a J.D. with distinction from Stanford Law School, where he was managing editor of the *Stanford Law Review*. He is married to Rachel Bloomekatz, a law clerk for the U.S. Court of Appeals for the Second Circuit.

#### Naomi Cottoms

Term: 2007-2011



Ms. Naomi Cottoms is the Director of the Tri County Rural Health Network, Inc. (TCRHN), a nonprofit, grassroots organization that works to improve access to health care in the underserved rural counties of Lee, Monroe, and Phillips in eastern Arkansas. TCRHN collaborates with community organizations, including the Phillips County Health and Human Services Department, the Eastern Arkansas Hospice Center, and the Fay Boozman College of Public Health of the University of Arkansas for Medical Sciences. TCRHN connects uninsured or underinsured disabled and elderly clients with available resources, including reduced-cost medicines.

One current TCRHN project, funded by the Robert Wood Johnson Foundation, is studying the value of using community outreach workers, or "community connectors," to direct uninsured and underinsured Arkansans toward home- and community-based care programs. By promoting early intervention, the community connectors help individuals get the services they need to stay at home while potentially saving the state substantial dollars on institutionalized care. Providing community-based services to the elderly and adults with physical disabilities is one-third the cost of placing them in a nursing home.

Ms. Cottoms is president of Walnut Street Works, Inc. (Common Stride), a nonprofit organization with programs that address health care, affordable housing, racial disparities, and community empowerment. She also volunteers with Habitat for Humanity and served as a founding board member of the Boys and Girls Club of Phillips County. Ms. Cottoms has coauthored two presentations for national conferences.

Ms. Cottoms earned a master's degree in human resource development from Webster University in St. Louis, Missouri. She has also received training in political leadership and the deliberative democracy process from the Kettering Foundation of Dayton, Ohio.

#### Elmer R. Freeman

Term: 2007-2011



Mr. Elmer Freeman is the Executive Director of the Center for Community Health Education Research and Service, Inc. (CCHERS), and an adjunct assistant professor and Director of Urban Health Programs and Policy for Bouvé College of Health Sciences at Northeastern



University. CCHERS is a network of 15 academic community health centers providing health care access for underserved patients in Boston. Prior to this, Mr. Freeman was Executive Director of the Whittier Street Health Center for 17 years. He is the co-chair of Critical MASS, a multi-organizational, multicultural, multi-community, statewide coalition to eliminate racial and ethnic health disparities in Massachusetts.

Mr. Freeman is a recognized expert in the implementation of models of community-based participatory research (CBPR) and served as such for the Agency for Healthcare Research and Quality Evidence Report No. 99, *Community-Based Participatory Research: Assessing the Evidence*, published in July 2004. He has coauthored a journal article on this topic, which was published in the *Journal of Urban Health* in November 2006. He is also actively involved in the development of CBPR partnerships between academic medical centers and the diverse communities of Boston. He is an advisory board member of the Tufts University Community Research Center and the Dana-Farber Cancer Institute Community Research Network, and he is a cofounder of the Community Health and Academic Medicine Partnership with Harvard Medical School and Brigham and Women's Hospital. Mr. Freeman is involved nationally with Community-Campus Partnerships for Health, the American Public Health Association, and the National Association of Community Health Centers.

Mr. Freeman has made more than 40 presentations at conferences and scientific meetings in the past seven years, including several keynotes. He is an accomplished facilitator with experience bringing consensus from groups with conflicting interests and serves as a consultant to schools and programs in public health in their efforts to promote community engagement and scholarship in research partnerships with communities.

Mr. Freeman received his M.S.W. from Boston College Graduate School for Social Work and is working toward a doctoral degree. He lives in the Jamaica Plain neighborhood of Boston with his wife of 30 years, Carlene, and their four-year-old grandson, Jakhari, who is their personal anti-aging agent.

### Beth Furlong

Term: 2007-2011



Dr. Beth Furlong is an associate professor at Creighton University's School of Nursing and a faculty associate in the university's Center for Health Policy and Ethics. In 2003, she received the Omicron Delta Kappa Teaching for Tomorrow Award from her students, and she was recognized with the Mary Lucretia Award for supporting women at the university and with two dean's awards for excellence.

Dr. Furlong has four decades of experience in community health nursing. She has presented at local, national, and international meetings and symposia, including several years at the conference of the national Association of Community Health Nurse Educators.

Dr. Furlong serves on the boards of the Visiting Nurse Association in Omaha and Seven Oaks Housing and is a member of the Advisory Council to the President of the University of Nebraska. She is a member of many professional associations in nursing, political science, and the law as well as social change organizations.

Her international experience includes working as a Peace Corps volunteer in India and Fulbright Fellowships in Jordan and Hungary. She has taught health ethics and related subjects to nurses and physicians in Azerbaijan, the Republic of Georgia, Lithuania, and Armenia.

Dr. Furlong is the recipient of an award for a "Decade of Outstanding Leadership and Service" from the Wellness Council of the Midlands. She also received the Elaine Osborne Jacobson Award for Women Working in Health Care Law from the Roscoe Pound Foundation, given to one law student nationally who demonstrates commitment to vulnerable populations.

Dr. Furlong has a Ph.D. in political science focusing on health policy from the University of Nebraska. Her dissertation discussed the early history of the National Institute of Nursing Research. Dr. Furlong also holds a J.D. from Creighton University and an R.N. from the Mercy School of Nursing. She lives in Omaha with her husband, a biochemist and microbiologist in the School of Medicine at the University of Nebraska.

### Brent Jaquet

Term: 2007-2011



Mr. Brent Jaquet is a Senior Vice President at Cavarocchi-Ruscio-Dennis (CRD) Associates in Washington, DC, managing programs in government relations, strategic planning, and public policy. Prior to his current position with CRD, he served as senior appropriations aide to Representative C.W. Bill Young of Florida. While working for Representative Young, Mr. Jaquet specialized in health and biomedicine across a wide spectrum of health policy and appropriations issues. His work on behalf of Chairman Young contributed to the enactment of the Stem Cell Therapeutic and Research Act of 2005, which reauthorized and expanded the nation's bone marrow registry program to include umbilical cord blood units.

In previous positions, Mr. Jaquet was a senior management official at NIH, where his experience included managing communications; science transfer; professional health education; planning efforts and information technology programs; and serving as Executive Secretary for the National Institute of Dental and Craniofacial Research (NIDCR) Board of Scientific Counselors, which manages the peer review process for the Institute's Intramural Research Program. He worked at the National Institute of Child Health and Human Development from 1981 to 1984 and NIDCR from 1984 until his retirement. Before joining the agency, Mr. Jaquet worked for the U.S. Department of Health and Human Services developing communications programs in the areas of health planning, professions, and facilities.

Mr. Jaquet was also a founding board member of the LAM Foundation, serving women with lymphangioliomyomatosis, a rare lung disease.

Mr. Jaquet attended graduate school in communications at the University of Maryland's College of Journalism in College Park following service in the Navy as a

journalist. He earned a B.A. in political science from Belmont Abbey College in North Carolina. He lives in Edgewater, Maryland, with his wife, who is a scientific program director, and he has three grown children and six grandchildren. He is also an artist whose depictions of the NIH campus have been published in calendars, note cards, and other formats.

## Matthew Margo

Term: 2007-2011



Mr. Matthew Margo is the Senior Vice President of Program Practices, New York, for the CBS Television Network. Mr. Margo's responsibilities include leading the department that determines and applies CBS Television Network's broadcast policies and guidelines for East Coast entertainment programming and all advertising and public service announcements (PSAs). He supervises the "CBS Cares" campaigns, which have won various media/entertainment industry and health industry awards, including the Paul Rogers Leadership Award. He executive produces the PSAs for CBS, featuring CBS stars discussing a wide variety of causes, including many health issues, such as HIV/AIDS, cancers, heart disease, and mental health.

Mr. Margo executive produced the first PSAs recorded by Nelson Mandela for the United States on the subject of tolerance. Mr. Margo supervises the award-winning CBSCares.tv Web site, for which he has interviewed medical and health experts on a variety of subjects, such as HIV/AIDS, women's heart disease, breast and colon cancer, depression, bipolar disorder, menopause, and osteoporosis. In the case of HIV, his interviewees included Dr. Anthony Fauci, head of the National Institute of Allergy and Infectious Diseases. Mr. Margo also initiated and executive produces the "CBS Cares" radio show, distributed nationally and hosted by Mr. Charles Osgood. Mr. Margo practiced international business law and litigation before joining CBS, where he started as a Senior Attorney for Finance, Law, and

Corporate Development.

Mr. Margo served on the advisory boards of the Harvard School of Public Health Center for Communications, the *Harvard Public Health Review*, and the Better Business Bureau Foundation, including the Philanthropic Advisory Service. He is a former pilot; was a global and U.S. judge for the British Airways Tourism for Tomorrow Awards program, which recognizes environmentally friendly tourism (eco-tourism); and served as a judge for the International Emmy Awards. He is a graduate of Harvard Law School and lives in Manhattan.

## Anne Muñoz-Furlong

Term: 2007-2011



Ms. Anne Muñoz-Furlong is the CEO of the Food Allergy and Anaphylaxis Network (FAAN), which she founded 15 years ago after her daughter was diagnosed with food allergies. FAAN currently has 30,000 members who work to increase public awareness, provide education, advocate, and advance research on behalf of the 12 million Americans with food allergies. Ms. Muñoz-Furlong also founded the Food Allergy and Anaphylaxis Alliance, made up of lay organizations in nine countries, which works to implement public policy changes on universal issues, such as food labeling and the availability of epinephrine.

Ms. Muñoz-Furlong is a member of the American Academy of Allergy, Asthma, and Immunology and serves on several committees, including Adverse Reactions to Foods, Anaphylaxis, and Public Education. She works closely with the American College of Allergy, Asthma, and Immunology and serves on their Adverse Reactions to Foods Committee. She has worked with many groups in the food and pharmaceutical industries, and her organization cosponsored the NIH/FAAN Anaphylaxis Symposium, the first multidisciplinary meetings to discuss a universally agreed upon definition for anaphylaxis, a life-threatening reaction. The findings were published in a peer-reviewed journal and will result in patients around the world experiencing more consistent care.

She worked with the food industry's Food Allergy Issues Alliance and the U.S. Food and Drug Administration to develop allergen labeling guidelines, which became the basis of the Food Allergen Labeling and Consumer Protection Act of 2004. She also served on the National Institute of Allergy and Infectious Diseases Advisory Council, where she provided input for grant review.

Ms. Muñoz-Furlong contributes to FAAN's monthly newsletter, *Food Allergy News*, and gives presentations to groups and committees. She has written book chapters and coauthored scientific studies as well as publications for families coping with food allergies.

Ms. Muñoz-Furlong received a degree in business administration and journalism from George Mason University. She is bilingual—Spanish is her first language—and she lives in Fairfax, Virginia, with her husband, Terry Furlong.

National Institutes of Health (NIH), 9000 Rockville Pike, Bethesda, Maryland 20892

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DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES

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FRIDAY  
MAY 6, 2011

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PRESENT:

STEPHANIE AARONSON

DONNA APPELL

SUSAN WOOLEY, PH.D., CHES

LORA CHURCH

MALE FOUR

MICAH BERMAN

J.D.

JOHN

GARDINER LAPHAM

AMYE LEONG

CARLOS PAVÃO, M.P.A.

GREG NYCZ

EILEEN NAUGHTON

LYNN OLSEN

FEMALE ONE

MALE ONE

FRANCIS S. COLLINS, M.D., PH.D.

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1 FEMALE ONE: Good afternoon,  
2 everyone, welcome back. I just want to let you  
3 know that we're--I'm entering the formal  
4 session of the meeting, so this is a public  
5 session. This meeting is open to the public,  
6 including members of the press and it's being  
7 webcast globally. We're also transcribing the  
8 meeting, so please speak into your microphones  
9 when making questions and comments. All  
10 meeting materials and handouts that are related  
11 to the business of COPR, they're in your  
12 folders. You can leave those here and we'll  
13 FEDEX them back to you after the meeting, so  
14 you don't have to worry about that. John, did  
15 you have any announcements?

16 JOHN: Welcome, everyone. And  
17 I'll turn it over Micah Berman.

18 FEMALE ONE: Micah.

19 MICAH BERMAN: Thank you.  
20 Welcome everyone. Welcome Dr. Collins and Dr.  
21 Tabak. I'm Micah Berman. I'm the co-chair of  
22 the agenda working group for COPR and Carlos

1 Pavão to my right is the other co-chair. We  
2 wanted to start out today by just going around  
3 the room and having everyone give a  
4 reintroduction of who they are and where  
5 they're from and also just brief comments, if  
6 they have some, on updates of issues of  
7 interest (unintelligible) that they've been  
8 working on over the last six months. So,  
9 Donna, I will start with you and we'll go  
10 around.

11 DONNA APPELL: Thank you, Micah.  
12 So my name is Donna Appell and I am very  
13 excited to be here. I am the founder of the  
14 Hermansky-Pudlak Syndrome Network. I'm on the  
15 public advisory roundtable for the American  
16 Thoracic Society and as well as a number of  
17 national boards. Since I was here last, I was  
18 very excited to bring the NIH doctors together  
19 with some communities, for instance, the  
20 Hermansky-Pudlak Syndrome Group, please the  
21 Albinism Community. And for the very, very  
22 first time, I arranged and hosted a meeting for

1 the Chediak-Higashi people, since they never  
2 had a meeting. So it was their very first  
3 conference and I was delighted to be able to  
4 mentor that group and assist the NIH doctors to  
5 meet the Chediak-Higashi families for the first  
6 time ever.

7           The meetings were valuable enough  
8 to our Japanese constituents and our Japanese  
9 group, that they took two days to travel  
10 because the trains were down. It was the week  
11 after the tsunami but they were so anxious to  
12 come and be with the NIH doctors that they  
13 actually came in larger number this year than  
14 last, so it was really exciting. The other  
15 part of that was I was able to bring up nurses  
16 from Puerto Rico to work on curriculum to help,  
17 Hermansky-Pudlak Syndrome happens to be very  
18 prevalent among Puerto Rican people, carried 1  
19 in 21 in many regions, so it's maybe their  
20 number one genetic disorder.

21           And I brought up nurses to create  
22 curriculum to teach nursing in Puerto Rico

1 about the standard of care for this group of  
2 people. And talk about, also, tissue  
3 procurement and hiring companies to help us  
4 with bringing tissue to the NIH, so that was  
5 part of it. The other thing that I've been  
6 working on is I'm working on the transitioning  
7 of complex medical issues with aging up kids,  
8 so children with complex genetic disorders are  
9 getting the value of great medical attention,  
10 so they're surviving to adulthood. And adult  
11 medicine is having a little trouble, I think,  
12 perhaps taking these kids on because they  
13 haven't been that familiar with these  
14 disorders.

15           So I looked at something and  
16 created an enhanced healthcare proxy, whereby  
17 people can actually not wait for their lack of  
18 capacity but have somebody on their team to  
19 help them in their healthcare decisions without  
20 having to go for guardianship because that's an  
21 access problem because you have to pay a  
22 lawyer. So I was able to get a bill number and

1 get it through, get it started in the House and  
2 Senate in New York and I've been kind of  
3 working on that.

4           And we recently had the honor to  
5 help the children in here at NIH by going to  
6 their gala. And myself and my daughter and  
7 worked at the (word?) chapter of On Forces  
8 Communications and Electronics Association to  
9 help raise money for the Children's Inn. So we  
10 really--it was a great opportunity for us to  
11 say thank you to the Children's Inn and the NIH  
12 for all they have given us for our lives. So  
13 we were pleased and honored to be able to do  
14 that. Thank you.

15           GARDINER LAPHAM: Hi. I'm Gardiner  
16 Lapham and I represent two groups. I just  
17 thought I'd briefly give you two tidbits of  
18 what these groups have been working on. One is  
19 Whitman-Walker Health and it's a local  
20 healthcare center, has an expertise in HIV AIDS  
21 and LGBT care. We were very pleased to see the  
22 release of the recent IOM report around LGBT

1     disparities and LGBT health.  And one sort of  
2     example of an issue that we hope will bring  
3     more light to and more research on is anal  
4     cancer in gay men, the instance is actually  
5     higher than cervical cancer in women but there  
6     are just no guidelines around the diagnosis of  
7     this.

8                     So this is one of the areas that  
9     we hope to see more research in.  And the other  
10    is just that Whitman-Walker has ongoing  
11    relationships with NIH and we participate in a  
12    number of research studies and one is a DC AIDS  
13    cohort study.  And I just think health centers  
14    have a great opportunity to do research.  And  
15    especially with healthcare reform coming,  
16    health centers will see lots more patients  
17    instead of just their good partnerships.  The  
18    other group I work with is Citizens United for  
19    Research in Epilepsy Cure, also an IMOM report.

20                    We--HHS, Dr. Koe was instrumental  
21    in helping us to have (unintelligible) look at  
22    epilepsy.  So there are a number of lay groups

1 and professional groups that have funded this  
2 study and it'll be released later this year.  
3 It's looking at the public health dimensions of  
4 epilepsy. So we're very excited that that'll  
5 lead to more research on epilepsy. And then  
6 lastly, I just wanted to mention that this is  
7 the issue probably closest to my heart because  
8 this is what we lost our son from, sudden  
9 unexplained death in epilepsy, just last year.  
10 And INDS released an RFA to establish a center  
11 without walls around this issue.

12           And I was part of that process.  
13 Very collaborative, lots and lots of  
14 investigators interested in this topic now, so  
15 it's exciting to see where that is going. I'm  
16 really happy NIH is supporting those efforts.  
17 Thanks.

18           GREG NYCZ: Hi. I'm Greg Nycz,  
19 director of Family Health Center, a federally  
20 and state funded health center that works in  
21 partnership with Marshfield Clinic up in  
22 northern Wisconsin. And I had an opportunity,

1 working with the Rural Assistance Center, which  
2 is really the place to go for information on  
3 rural health and human services issues. And  
4 participating with them, one of the things I  
5 realized is there was really no linkage in any  
6 way to all the wonderful resources that are  
7 here at NIH. So I suggested to them that what  
8 they ought to be doing is not duplicating what  
9 NIH does but finding ways to link with them.

10           Because many of the folks who go  
11 there regularly for information on rural health  
12 are probably not really aware or fluent on how  
13 to access some of the resources at NIH. I  
14 spoke with Marin Allen and she said that's in  
15 process, trying to bring those together. So  
16 that's a whole new community that might be able  
17 to be brought into the wealth of resources here  
18 at NIH. And I'd be remiss if I didn't also  
19 mention that we are working to integrate  
20 medicine and dentistry at Marshfield Clinic,  
21 yes, absolutely.

22

1           And we were invited to participate  
2   in New Springer Text, a publication that's  
3   being prepared. There will be a chapter on  
4   what we're doing in Marshfield to do that  
5   integration. And I was asked also to do a  
6   sidebar, pretty much answering the question  
7   why, why are we doing this? And so I was able  
8   to do a little sidebar that provides the credit  
9   that NIH deserves because if it wasn't for our  
10   nation's investment in science, we wouldn't  
11   know enough to know that this was important to  
12   do.

13           So I think being a member of this  
14   committee helps us understand that when those  
15   connections can be made out in the public, they  
16   ought to be. And lastly, I'll just say that I  
17   am really looking forward to the future because  
18   I believe that things are falling in place that  
19   will allow the community health center movement  
20   to become a much better consumer of research  
21   results and also to actively participate in  
22   research with academic intuitions funded by

1 NIH. And I look forward to working to help  
2 develop that further, so thank you.

3 SUSAN WOOLEY: Hello. I'm Susan  
4 Wooley. I've transitioned in this period since  
5 the last meeting between being Executive  
6 Director of the American School Health  
7 Association, which is an organization for  
8 people in schools who work on children's health  
9 issues, to being Executive Director of The  
10 Directors of Health Promotion & Education,  
11 which people working in state health agencies  
12 on wellness and prevention. Which is going to  
13 be a big area with (stammers) as things are  
14 coming through with healthcare reform, in terms  
15 of controlling healthcare costs.

16 Because I'm in the transition  
17 right now, it's been a lot of shutting down and  
18 starting up, so I haven't done a lot of new  
19 things. But I did complete, during this  
20 transition time, a chapter in a book by the  
21 American Public Health Association on  
22 children's safety, the part on school health.

1 I'm also the immediate past chair of the  
2 National Coordinating Committee on School  
3 Health and Safety, which is an organization  
4 that brings together national organizations and  
5 federal agencies. I first heard about COPR  
6 through them and I feel that this is a way of  
7 bringing together with the science and  
8 education initiatives, the education community,  
9 the health community, and various others. And  
10 I think I bring the resources to be able to get  
11 the word out.

12                   STEPHANIE AARONSON: Hi. I'm  
13 Stephanie Aaronson. I work at the Public  
14 Broadcasting Service. A couple of projects  
15 that I've been working on lately, I just wanted  
16 to share, include a new Sid the Science Kid  
17 mobile app for preschoolers, which we're really  
18 excited about, some teacher innovation awards  
19 to highlight teachers who are incorporating  
20 science and media, creative ways of engaging  
21 kids in science education. We're in the  
22 development of a new math pilot, again, also

1 for preschoolers. And working in collaboration  
2 with the White House Let's Move project on a  
3 new website and several PSAs for the early  
4 elementary school age, around their key  
5 components for Let's Move. Thanks.

6 MICAH BERMAN: I'm Micah Berman  
7 again. I'm a law professor at New England Law  
8 in Boston and I also direct our law school  
9 center for public health and tobacco policy,  
10 which works with local governments and state  
11 governments on tobacco control issues. We've  
12 mostly been working with New York State. We're  
13 now branching out to work with some other  
14 communities around New England. And a couple  
15 of my students are testifying on Tuesday before  
16 the Massachusetts legislation regarding  
17 regulation of new emerging tobacco products and  
18 how to regulate and tax those, so they're very  
19 excited about that.

20 Just one point I wanted to bring  
21 up. A current theme that's been coming up a  
22 lot in the tobacco control work has been the

1 courts wanting to see more evidence of the  
2 success or failure of tobacco policies when  
3 they are testing whether or not those can be  
4 upheld under the first amendment or other types  
5 of legal tests. And so the information coming  
6 out of the NIH has actually been very helpful  
7 to communities around the country that are  
8 trying to defend their laws in court from  
9 lawsuits from the tobacco industry. So good  
10 resources from the CDC, some starting to come  
11 from the FDA but a lot of it is really based  
12 out of the work that the NIH does.

13 So on a personal note, I'm  
14 actually going to be on loan next year to the  
15 FDA to help them establish and build their  
16 office of policy within the Center for Tobacco  
17 Products, so I will look forward to working the  
18 NIH from that other role.

19 CARLOS PAVÃO: Good afternoon,  
20 Dr. Collins and Dr. Tabak, nice to see you both  
21 again. Carlos Pavão from Atlanta, Georgia. I  
22 actually work with a (word?) contract and we

1 work with states tribes and territories on  
2 looking at substance abuse, mental health, and  
3 also HIV. And for us, it's really about  
4 providing technical assistance on helping them  
5 really integrate the public health systems to  
6 really look at an integrated model when it  
7 comes to healthcare.

8           And one of things that I've  
9 noticed, that might be of concern to you all,  
10 and actually just touching base on what  
11 Gardiner said about the GLBT IOM report that  
12 just came out and piggybacking on the It Gets  
13 Better campaign about gay youth and suicide and  
14 bullying. One of the things that we've noticed  
15 from our states and our communities is that  
16 folks are ready to embrace this  
17 (unintelligible) bullying issues. But the  
18 issue, when it comes to data collection and  
19 data standardization, is a problem and I'll  
20 give you an example.

21           When you look at HIV clinical  
22 trials, you look at the words MSM, men having

1 sex with men, but under that, you're looking at  
2 transgendered women, you're looking at bisexual  
3 men, and you're looking at men that don't even  
4 identify with being gay. That's just one  
5 example of how do we start measuring and  
6 collecting data, if we're going to be looking  
7 at the wellbeing of GLBT populations, how do we  
8 start looking at that. Another piece is  
9 looking at the issue of stigma and  
10 discrimination and sort of the wellbeing of a  
11 child and how does a child feel good about  
12 themselves if he or she is coming out.

13           So one of the things that we're  
14 really looking at and are actually presently  
15 working on is assessment of vulnerable  
16 populations as a whole and what are the  
17 strategies and what are the methods. But also  
18 breaking it down to looking at migrants,  
19 refugees, and also the GLBT. Because I don't  
20 think our states and communities can really  
21 wrap their brain around it because I'll give  
22 you an example. The National Longitudinal

1 Study for Adolescent School Health, they  
2 include sexual orientation and gender identity  
3 but that's not to say a lot of studies do. So  
4 when you start looking at the data, it's hard  
5 to prove a case that this is a need that we can  
6 address in the community, so--thank you.

7 LYNN OLSEN: Good afternoon. I'm  
8 Lynn Olsen. I'm a sociologist but I am at the  
9 American Academy of Pediatrics. I direct the  
10 Department of Research there. I just came back  
11 from Denver a few days ago, it was the annual  
12 Pediatric Academic Society's research meeting.  
13 And hard to imagine that meeting with NIH, so  
14 this is the annual gathering of pediatric  
15 researchers around the country. Largest  
16 meeting ever, I understand, close to 7,000  
17 registrants at that meeting. We were pleased  
18 that Dr. Guttmacher came to the Academy's  
19 plenary session to talk about the visioning  
20 process and plan for NICHD.

21 And I know that process and his  
22 talk were well-received. I mention a couple of

1 key themes that I certainly noted at the  
2 meeting. Pediatric obesity issues of course  
3 continue to be a major issue in pediatrics, as  
4 pediatricians struggle with what's their role,  
5 what can be done. And that was the theme at  
6 the (word?) plenary session. In fact, the  
7 First Lady joined by a video message to speak  
8 to the pediatricians because we also have been  
9 involved with the Let's Move campaign and she  
10 spoke and urged pediatricians to continue their  
11 role and their linkage in that.

12 I also felt that, you know, a  
13 couple of other really important key themes  
14 throughout the meeting--and it effects both  
15 primary care and specialty care and, you know,  
16 research in both, themes related to health  
17 disparities, health literacy, really have, I  
18 think, got an increasing attention and concern.  
19 These sessions, I think, were really well-  
20 attended. I know we personally were involved  
21 with sponsoring one workshop eight o'clock  
22 Sunday morning that was really--the room was

1 packed. And we had a lot of young researchers  
2 there.

3 And the focus was really about  
4 some of the practical needs and realities of  
5 doing health disparities research. Nuts and  
6 bolts, things like recruitment, tools to  
7 measure race-ethnicity income discrimination  
8 and so on. So it really shows the interest and  
9 the ongoing needs in those areas, so thank you.

10 EILEEN NAUGHTON: Hi. I'm Eileen  
11 Naughton. I'm from the smallest state in the  
12 union, Rhode Island. And I serve in the House  
13 of Representatives as the Deputy Chair of the  
14 entire House Finance Committee. And as the  
15 chairperson of Health and Human Services, where  
16 we concentrate on developing health policy and  
17 on funding that policy. And I can't express to  
18 you how intently we look for NIH information,  
19 best evidence because we are very much  
20 interested in outcomes and improving the health  
21 of the people of Rhode Island.

22

1           And toward that effort, we have  
2 worked very intensely in the area of science  
3 education using the world around us and  
4 developing a close-knit network between top  
5 scientists very active in research with  
6 teachers and students. We develop curriculum,  
7 and we are also able to use tele-devices to  
8 help communicate this, not only among our state  
9 but also among the world. So even though we  
10 are the littlest state, we are very interested  
11 in not only the state but region, nation, and  
12 global. We love to partner, we excel at trying  
13 to find ways to partner and leverage.

14           And some of the things we've  
15 worked on recently, with the guidance and  
16 research of NIH and of course CDC, has been the  
17 HIV. Rhode Island was very high in reporting  
18 transmissions of HIV to newborns. And with the  
19 appropriate guidance and policy and best  
20 evidence, we were able to--and believe me, we  
21 had opponents. The ACLU. There were opponents  
22 to this and they had their belief system. And

1 we were able to work so that we changed the  
2 law, placed the--in the prenatal screens the  
3 HIV panel and, yes, we identified more with  
4 HIV.

5 We're able to improve moms' health  
6 and the babies', best of all, immediately, we  
7 were reporting a reduction in that  
8 transmission, which I'm happy to say is still  
9 continuing today. We were so excited about  
10 that. We went on to change the entire HIV  
11 statutory system in the state, reflecting,  
12 again, best evidence and we now follow that  
13 advice in our statutes and in our coverage with  
14 insurance policies. And have been able to  
15 overcome the prior restrictions on coverage and  
16 on having people identify HIV before we have  
17 any other consequences.

18 And we know, we can see, through  
19 your research, that it early involves the  
20 central nervous system, as well. Just this  
21 week, I had the pleasure of attending a meeting  
22 among two grant principals that have grants for

1 the Children's Health Center--Environment and  
2 Health Center that EPA funded and NIH funded.  
3 And the individuals there included, not only  
4 the researchers, but they included the  
5 community leaders from a diverse  
6 representation. Eager and anxious to be able  
7 to implement those practices and get them  
8 individually into homes, so that we really  
9 could accomplish goals of reducing asthma and  
10 reducing prematurity.

11           So it's very exciting to see that  
12 translation and that implementation. Shortly  
13 after NIH published their strategy on diabetes,  
14 that was looked over and immediately, we began  
15 to look for ways to get health and wellness and  
16 diabetic preventions into the community. And  
17 legislation is before the general assembly to  
18 do that. I just heard this morning that the  
19 legislation on tanning booths passed. And we  
20 had quite the fight from the tanning industry.  
21 The bill simply followed World Health  
22 Organization guidance of now identifying

1 tanning booths as a number carcinogen, similar  
2 to tobacco.

3           And this legislation puts a  
4 requirement for individuals under 18. They  
5 need a prescription, which we feel will be  
6 scarce and hopefully, get to preventing our  
7 young population, particularly young women,  
8 from experiencing melanoma before the age of  
9 25. So I am really excited about the  
10 healthcare act and the new assignments that NIH  
11 has in that act and want to assure you that we  
12 can also develop the model to get that into the  
13 neighborhoods, to the homes and our  
14 communities.

15           AMYE LEONG: I'm so glad I don't  
16 have to tanning salons anymore. No. Good  
17 afternoon, Dr. Collins and Dr. Tabak, it's nice  
18 to see you again. I was not able to attend the  
19 meeting in November because I was actually in  
20 Southeast Asia. My name is Amye Leong from  
21 Santa Barbara, California. I am head of a  
22 patient advocacy and patient communications

1 firm based in the United States and based in  
2 Europe. And I also serve as the international  
3 spokesperson for the United Nations initiative  
4 called the Bone and Joint Decade.

5 And, Dr. Collins, thank you for  
6 helping endorse the second decade in our second  
7 series of objectives as we move that decade  
8 into its second decade. A lot of my time in  
9 the last several months has been spent  
10 providing motivational speaking in the area of  
11 musculoskeletal. And I secure a lot of my  
12 information, of course, from my colleagues at  
13 the Nation Institute of Arthritis and  
14 Musculoskeletal and Skin Diseases. But also,  
15 people want to know, from the experimental  
16 side, I have several musculoskeletal disorders  
17 and, in fact, was disabled and on Medicare  
18 disability because of it.

19 But because of personal  
20 determination and having access to resources  
21 based on evidence-based medicine, I was able to  
22 pull myself out of a wheelchair back up on my

1 feet again. It's a little more difficult for  
2 me to go through security at airports because  
3 of all the metal in my body but its well worth  
4 it because I'm walking today. So I've done a  
5 lot of speeches in Southeast Asia and I can  
6 tell you that when we look at a variety of  
7 different diseases that we all deal with and  
8 what NIH deals with, the aspect of the culture  
9 and of the environment and a person and a  
10 family's ability to get help makes a huge  
11 amount of difference.

12 In speaking in some parts of  
13 Southeast Asia, as in Africa (Dr. Collins, I  
14 know you were there), when someone says--a  
15 health professional says they need to get into  
16 water therapy, some people's closest access is  
17 getting into local bacteria-infested water and  
18 what will that do for them? It might help in  
19 rehab but its cold water but it might also lay  
20 them susceptible to all sorts of other co-  
21 morbidities. So we have to consider our  
22

1 environment, we have to consider those kinds of  
2 things.

3           Arthritis, unfortunately, is still  
4 the number one cause for work, a disability in  
5 the United States. Through the Bone and Joint  
6 Decade, we're finding out this is also similar  
7 in other developed countries. We don't know  
8 what those incidents are in developing  
9 countries. But we are making in-roads to help  
10 the governments, the institutions, and the  
11 comparable research entities like NIH in those  
12 countries better understand their need to do  
13 more surveillance work. So the work done by  
14 NIH and the CDC is actually leading the way in  
15 the strategic area of how other countries are  
16 investing their research dollars, as well.

17           The other things I've been working  
18 on at the international level is, June 9, the  
19 WHO is going to be releasing its first report  
20 in 30 years, a world report on disability. A  
21 big portion of that report is going to talk  
22 about the need for research. What we're trying

1 to ensure that they incorporate, and they've  
2 already written the report, is really the role  
3 of the background and the foundation of NIH  
4 kind of work toward the end of reducing  
5 disability. So they're going to take a global  
6 approach to this.

7           They're looking at risk factors,  
8 there is a large piece of this on prevention of  
9 disability. So we've been very active in that.  
10 That is all leading up to the UN meeting  
11 September 19 and 20. As you well know, Dr.  
12 Collins, the very first time that the World  
13 General Assembly is going to be addressing non-  
14 communicable disorders on a global basis  
15 through the UN. So it's an opportunity for  
16 every country who's a part of the UN to begin  
17 to take a look at this. And certainly, the  
18 research component is going to be a very large  
19 piece.

20           We will be there for that and  
21 we'll make sure that research plays an  
22 important role in that. Third piece is that

1 we've been asked, after a decade of the Bone  
2 and Joint Decade, I'll be taking the lead  
3 author role on doing a chapter for best  
4 practices in clinical rheumatology. A chapter  
5 on advances in consumer involvement in patient-  
6 centered care and research. And so this is an  
7 important chapter because it sets the stage for  
8 how other countries involve consumers and the  
9 community in the work of research and in the  
10 work of treatment and care and prevention.

11 This, particularly, for  
12 musculoskeletal disorders but certainly,  
13 hopefully, a model for other areas. The fourth  
14 piece is, I was actually in Washington DC and  
15 through the Agency for Healthcare, Research and  
16 Quality, was one of the stakeholder groups,  
17 giving input about the registry for patient  
18 registries. Very important piece. With so  
19 many registries available, how do we help  
20 consumers get access, and healthcare  
21 professionals get access, for their patients,

22

1 to the latest research that they can get into  
2 clinical trials.

3           We do have [clinicaltrials.gov](http://clinicaltrials.gov).  
4 It's been around for a long time. It is  
5 updated but the parameters and the sections  
6 that could be available for increased  
7 participation, we're actually suggesting that  
8 they somehow be merged in some way. So we'll  
9 see how that goes but they still have a long  
10 way to go on that. Delighted to be a part of  
11 that process. The fifth thing is the outcomes  
12 measures in rheumatology clinical trials. I'm  
13 taking a lead role in engagement of consumers.  
14 In our case, we call them patient research  
15 partners.

16           In the development and design of  
17 research and, in our case, at international  
18 research, as it relates to developing outcoming  
19 measures in rheumatological care. And we have  
20 been invited, based on over two-and-a-half  
21 years now, of patients, people, community  
22 members, and healthcare professionals, moving

1 together to develop international research.  
2 These are researchers and patients from 50  
3 (stammers) 50 individuals representing 15  
4 countries. And we sit around the table as  
5 equals.

6           And we've been told it's a  
7 wonderful model for patient engagement and  
8 design and development of international  
9 research. We've just been invited to do a  
10 piece for the International Journal of Self-  
11 Help, more of an experiential end. So what's  
12 it feel like to be a community partner in  
13 dealing with international researchers? And  
14 then we've also been invited to begin to take a  
15 look at developing evidence-based research,  
16 qualitative and quantitative data about the  
17 impact of engaging the community in research.

18           So we talk about the benefits of  
19 it but from a clinical perspective or science  
20 perspective, we want to see numbers, as well.  
21 So this is a first attempt to really try to  
22 quantify the role of engagement in research by

1 the community. So we're delighted about that.  
2 The last thing I want to talk about is that,  
3 Dr. Collins, you and I will be together on June  
4 13 as we celebrate the 25th anniversary of the  
5 National Institute of Arthritis and  
6 Musculoskeletal and Skin Disease. And  
7 certainly, the theme of that particular  
8 symposium is certainly mirrored in the themes  
9 of the National Institute of Health.

10 This one is "improving lives  
11 through discovery" and it really is about that,  
12 so I'm delighted to be with you on that day to  
13 give a patient perspective. Thanks.

14 LORA CHURCH: (speaks  
15 foreign language) Greetings from the Land of  
16 Enchantment, New Mexico. My name is Lora  
17 Church. I am, through my clans, as Navajo,  
18 Bitter Water, mourn for the Blackstreet Wood  
19 Clan. My maternal grandfather's clan is the  
20 Cliff Dwelling Clan and my paternal  
21 grandfather's clan is the Green Meadow People.  
22 So I'm not sure how many Navajos are in the

1 audience but I am related to them, I'm sure. I  
2 would like to just share real briefly some of  
3 the work that has occurred lately.

4 Right now, I am in an employment  
5 transition from working with the University of  
6 New Mexico to another organization that is not  
7 yet confirmed, so right now, I am a community  
8 member. I also am on an advisory committee,  
9 along with Amye, with the NIH National  
10 Institute of Arthritis and Musculoskeletal and  
11 Skin Diseases in their multicultural workgroup,  
12 which we provide advisement on a qualitative  
13 research that looks at developing and  
14 delivering culturally-appropriate health  
15 messages for those that have those particular  
16 diseases or health conditions.

17 Right now, in terms of the Native-  
18 American workgroup, in process, is conducting  
19 two--well, actually, four more focus groups.  
20 Two in the state of Alaska and two in the state  
21 of Oklahoma. So we are--we just keep apprised  
22 on the work that is done through the focus

1 groups and the in-depth telephone surveys.

2 Also, I feel like for many years, I have also  
3 been a student at UNM. I'm a graduate student  
4 and will graduate next weekend, Saturday, with  
5 a Masters of Public Administration and a  
6 Masters of Science and Health Education. Yes.

7           And one of my graduating papers,  
8 which I carry with me because it is done, but  
9 it was a case study looking at the  
10 effectiveness of a school health advisory  
11 council in its performance of developing  
12 cultural competency policies for an American-  
13 Indian-serving school-based healthcare center  
14 in New Mexico. And I wanted to publicly  
15 acknowledge, which they don't know now, but I  
16 do want to publicly acknowledge Dr. Lynn and  
17 Dr. Woodley (sic) because, in my literature  
18 review, I did look at sources from the American  
19 Academy of Pediatrics.

20           And I also pulled some of the  
21 studies that Dr. Woodley served as a co-author,  
22 so I wanted to thank you both on the work--the

1 good work that you do. And in terms of, just  
2 real quickly, on the paper that I was looking  
3 at, and this is where, probably, the link of  
4 community engagement really fits in  
5 beautifully, is looking at school health  
6 advisory councils. The particular one that I  
7 worked with had a membership of 35 individuals  
8 and this is for three Native American  
9 Communities or sovereign nations and two  
10 Hispanic communities located west of  
11 Albuquerque.

12                   And the investment that they have  
13 in working in developing cultural competency  
14 policies, there's no question to their  
15 commitment. No question to their involvement.  
16 And for the university and the work that we had  
17 done through the school-based healthcare  
18 centers is really capturing the richness that  
19 we can get from community members to help us  
20 look at improving healthcare services to youth  
21 and their families. And what we also found or  
22 what I've found in my study is that not only is

1 the school health advisory council effective in  
2 developing cultural competency polices but the  
3 quality of work that they produce also--the two  
4 cultural competency policies that they develop  
5 also aligns and supports 5 of the 14 national  
6 standards for the culturally and linguistically  
7 appropriate services class, which is from the  
8 U.S. Department of Health and Human Services  
9 Office of Minority Health.

10           So again, I think that really  
11 highlights the work that community members,  
12 with investment, with resources, with  
13 commitment and loyalty to the health and  
14 wellness of the community members, can really  
15 produce good, quality work. And I was able  
16 work with them to highlight their work that  
17 they did. Also, just real briefly, what I also  
18 have found, that the U.S. Census Bureau  
19 projects that by 2020, 44.5 percent of American  
20 children ages 0-19 will belong to a racial and  
21 minority group.

22

1                   And then jumping ahead 22 years  
2                   from that point, by year 2042, minorities in  
3                   the U.S. will have become the majority. So not  
4                   only does that mean healthcare delivery  
5                   practices need to change in order to  
6                   accommodate the changing patient population,  
7                   but also, I feel that our biomedical research  
8                   protocols would also need to continue looking  
9                   at and exploring ways to make more appropriate  
10                  adaptations to the changing patient population.  
11                  Last, which kind of ties into my study, which  
12                  was looking at not only the effectiveness of  
13                  the school health advisory council, but using  
14                  that, along with the multiple-constituency  
15                  model, is what I had based my research on.

16                         But I also feel that there, the  
17                         beauty of COBRA. The advisement and the  
18                         guidance that we can provide NIH, we are that  
19                         example of a multiple-constituency model here.  
20                         And that we bring in our own knowledge, skills,  
21                         abilities, passion, commitment, our networks,  
22                         our resources, that we want to continue to

1 offer that to NIH and look at whether it's  
2 making recommendations. And we'll share with  
3 you, also, the recommendations that we have  
4 from several of our workgroups.

5 But I just wanted to express, you  
6 know, my gratitude in participating on COBRA  
7 but also want to highlight the good work that  
8 people around the table do on a daily basis,  
9 and even sometimes into the night, on the  
10 weekends. And that we are here in the best  
11 interests for NIH and all of the work that is  
12 being done with the 27 institutes and centers.  
13 And again, thank you for taking your time today  
14 to be here with us and to listen, participate  
15 and take in and consider the recommendations  
16 that we will make. Thank you.

17 FRANCIS S. COLLINS: Well, thanks  
18 to all of you for a really interesting and  
19 amazing array of activities that you're engaged  
20 in. Breadth of involvement is really  
21 impressive and the dedication that you all show  
22 to these many causes is really a credit to each

1 one of you and certainly is an awesome  
2 demonstration of how people with really serious  
3 dedication can make a difference. And that's  
4 why we're glad you're here as part of COPR to  
5 try to help us make a difference in an even  
6 broader way than we might otherwise be able to.

7           You know, I have a bunch of  
8 different advisory groups but none like this  
9 one. I have a group called the Advisory  
10 Committee to the Director, which provides me  
11 with advice about scientific directions that we  
12 might be taking and has a lot of people, like  
13 university presidents, represented on it. And  
14 it's an important group but it certainly does  
15 not convey the same voice that you all do about  
16 the public and does not provide the same  
17 opportunity for us to get our message out and  
18 to receive information back that you all do.

19           I have a scientific management  
20 review board which is charged with overseeing  
21 NIH's organizational structure and whether  
22 there are changes that we should make to make

1 our structure fit our ever-evolving function.  
2 And they've created some (unintelligible)  
3 lately by making such recommendations and  
4 change is not always easily absorbed. So I'll  
5 mention a little bit about that in a moment. I  
6 have a council of councils, which actually  
7 reports to Jim Anderson, who is the person who  
8 oversees the common fund. And that council of  
9 councils has representation from the councils  
10 of each of the 27 institutes and centers, to  
11 give us advice about how best to use that new  
12 part of NIH called the common fund, which is  
13 supposed to be devoted to projects that don't  
14 fit within any of the institutes, but which  
15 could be transforming for the whole place.

16 And, of course, each of the  
17 institutes and centers have their own advisory  
18 councils, their boards, scientific counselors,  
19 and other means by which they seek input from  
20 the public. And we're really glad about that  
21 because their decision-making needs to have  
22 that kind of input all the way along the way.

1 But I, as the NIH director, have no other  
2 public input that comes anywhere near what COPR  
3 represents. And with all of your expertise in  
4 these various areas, I think our efforts have  
5 always to try to see how we could make the  
6 whole greater than the sum of the parts.

7           How we could encourage you, as  
8 you're coming to this group, to take what you  
9 have been doing in a particular area of your  
10 personal dedication and then enlarge it to  
11 think about the whole picture upon medical  
12 research and how it can be applied to result in  
13 better health for our nation and for the world.  
14 And for that, I thank you because this is an  
15 amazingly complex and enormous task. And I  
16 think, once again, as we meet here today, we  
17 may talk about how best to try to conduct that.

18           We're still in a situation where  
19 most people in the United States do not know  
20 what the National Institutes of Health does.  
21 The abbreviation NIH means nothing to the  
22 majority of Americans. They might've heard of

1 NASA but for the most part, they haven't heard  
2 of NIH. And I think that is, in many ways, an  
3 indictment of our failure to be able to get our  
4 message out because it's a really exciting,  
5 inspiring message. But it has not reached the  
6 ears of an awful lot of people out there.

7           And this is certainly a vulnerable  
8 moment for that to be the case, given that  
9 support for biomedical research is part of the  
10 whole deliberation about government investment  
11 in practically everything. We are part of that  
12 package, that 16 percent of the federal budget  
13 called discretionary. That's an interesting  
14 word, isn't it, that maybe medical research  
15 could just be zeroed out, because, after all,  
16 it was discretionary to begin with. Believe  
17 me, we have felt that vulnerability, especially  
18 lately and I think we could certainly stand to  
19 get lots of good advice about how better to get  
20 our mission recognized for the way in which it  
21 can benefit the public in so many different  
22 ways.

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So I'm glad to be here with you and I did want to make a few remarks about some of the things that are particularly on the front burner right now at NIH and be interested in hearing your reactions about the directions we're taking in that regard. Before I go any further, though, I do want to recognize Micah Berman for his contributions to COPR and congratulate him on his new role in our sister agency at FDA on tobacco product issues. The downside of that congratulations is we have to recognize that he can't do both.

And so he's had to resign as a member of COPR and there's a certificate floating around somewhere to thank you for your contributions to this. There it is. So maybe we should give you a little round of applause right now. (applause) We're glad you're here. You don't have to walk out right now, you can stay of for the rest of this here. (laugh)  
Yeah, speaking of transitions, I also want to

1 share with you a happy tale of three dentists.

2 Think about that for a minute.

3           So earlier this week, I announced  
4 the appointment of a new institute director,  
5 Dr. Martha J. Somerman, who is a DDS as well as  
6 a PhD, who will join us as the Director of the  
7 National Institute of Dental and Craniofacial  
8 research at the end of August. She has been  
9 Dean of the University of Washington School of  
10 Dentistry, a very highly regarded dental  
11 school, for the last nine years. And I am  
12 delighted to be able to bring her here, both  
13 because of her administrative skills and her  
14 research expertise.

15           And she will be an able leader,  
16 adding to our family of senior leadership. The  
17 second dentist in my story that I want to thank  
18 is Dr. Isabel Garcia, who has served as acting  
19 director of NIDCR since August 2010 and really  
20 been an outstanding interim leader, while  
21 bringing us through some challenging times.  
22 And she was acting because the third dentist

1 sitting to my right, Dr. Larry Tabak, accepted  
2 and, I'm so glad he did, my offer to come and  
3 serve as my principal deputy director.

4           So I have lots of dentists to be  
5 grateful here today. And that is not something  
6 I would normally have said during my childhood,  
7 so I'm becoming a convert to the value of your  
8 discipline. And it's great, Larry, to have you  
9 in such a critical role and thank you for being  
10 here. I know you can't stay for the whole  
11 meeting but I'm glad you're able to be here for  
12 part. So I want to spend most of the time  
13 having a discussion, so I'm not going to go on  
14 too long about this sort of opening set of  
15 reflections.

16           But I did want to share a few  
17 things in front of you and see what kind of  
18 thoughts you would have about a number of ideas  
19 that we're pursuing. I know you had a  
20 productive workshop yesterday and I'm  
21 interested in hearing your thoughts about  
22 getting young people intrigued and curious

1 about science and how best we can oversee our  
2 contributions to COPR and its accomplishments.  
3 Because I think we're always thinking of this  
4 as a work in progress about how best to utilize  
5 the talents and energies of a distinguished  
6 group like this.

7           And I recognize how dedicated you  
8 all are. I understand some of you, just to  
9 come to this meeting, have to take vacation  
10 days. That is really quite a sacrifice and we  
11 want to take that seriously and make the most  
12 of the opportunity. So let me touch on a few  
13 highlights and one of them will be talking  
14 about the National Center for Advancing  
15 Translational Sciences, or NCATS. So this all  
16 relates to a sense that we all have that  
17 there's a unique opportunity right now to  
18 accelerate the process of developing new  
19 therapeutics, diagnostics, and devices.

20           This is something that NIH has  
21 been involved in for a long time but the  
22 science right now has put us in a position to

1 be able to take on a particularly audacious  
2 role here and that is what we're all about, is  
3 trying to see if there are moments where NIH  
4 can, by identifying a need, make sure that we  
5 step into the role that we are able to provide  
6 and speed up the development of advances that  
7 will improve health in prevention and in  
8 treatment.

9           So looking at that situation and  
10 noting last year when we met, we were talking  
11 about the Cures Acceleration Network. As you  
12 know, we're under a continuing resolution. We  
13 weren't funded for that Cures Acceleration  
14 Network in this current fiscal year. But it  
15 had caused us--and this goes back, actually,  
16 several years--to think about ways that NIH  
17 could be aligning our staffing and resources to  
18 address this daunting challenge of advancing  
19 the translational steps into therapeutics.  
20 Translation in this particular paragraph has  
21 multiple definitions and nobody quite agrees on  
22 what we're talking about.

1           And let me tell you about what I  
2       mean when I say translation. I mean, the  
3       process of going from a basic science discovery  
4       about the molecular cause of a disease to the  
5       point where ultimately, you have a clinical  
6       application that benefits patients. And that  
7       can be a very long and drawn out, slow,  
8       expensive, and risky procedure. If you're  
9       talking about drug development, for instance,  
10      the average time from starting a drug  
11      development protocol based upon a new molecular  
12      discovery and actually having that drug in the  
13      clinic is 14 years.

14                We don't think that's acceptable.  
15      There's got to be a better way. And we have  
16      this big pileup of discoveries that are pouring  
17      out of laboratories at the front end of that  
18      pipeline, where some 4,000 diseases now have  
19      had their molecular cause understood, many of  
20      them in just the last few years. Only about  
21      200 of those have treatments available. It  
22      would be terrible if we had to wait 14 years or

1 more for all of those to get attended to. So  
2 we are interested in trying to see what else we  
3 could do to speed this process.

4           So here's where the process got  
5 engaged with that scientific management review  
6 board that I mentioned, to ask them to look at  
7 NIH and say are we doing everything we can to  
8 encourage translation. And they looked  
9 carefully at all the activities of the 27  
10 institutes and centers and concluded there's a  
11 lot of translation going on here, some 500  
12 projects last year were identified that were  
13 clearly in that translational space. And  
14 adding up the budgets, well, it was probably  
15 somewhere in the neighborhood of 15 to 20  
16 percent of the NIH budget.

17           But it was, for the most part,  
18 individual projects that we're trying to find a  
19 new treatment for cancer, or a new infectious  
20 disease antibiotic, a new, particularly needed  
21 approach to a rare disease, like spinal  
22 muscular atrophy. But there was not a focus on

1 trying to actually look at the development of  
2 therapeutics itself as a scientific problem in  
3 need of reengineering. The steps in going from  
4 those basic discoveries to that approved drug  
5 have kind of been the same steps for 30 or 40  
6 years. And yet the science has advanced  
7 substantially during that time.

8           And it seemed like there was a  
9 real opportunity here to look, like an engineer  
10 would look, at the process and see could this  
11 be optimized? Now, you might say, oh, come on,  
12 the private sector must be doing that. After  
13 all, this is their business. And they are  
14 doing drug development but they are, for the  
15 most part, also looking at individual projects,  
16 trying to get something to the point of FDA  
17 approval. And because companies do their  
18 business behind a bit of a curtain in terms of  
19 confidentiality and company secrecy, they're  
20 not in a position to know what other companies  
21 are doing in terms of advancing the process.

22

1                   Seems like it would be a good  
2 thing to do this in an open-access environment.  
3 Well, that's what we're all about. So the  
4 scientific management review board received a  
5 lot of public input and ultimately, last  
6 December, concluded that we should, for the  
7 first time in quite a while, create a new  
8 center. Which I agreed was the right idea and  
9 we ultimately named that center the National  
10 Center for Advancing Translational Sciences,  
11 NCATS. And it will stand up on October 1,  
12 assuming that congress does not object and  
13 assuming that congress is comfortable enough  
14 with the plan to put some money in the budget  
15 for this particular enterprise.

16                   But let me hasten to say that we  
17 don't really have to have new money to do this.  
18 The plan is to take various pieces of what we  
19 need to assemble into an integrated pipeline  
20 engineering kind of project that are already  
21 present at NIH in various other spots. And put  
22 them together in a very synergistic and

1 exciting way. The only new money that we do  
2 hope to get would be for that Cures  
3 Acceleration Network which did not get an  
4 appropriation this year because we never got  
5 any new money. It was all the continuing  
6 resolution.

7 But it is in the President's  
8 budget for FY12 at \$100 million. That is a  
9 very modest increment, of course, of our 31  
10 billion but I think actually having something  
11 of this sort that's new and exciting may be a  
12 useful way for us to try to defend our budget  
13 in the current crunch, where everything is  
14 somewhat suspect by some parts of the congress.  
15 So I'm excited to see this moving along. It  
16 has been somewhat controversial. It has been  
17 controversial in part because people were  
18 concerned that this represented some deviation  
19 away from basic science and that we might be  
20 taking money away from the basic sciences  
21 agenda.

22

1           Which is, of course, crucial for  
2     our future and I'd be the first to defend it.  
3     Most of my own research has been basic science.  
4     This will not do that. It won't change the  
5     proportionalities in a visible or even  
6     discernable way between basic and clinical.  
7     Other concerns were that we were trying to turn  
8     NIH into a drug-development company, that this  
9     was going to be (unintelligible) pharmaceutical  
10    right here. Not at all. We would not take on  
11    any projects through this effort that the  
12    private sector was interested in.

13                 We would be much more focused,  
14    though, on trying to reengineer the drug-  
15    development process in a way that would benefit  
16    companies, as well, if we could get it to work.  
17    Just one example: One of the things that  
18    causes many drugs to get actually lost along  
19    the way and which is terribly expensive and  
20    slow is how do we test whether a drug is safe  
21    before you give it to a human. And the  
22    standard is it has to be tested in small

1 animals and large animals, at certain doses and  
2 certain numbers of animals with certain kinds  
3 of analysis made to see whether there was any  
4 signal that might suggest toxicity.

5           When you look at how successful  
6 that has been, it's not very impressive. It's  
7 clear that things that appeared safe in monkeys  
8 and mice are not always safe in humans. And  
9 it's also very clear that we lose a lot of  
10 drugs along the way because they happen to be  
11 associated with some problem in a mouse that  
12 might never have been a problem in human but  
13 that does it once that's happened. So why  
14 don't we do something a little more in the  
15 modern era here?

16           If we can, at this point, take  
17 human cells maybe derived from embryonic stem  
18 cells or IPS cells, differentiate them into  
19 little mini organs, mini livers, mini kidneys,  
20 mini hearts--and you can do this--and develop  
21 readouts from those organoids that would tell  
22 you if you have a compound that's going to be

1 bad for an actual person. That's probably a  
2 lot closer to the biological signal you're  
3 looking for than a mouse or a monkey. And yet  
4 that has not really been pursued.

5           When I talk to companies about  
6 that idea, they're like, oh, yeah, I wish you  
7 would do that. But by the way, please talk to  
8 the FDA because if you're going to do this and  
9 if it's going to succeed, FDA has to agree that  
10 this is useful information that they can  
11 include in their evaluation about whether to  
12 approve a drug for first-human use. In that  
13 regard, we have built a very strong  
14 relationship with FDA for just that reason and  
15 others, so Micah, we'll be seeing a lot you  
16 over there.

17           We have this joint leadership  
18 council that Peggy Hamburg and I have set up  
19 with six working groups--one of them on  
20 tobacco, another one on toxicology, and four  
21 others on other topics--to try to be sure that  
22 we're making the most in 2011 of how these

1 agencies can inform each other about research  
2 and about regulatory science, which they very  
3 much want to see advanced. So this is, I  
4 think, turning out to be a pretty interesting  
5 moment.

6           The other part of the controversy,  
7 which you may have been hearing about, is sort  
8 of what goes into NCATS has been deliberated by  
9 the SMRB and others. And one of the decisions  
10 SMRB made was that all of the CTSA's, these  
11 clinical research centers around the country,  
12 55 of them, soon to be 60, should move from  
13 where they currently are located in the  
14 National Center for Research Resources and  
15 should be moved into NCATS. That means that  
16 its budget would go with it, which is about  
17 half a billion dollars.

18           That's the largest component,  
19 actually, the NCATS budget, starting in  
20 October. But it also raised a question about,  
21 okay, that's also a big chunk of NCRR. Are  
22 there other places, other aspects of NCRR that

1 might actually function in a more synergistic  
2 way if they were relocated to other parts of  
3 NIH? And I asked Larry Tabak to look at that  
4 question and he and a team that he put together  
5 spent intense weeks going through the  
6 components of NCCR, trying to see where would  
7 be the best scientific location for the  
8 programs, with the intention of sustaining the  
9 programs, sustaining their staff.

10           But wondering whether there were  
11           adjacencies that could be promoted that would  
12           make them even better. And ultimately, that  
13           led to a conclusion that, yeah, there probably  
14           was a real opportunity here, as long as we're  
15           doing a reorganization, to move those programs  
16           into other places. And basically then to  
17           dissolve NCCR. That caused a lot of anxiety,  
18           especially for people who had grants from NCCR  
19           who seemed to think that meant their grants  
20           were going away, which, of course, is not the  
21           case. They're moving to another part of NIH but  
22

1 we don't expect there to be any serious  
2 implications on the programs by that action.

3 I think we have, over the course  
4 of several months of town meetings and a  
5 website, which you may or may not have seen on  
6 the homepage, the feedback website, received a  
7 lot of input, tried to put out a lot of  
8 explanations. And I think people are beginning  
9 now to recognize, hey, this could actually be a  
10 good thing. And there's a lot of more calming  
11 of the waters. Would you agree, Larry, since  
12 you've been the receiver of a lot of the input,  
13 not all of which was friendly?

14 (all talking at once)

15 So we are on track, I think, to do  
16 something that's pretty bold and yet it does  
17 seem, to many of us, like, if we didn't do  
18 this, we would be showing a lack of leadership  
19 at a critical scientific opportunity time.  
20 Some have said, oh, what, you're doing  
21 something bold like this when budgets are so  
22 tight? Well, sure. Just because finances are

1 tough doesn't mean you shouldn't try to be  
2 creative. It may mean, when budgets are tight,  
3 it's a little tougher to make the case but I  
4 think we have to do that.

5           Just a couple of other things and  
6 then I will want very much to be involved in a  
7 discussion with you all. I think I would be  
8 remiss if I didn't mention the almost shut-down  
9 of parts of the federal government, including  
10 NIH and the outcome of that, in terms of what  
11 happened to the current budget. This was a  
12 nail-biter and we at NIH did take very  
13 seriously the high likelihood of a shut-down  
14 and a lot of very, very busy people who really  
15 thought that they were going to be doing  
16 something else, spent a lot of time two weeks  
17 before the deadline preparing a plan about how  
18 we could be sure not to have patients damaged  
19 if the government shut down.

20           And figuring out who absolutely  
21 had to be here and who would have to be  
22 furloughed. That was very painful in terms of

1 its impact on morale. People who come to NIH  
2 have a great believe in the value of what  
3 they're doing and the desire to help people and  
4 the idea that could be delayed, taken away from  
5 them, on the basis of a failure of political  
6 process was really demoralizing. And the fact  
7 that some people were considered excepted, that  
8 is they were told you will come to work because  
9 they were involved in critical patient care or  
10 animal care.

11           Whereas the majority were  
12 considered non-excepted, that also, despite our  
13 best efforts, made the non-excepted people feel  
14 also like they were non-essential and perhaps,  
15 there was some statement being made their about  
16 the value of their work. And that is still  
17 sort of a lingering bad taste. So this was  
18 clearly a very unfortunate--coming close to the  
19 brink. And of course the brink really came  
20 extremely close. How many of you were up on  
21 that Friday night, yes, watching to see what  
22 would happen, so it was about an hour to spare.

1           And when the announcement was made  
2   that a deal had been done, it wasn't clear the  
3   deal was actually fleshed out in terms of the  
4   details. In fact, it was not and so over the  
5   course of the next few days, there were frantic  
6   negotiations about what this actually was going  
7   to mean, in order to find the \$30-some billion  
8   in cuts. And we had lots of inputs that we  
9   tried to put forward in terms of the  
10  consequences of various types of decisions.  
11  Ultimately, considering how awful it could have  
12  been, we all, I think, should be grateful to  
13  those and maybe some of them around this table,  
14  who got the word to decision-makers that  
15  medical research really is a governmental  
16  activity of substantial value for health, for  
17  the economy, for American competitiveness.

18           You may know that in the original  
19  version of what was going to be the rest of the  
20  fiscal year '11 budget, the version passed by  
21  the House of Representatives, the bill called  
22  HR1, NIH would have seen a \$1.6 billion cut

1 coming halfway through the year, representing a  
2 more than 5 percent loss of funding. Five  
3 percent may not sound like a big number but  
4 think about the problem we're in because our  
5 grant commitments, generally, on the average,  
6 are for four years. So when you make that  
7 commitment, you made that commitment, that  
8 means what's turning over in any given year is  
9 only about a quarter of the budget.

10 So that five percent that would be  
11 cut would be applied to a much smaller  
12 proportion and would have resulted in the  
13 smallest number of new and competing grants in  
14 history being able to be given this year.

15 Fortunately, the ultimate decision was a 1  
16 percent cut, \$321 million pulled out of our  
17 budget. Again, I guess I tell you this as we  
18 should be grateful it wasn't worse but I will  
19 also tell you that this is pretty painful. And  
20 this is the first time in a generation that NIH  
21 has sustained an actual cut in the budget in  
22 real dollars.

1                   That's almost never happened. And  
2 I'm afraid we may be on track for worse things  
3 in the future, considering the very, very  
4 serious discussions about government spending  
5 and how it has to be reined in because of the  
6 seriousness of the deficit. I would say maybe  
7 if there was a silver lining in these really,  
8 really painful discussions, it is that NIH did  
9 get higher on the radar for some of the  
10 decision-makers in the administration, where,  
11 clearly, they have been in favor of science and  
12 innovation all along.

13                   Medical research began to appear  
14 in the President's speeches, along with clean  
15 energy, as an example of innovation that the  
16 administration could not support seeing  
17 damaged. And in congress, certainly members  
18 who had not previously paid much attention to  
19 NIH, hearing that, for instance, a government  
20 shutdown would have forced us to stop enrolling  
21 patients in clinical trials, who were already  
22 scheduled to come to the clinical center and

1 would have to be turned away, kids with cancer,  
2 for instance, that got their attention, also,  
3 that this is not a bunch of people in the lab  
4 playing around, this is really significant for  
5 human health.

6           So maybe there was a silver lining  
7 of that sort, although I'm not sure it's the  
8 way I wanted to get that kind of recognition.  
9 Final thing I'll just mention in the way of a  
10 good-news event from last week, as you likely  
11 heard, the Court of Appeals reversed the lower  
12 court's injunction against federal funding of  
13 human embryonic stem cell research. And that  
14 had, certainly last August, thrown the whole  
15 field into a state of great uncertainty. The  
16 court ruled in our favor and we can continue to  
17 go forward funding use of human embryonic stem  
18 cell lines.

19           Although, we may not use federal  
20 funds for derivation of new lines and that has  
21 been our understanding all along of the famous  
22 Dickey-Wicker Amendment. This is good, not

1 only for science but especially for patients  
2 and their families at a time where this field  
3 is showing exceptional promise without  
4 certainty about how that promise will play out.  
5 You probably know the first real clinical trial  
6 of human embryonic stem cells is under way for  
7 spinal cord injury. And interestingly, that  
8 first patient has become very public describing  
9 his own experiences in the treatment for this.

10           And we should all be careful not  
11 to hang too much weight on the first trial or  
12 the second trial or the tenth trial because  
13 this is very new and most of these are being  
14 done to look at safety and not necessarily at  
15 efficacy. But it is a relief to see that at  
16 least some of the cloud that was hanging over  
17 this seems to have been pushed back. It's not  
18 over. The original judge who issued that  
19 temporary injunction has yet to decide about a  
20 permanent injunction. Some people think that  
21 he would be unlikely to issue a judgment that  
22

1 would be contrary to the court that is going to  
2 be then viewing his actions again.

3           But this is not a judge who, I  
4 think, has turned out to be all that  
5 predictable and there's certainly questions  
6 about whether this will go to the Supreme Court  
7 and whether the Supreme Court would take the  
8 case. So there's still an anxiety out there in  
9 the stem cell research community about their  
10 future. An anxiety which, I think has been  
11 pretty destructive, in terms of particularly  
12 young scientists making decisions about whether  
13 this is a field that they can afford to stake  
14 their careers on or whether they will be  
15 prevented from pursuing it at some future time.

16           But at least this particular  
17 battle turned out the right way, although the  
18 war, I guess, is not yet over. So I guess I  
19 have said enough here about various things. I  
20 could talk a long time about lots of other  
21 issues that are happening at NIH. That was  
22 just a brief review of a few of them. But now

1 I'd really like to spend the rest of our time  
2 understanding, from your perspective, how you  
3 think we're doing and maybe talking a bit about  
4 COPR's role in all this. So thank you, all of  
5 you.

6 MALE ONE: Thank you very much  
7 for the update, Dr. Collins. We're running a  
8 little bit behind schedule.

9 FRANCIS S. COLLINS: I know.

10 MALE ONE: So I guess we'll do a  
11 couple minutes of discussion and then we'll  
12 move onto our (unintelligible) presentations,  
13 as well. So Donna?

14 DONNA APPELL: So Dr. Collins,  
15 it's so exciting to hear about NCATS and I was  
16 wondering--I imagine that there is going to be,  
17 you know, an advisory committee for that and  
18 would there be a possibility that a member of COPR  
19 could maybe be on that advisory committee, so  
20 that they could bring back information and help  
21 us learn what we could do to help you?  
22

1                   FRANCIS S. COLLINS:  Yes.  There  
2     will be an advisory council because this will  
3     follow the same format as all the other  
4     institutes and centers and that council will  
5     need to be put in place as a chartered  
6     committee, a so-called FACA committee, sometime  
7     around October, as soon as the center itself  
8     stands up.  We have not really, I think, gotten  
9     very far with thinking about membership of that  
10    council.  I take your point that a connection  
11    between NCATS's advisory process and COPR could  
12    be a pretty useful way to keep these entities  
13    connected.  So thanks for the suggestion,  
14    Donna.

15                   GREG NICZ:  Is there any way--  
16    everybody's worried about cost.  Cost of the  
17    medical care system.  Congressman Obey was  
18    always pointing out how little we spend on  
19    research relative to what we're spending in  
20    treatment.

21                   FRANCIS S. COLLINS:  Yeah.

22

1                   GREG NICZ:    And we know that  
2    there may be some sort of flex point here where  
3    you're getting closer on cures as opposed to  
4    moving to help people with disease that used to  
5    be acute and now become chronic at great  
6    expense.    So with this NCATS that you're  
7    talking about, if there's an acceleration in  
8    this, it sounds to me, as a consumer, that an  
9    acceleration in this means that we might be  
10   able to get these things to therapeutics more  
11   cheaply.    And I hear from the drug companies  
12   all the time what an arduous process it is, how  
13   much money we have to spend to get there and  
14   that's one of the reasons that we, as  
15   consumers, are paying high rates at the  
16   pharmacy.  Are there any quid pro quos?  Because  
17   recapture of that is always a problem with  
18   these things.

19                   FRANCIS S. COLLINS:   That's a  
20   really important issue, Greg.  And, yet, NIH is  
21   not in a great position to be able to have much  
22   control over pricing.  And I guess I have

1 learned that when a company gets FDA approval  
2 for a product, their decision about how to  
3 price it may have relatively little to do with  
4 what it costs them to produce it and really, is  
5 a market analysis of what they think the market  
6 can bear. Back 15 years ago, NIH got into  
7 quite a tangle and the congress got involved,  
8 as well, where there was an argument that if  
9 NIH was engaged in any part of the development  
10 of a drug--and we are engaged in the  
11 development of hundreds of drugs, some of them  
12 actually fairly far down the pipeline.

13 But ultimately, a company picks  
14 them up and carries them through. Then, if NIH  
15 played a role, there should be an opportunity  
16 for NIH or the government to set a reasonable  
17 price. That was a discussion that went  
18 nowhere. Companies, universally and with great  
19 clarity, said if that were the case, then they  
20 would never again want to develop any product  
21 that NIH or its researchers or grantees had  
22 touched. Because they did not want to take the

1 chance of having their hands tied. So you  
2 could see how devastating that would be.

3           Because we need companies to do  
4 what they do and they do it very well. The  
5 only thing that we could do that may, in fact,  
6 sort of recoup some of the public expense--and  
7 this is a much more acceptable model to  
8 everybody, is if NIH is involved in developing  
9 a product to the point where it actually is an  
10 invention, and intellectual property is  
11 appropriate to claim, then NIH should enjoy  
12 should some sharing of the royalties if this  
13 ultimately comes to market.

14           We will certainly do that and  
15 companies will be fine with our doing that.  
16 But setting the price is going to have to have  
17 other kinds of controls attached to it. And,  
18 of course, that's maybe where the healthcare  
19 reform process may kick in.

20           MALE ONE:     Great. Well, we'll  
21 turn it over to Carlos, then, to tell you about  
22 what the Agenda Working Group has been doing

1 and then we'll talk about--the YES group will  
2 be second. So Carlos will do the quick version  
3 of our PowerPoint.

4 CARLOS PAVÃO: Thank you,  
5 everyone. And again, welcome. Before I begin,  
6 I was told by Cathy Hudson that I have a very  
7 pink tie, so if you remember anything I say,  
8 remember the pink tie. That will be my  
9 signature mark from now on. Again, my name is  
10 Carlos Pavão. I actually co-chair on the  
11 Agenda Workgroup with Micah Berman. And before  
12 I begin, I actually want to thank my colleagues  
13 who worked very, very hard in putting this  
14 presentation together.

15 Ms. Lynn Olsen, Eileen Naughton,  
16 Greg Nicz and Ms. Amye Leong, thank you very,  
17 very much. For our Agenda Workgroup, we were  
18 looking at sort of piggybacking on what we were  
19 here last time about, talking about sort of  
20 strategies to sort of work internally, but also  
21 how to move things to the next level. And what  
22 we want to propose today is looking at some

1 communications--internal communication  
2 strategies, and even some external  
3 communication strategies. But also looking at  
4 how do we take the concept of community  
5 engagement to a new level.

6           So--but before I begin, I'm sure a  
7 lot of you have actually seen the slide and  
8 this is really what the purpose of COPR is, is  
9 to really--and I want to piggyback on--not  
10 piggyback but just use John Burklow's word  
11 about--and I'm glad that you said, Dr. Collins,  
12 that we actually have a very (stammers) skills  
13 and--that we can bring to the table. But also  
14 that our--basically, our goal, unlike any other  
15 IC, is that we can shed light on things that  
16 other ICs (stammers) that are very specific to  
17 diseases or specific to their institutes and  
18 divisions (stammers) we can do that but they  
19 can't do that.

20           So I think that's an added value  
21 for COPR. Another one is that we really want  
22 to see how do we increase public participation

1 across NIH, more from (unintelligible)  
2 perspective. So an overview of the  
3 presentation is--and we wanted to understand  
4 how do we set up a platform and also a tool to  
5 do bidirectional communication back and forth.  
6 Last time we were together, we were thinking--  
7 we are doing great work, we come here twice a  
8 year. We not only want to do work in between  
9 meetings but we also want to make sure that we  
10 document the work that we do for posterity but  
11 also for the future and also for other COPR  
12 members that actually have been involved.

13           So one of the things that we're  
14 thinking about is how do we look a tool.  
15 Another piece is how do we tie all that we do  
16 into community engagement and making it a  
17 value-added for NIH when it comes to enhancing  
18 the work that they do. And ultimately, we have  
19 to keep in mind that the mission of NIH and  
20 really turning discovery into health and what  
21 we do really has to be mission-focused. Okay.  
22 I'll be getting there. Okay. I actually want

1 to begin this slide by telling a story. Not  
2 too long ago, I actually reached out to Shaira  
3 and she put me in touch with Andrew Gootee and  
4 also (unintelligible).

5 I actually have done a lot of work  
6 with HIV. And one of things that I've noticed  
7 is that there's a disconnect between HIV  
8 advocates and when it comes to the biomedical  
9 clinical trials in HIV here at NIH. They have  
10 a wonderful relationship in some respects with  
11 CDC when it comes to the prevention and all the  
12 work that they do. But when it comes to  
13 understanding NIH and what they do here in our  
14 HIV clinical trials, it's basically a misnomer.  
15 They're not really sure what they do here.

16 A couple years ago, I attended an  
17 NIH--not NIH, HIV conference and there was a  
18 whole presentation about how do you engage NIH,  
19 what does NIH really stand for, what do the  
20 acronyms really, really mean. So--and that  
21 said, I've been working with Ms. Siskin and  
22 also Mr. Andrew to really figure out how do we

1 craft our presentation to really demystify when  
2 it comes to clinical trials and HIV prevention  
3 work, but also the work that we do  
4 individually, how do we actually archive that  
5 for the future for other members to use?

6           So for instance, if Greg wanted to  
7 use this in Wisconsin in doing rural health, he  
8 can actually use a presentation that was  
9 created. So in thinking of that and our  
10 eagerness to work and our eagerness to really  
11 do products, we wanted to create a platform to  
12 really capture all the work. So we actually  
13 had a very good, healthy discussion and  
14 (unintelligible) became the sort of vehicle and  
15 the tool that we want to use when it comes to  
16 documenting the work that we do in between  
17 meetings but also planning for the future.

18           And the key piece to this is that  
19 it's not only an internal collaboration tool  
20 but we wanted to reach out to the alumni  
21 association. We realize that, and this was  
22 said last time, that the alumni association are

1 very expertise. And that to get them engaged  
2 would be an added value and also an opportunity  
3 to keep our COPR family, which is a very select  
4 group of folks, advocating for NIH on different  
5 levels. Another piece is the shining of the  
6 light on issues. We want to make sure that  
7 there's an opportunity that NIH can use this as  
8 a tool to really understand the emerging issues  
9 of what's going on in the community.

10 We did a quick sort of scan of  
11 what we would like to have on the page and one  
12 of the things that we would like to have on  
13 there is a section on emerging issues. So as  
14 we talk among COPR members and as we talk to  
15 other folks here at NIH, you can quickly scan  
16 to see what some of the emerging issues are in  
17 a community. Today, Dr. Collins, you were  
18 very, very thrilled to see sort of the work  
19 that's been going on in our different  
20 communities. This could be something that we  
21 can document on a regular basis that you can  
22 just basically scan and see what's going on and

1 not going on and how does that help the work of  
2 NIH?

3           Okay. I'm going to use the other-  
4 -okay. Okay. Sorry about that. I will not  
5 use a mouse. One of the things that we thought  
6 about is, we don't want to just (word?) have a  
7 tool to really have internal and external  
8 communications. We want to take it to the next  
9 level. We recognize that under your  
10 administration, Dr. Collins, that you're really  
11 looking at sort of working smarter not harder  
12 and how do we look at what we're doing to see  
13 whether or not it's being effective.

14           That said, we want to work with  
15 Office of Public Liaisons to really share  
16 communication back and forth. We have very  
17 varied expertise in what we can offer to  
18 different institutes and centers and one of the  
19 things that we're thinking about is possibly  
20 having partnered with a couple of them so we  
21 can get that information and share it with the  
22 community and vice versa. And the key thing

1 and the beauty about NIH--not NIH but about  
2 COPR is that we're really a trans-NIH advisory  
3 council.

4           And as you said, Dr. Collins, in  
5 the beginning, is that there's various, various  
6 workgroups out there that are very, very  
7 specific. We're not that. We are literally--  
8 we represent a lot of different constituents  
9 and when we walk in here, we don't walk in here  
10 with hats of agendas, we walk in here trying  
11 figure out how do we work with all of NIH, not  
12 just one particular institute or center. And  
13 one of the key things that we want to think  
14 about is having using the LinkedIn platform and  
15 working with the Office of Public Liaisons to  
16 really push the NIH brand.

17           When we were here last, one of the  
18 conversations that we had is there are  
19 (stammers) there's research being done at the  
20 local level but does the community realize  
21 who's actually funding the work? So the  
22 question becomes, is how do we explore that for

1 the future to make sure that NIH is getting the  
2 credit that it does deserve and that it is NIH  
3 funded and it is part of a greater, greater  
4 agenda for NIH. Last time we were here, Dr.  
5 Collins, we had a litany of recommendations  
6 where we wanted to sort of see what your  
7 feedback was to those recommendations and how  
8 do we move forward from there.

9           And we saw a glimmer of happiness  
10 and--from you and Dr. Tabak when it comes to  
11 sort of a community engagement award. So we've  
12 been thinking on our end, sort of, before we  
13 get to so sort of (stammers) making that sort  
14 of happen and laying that foundation for that,  
15 we want to make sure we're organized  
16 internally. But also, that there were  
17 procedures in place that we can actually  
18 (unintelligible) within NIH but also make it  
19 happen.

20           So one of the things that we're  
21 thinking about is that by the next meeting in  
22 the fall, that we could start thinking about

1 those procedures. You know, what does this  
2 mean, what's realistic, what's not realistic,  
3 are we working smarter and harder, not harder,  
4 and just thinking through those issues. But  
5 also making sure that when this does happen,  
6 how do we piggyback on the other work that's  
7 begin happen here at NIH. You mentioned the  
8 NCATS. One of the things that we really were  
9 thinking about in our group is really the  
10 CTSAs.

11           They're the hotbed and the centers  
12 of excellence when it comes to researcher and  
13 community engagement. That's just an example  
14 of the work that we can do. And thinking of  
15 are there examples of effective community  
16 engagement strategies and how does that back up  
17 into NCATS and whether or not, as you're  
18 creating that by October, how does that make it  
19 into a more effective and efficient way of  
20 having community engagement a part of that.  
21 And I'm glad that Donna brought that up because  
22 that's one of the questions that we had. Is how

1 do we help you move that forward and thinking  
2 about community engagement?

3           And this is, in summary, and it's  
4 a very, actually, quick presentation. But in  
5 summary, we really wanted to map out an  
6 internal platform and a tool to really have  
7 internal and external dialog. Mapping out  
8 activities that we can do and only for us to  
9 share as COPR members and some alumni. But  
10 also to look at how the Office of Public  
11 Liaisons can be a part of that. We wanted to  
12 make sure that there was a section in there  
13 that your office and--can really tap into as a  
14 vehicle to understand what are the emerging  
15 issues in the communities but also in states or  
16 even in tribes and territories, for that  
17 matter.

18           And how do you actually take that  
19 back here and make it work for you all in the  
20 sense of how do we enhance the work that we're  
21 doing. And also looking at the community  
22 (unintelligible) one of the things that we're

1 thinking about, and I'm glad you mention NCATS,  
2 in--is how do we become a value to you to help  
3 you to start defining the community engagement  
4 piece around that. So that's one of the things  
5 that we're thinking about. And I think that's  
6 the end of my presentation. Any questions?

7 MALE ONE: Well, I think since  
8 we're a little behind on time...

9 CARLOS PAVÃO: Okay.

10 MALE ONE: ...we'll just go  
11 straight to the second presentation and then we  
12 can have some reaction and discussion about  
13 them.

14 SUSAN WOOLEY: I appreciate the  
15 opportunity to present the report of the YES--  
16 and I'll explain it in a moment, working group.  
17 This is a brand-new working group that evolved  
18 out of the meeting last time when, as you  
19 indicated, there was an interest on the part of  
20 NIH to do more with youth engagement in  
21 science, education, and the pipeline. And  
22 that's what this is about. The working group

1 members are Donna Appell, Lora Church, Gardiner  
2 Lapham and my co-chair, Stephanie Aaronson. So  
3 I want to acknowledge their work on this.

4           This is the way we saw our  
5 assignment from the last meeting, that we were  
6 to--we wanted to support NIH's efforts to  
7 advance youth education in science for the  
8 purposes of two things: increasing science  
9 literacy across the population as a whole and  
10 then also increasing the people who are in the  
11 pipeline for careers in science, medicine,  
12 prevention. So to do that, we did launch this  
13 working group, the Youth Education and Science  
14 working group. When we started to look at how  
15 we might interact and how we might support the  
16 work of NIH, we decided that the--for any work  
17 that COPR does, we probably have three levels  
18 in which we can do that.

19           The first one may be what we can  
20 do as individual people but in our own  
21 communities and our own networks. The second  
22 is that most of us or all of us are connected

1 in some way with larger groups, professional  
2 associations, other organizations. And so on a  
3 professional level, there are ways that we  
4 could support the work of NIH and help this  
5 two-way communication. And then the third  
6 level is that there may be things that we, as  
7 group at COPR, can do jointly.

8           And so we want to look at what  
9 some of the way that we, the YES working group,  
10 could work with that. So we had some  
11 recommendations that we wanted to make to NIH  
12 based on just our preliminary findings. And we  
13 realize that these are very preliminary. One  
14 of the first ones is we know that NIH has  
15 developed science education materials. A lot  
16 of the supplements are geared for middle school  
17 and high school. We think that there is a  
18 need, if we really want to increase science  
19 literacy across the board, that we need to be  
20 starting at a younger age.

21           Because in our experience, there  
22 are an awful lot of young people, who, by the

1 time of middle school, are already turned off  
2 to science. And if we don't keep that interest  
3 and keep that excitement and keep that  
4 engagement, that's going to be too late. The  
5 importance of collaborating with other federal  
6 agencies, many of us are aware of programs in  
7 science education that other federal agencies  
8 are doing. And there may be opportunities to  
9 enhance that. One possibility could be working  
10 with the Department of Agriculture, which has  
11 wellness programs and grants.

12           And as they're developing  
13 materials, perhaps being jointly done so that  
14 there is an eye to the science education and  
15 the science aspects of what is going on, in  
16 addition to the health aspects and to keep that  
17 conscious and being partners. Partnering with  
18 membership organizations that reach teachers  
19 and other perspectives that can help get the  
20 word out and can help use--increase utilization  
21 of the various materials. Some of the  
22 organizations that we thought of as examples

1 would be the Parent Teacher Association, the  
2 National Head Start Association, the National  
3 Association for the Education of Young  
4 Children, the American School Health  
5 Association, the unions, the NEA and AFT, the  
6 National Indian Education Association, the  
7 American Indian Science and Engineering  
8 society, the National Association of Black  
9 School Educators.

10 Another recommendation is that  
11 there may be opportunities to partner with  
12 industry members that have expertise outside of  
13 education, such as media and technology. And  
14 many of us have contacts or experience there  
15 that might be useful and that NIH could expand  
16 on. We think that it's important to encourage  
17 that the education outreach programs continue  
18 to reach beyond what they're doing now and  
19 making their services available to the various  
20 NIH institutes and centers. We know that the  
21 Office of Science Education and SEPA have both  
22 offered their services to other centers and

1 institutes to use their mechanisms to help  
2 increase the awareness and the knowledge that  
3 are related to individual institutes and  
4 centers, rather than creating other ones.

5           And I think that--you mentioned  
6 about the consolidation that was going on, Dr.  
7 Collins, and by one of the moves we understand  
8 is the Office of Science Education moving into  
9 a more NIH-wide, that this may actually  
10 facilitate this recommendation, that it would  
11 be more likely that the various institutes and  
12 centers would take advantage of this expertise.  
13 We think that there may also be a possibility  
14 of initiating teacher recognition programs.  
15 One of the things we're experiencing,  
16 witnessing, is that a lot of the teaching force  
17 is fairly demoralized.

18           You talk about the demoralization  
19 of the federal employees, with the potential  
20 shutdown, but I think you know that there've  
21 also been political movements in many of the  
22 states. I'm from Ohio where a lot of our

1 people in education are feeling under attack.  
2 And if we're going to ask them to do more of  
3 improving science literacy and science  
4 education, we need to let them know that we're  
5 supporting them and not being critical of them  
6 and help to do that. Another recommendation.

7           There are now being developed,  
8 common core standards in education. We know  
9 that the modules that are being (stammers) that  
10 are already done supplements by NIH do align  
11 with National Science Education standards,  
12 English language literacy standards, math and  
13 health education standards. But that as new  
14 materials are developed, that we also need to  
15 look at these common core standards because  
16 that will increase the likelihood that people  
17 in the field of education will adopt them. So  
18 we might have great materials but if nobody  
19 uses them, they sit on the shelf, it doesn't do  
20 any good.

21           We know that you are often  
22 (stammers) involving teachers as advisors in

1 the development of education outreach programs  
2 but we're not sure how much the target  
3 audience, the students themselves, are engaged.  
4 They may be in pilot programs, but are they  
5 involved in the development? And so that's  
6 something to think about. There are some  
7 things that we think, for this working group to  
8 be effective, we would need--we do want to  
9 continue to have collaboration with the SEPA  
10 and the Office of Science Education on these  
11 recommendations and on other ways that we may  
12 be helpful to NIH.

13 We (stammers) we feel that we can-  
14 -one of the ways we can help is to, perhaps, be  
15 on review boards. There is a new program,  
16 thechallenge.gov. This is a multi-agency  
17 initiative in which NIH is going to be  
18 participating. We know that it's--it's to  
19 empower the public to bring forth its best  
20 ideas and top talents. So NIH's project will  
21 be to challenge the public to submit the best  
22 hands-on experiments and make them available

1 for free in print, online, and in mobile  
2 devices.

3           And these would be ones that are  
4 accessible and available and not costly. But  
5 we feel that we may be able to contribute to  
6 that by perhaps being on review boards for  
7 considering the applications that come in and  
8 which ones would be the ones that would be  
9 selected as the top ones. We--we feel that we  
10 also are in a position where we can perhaps let  
11 people know about the resources that are  
12 available from NIH. But we need resources from  
13 NIH to be able to take forward.

14           And then we also know that we  
15 would need responses if we were wanting to do  
16 things, if we had questions, and we need  
17 logistical support. So what are we going to  
18 do? Well, what we have done already, we have  
19 conference calls, we have a preliminary review  
20 of the website, we have met with Dr. Fukes and  
21 Dr. Beck about what they're doing. And we have  
22 identified a few pilot sites that could be used

1 for the Challenge program. Between now and the  
2 next meeting, what we think we can do is we can  
3 collaborate and find out more about what's  
4 going on in ways that we can work strategically  
5 with NIH on these science education  
6 initiatives.

7           On the level--the--sort of the  
8 tier one, the personal networks, we have COPR  
9 member, who knows the national PTA president  
10 and is willing to talk to that person about  
11 perhaps getting an item in a newsletter about  
12 the importance of science education and some of  
13 the materials that NIH has to offer. And we  
14 could draft a letter for the PTA membership  
15 that could go into their newsletter, assuming  
16 that that was received well. On the tier one  
17 or two, we could begin to develop resources  
18 that could be used for presentations to our  
19 all-owned networks.

20           And then on a tier two, we can  
21 share with our--through our networks,  
22 information about the availability, the launch

1 of the possibility for thechallenge.gov lessons  
2 to get the word out to people. So the phase  
3 three, after our next COPR meeting would be to  
4 actually participate in the panel review for  
5 the submissions, begin sharing information  
6 based on the presentations that we would be  
7 working on with constituents and community  
8 groups. And perhaps make further  
9 recommendations based on more knowledge about  
10 what's going on at NIH.

11           And then the last thing we would  
12 do, we understand that working groups exist for  
13 two years, so at the conclusion of this, to  
14 help roll out the programs that are identified  
15 through challenge and create a final report.  
16 And part of the final report might be to  
17 explain not only how this project but figure  
18 COPR projects could work together and how we--  
19 the--what processes they might be able to use  
20 to support NIH initiatives. So I think at this  
21 point, then we open it up for any questions,  
22

1 comments, feedback on either of the  
2 presentations.

3 MALE ONE: Okay. I'm told that  
4 we don't have any public comments that have  
5 been submitted, which means that we have as  
6 much time as we expected to have for discussion  
7 and discussion of the next steps. So I'll turn  
8 it over to you, Dr. Collins, if you had any  
9 comments to make on this presentation first and  
10 then open it up for discussion.

11 FRANCIS S. COLLINS: Well, thanks  
12 to both of you for a very helpful presentation  
13 about the discussions you've been having.  
14 Maybe I'd like to start sort of in the bigger  
15 picture and then come back to YES as a specific  
16 targeted project. I think it would be helpful  
17 to get a sense about your views about COPR's  
18 most effective role in this enormous landscape  
19 of needs. Let me just say how much, over the  
20 course of my decades and biomedical research, I  
21 have been influenced and value the input from  
22 public representatives.

1                   Sometimes that has come in the  
2 form of individual relationships with  
3 individuals who are, themselves or in their  
4 families, facing a medical challenge and  
5 seeking research as a hope for, at least, in  
6 the long term, potential solution. Sometimes  
7 it's been in more general conversations about  
8 policies that we should be implementing about  
9 privacy or discrimination, for instance. But  
10 it has always been a critical part of ways in  
11 which I have found this to be such an  
12 interesting and important field to try to get  
13 things right.

14                   And so it does seem to me that one  
15 of the things I would most like to hear from  
16 you is how can we, with this group of 11  
17 dedicated people, each with your own area of  
18 special expertise, sort of chunk up the  
19 discussion as much as we can, to the point of  
20 the bigger questions of how can NIH do a better  
21 job of getting our message out and how can we  
22 do a better job of hearing, coming back to us,

1 the messages from the public about what their  
2 concerns are, that perhaps that we haven't  
3 fully addressed.

4           And that means going beyond any  
5 specific special knowledge that each one of you  
6 has and trying to create this community of  
7 expertise represented around the table to  
8 advise us. Another thing I'd like to sort of  
9 emphasize, we don't expect you to both advise  
10 us and implement that advice. You're 11  
11 people, you probably can't be the sole  
12 purveyors of NIH's message, as much as you  
13 might desire to do so and have been doing so.  
14 Clearly, if we're going to make a difference in  
15 terms of getting the word out, it's going to  
16 have to come through many other channels and  
17 not just you personally.

18           In fact, I would worry that you  
19 may have taken on board, in terms of your own  
20 responsibilities for being COPR members, some  
21 sense that you should be out there talking to  
22 your own rotary club and making the case for

1 NIH. If you feel like doing that, that's great  
2 but I think our expectations, our hopes, are  
3 that you're primarily to give us advice about  
4 how to come up with programs that then can be  
5 implemented by a much broader group of experts  
6 with various communication channels. And it's  
7 not just you that needs to take that to the  
8 next step.

9           So maybe I'll stop there and see,  
10 does that sort of general framework fit with  
11 what you've been expecting or does that sound  
12 different?

13           GREG NICZ: Great. Yes. And I  
14 think an example of that advice, some of the  
15 things we've talked about is, first of all, the  
16 branding. We only--if half the people don't  
17 know what we are, we don't, you know, what's  
18 the input from the folks who don't even know  
19 who you are? So that's an issue that I think  
20 we all need to push on. But if you think about  
21 what the private sector does really well and  
22 with all the new techniques that they have, is

1 they're very good at targeting their messages.

2 Okay.

3 FRANCIS S. COLLINS: And they  
4 spend a lot of money on it, too.

5 GREG NICZ: Very good at  
6 targeting their messages. So in (stammers) my  
7 world, with the Community Health Center  
8 program, you guys have embraced the--the health  
9 disparities and--and saying what we want to do  
10 as NIH is we have an obligation to try to help  
11 this country resolve some of those health  
12 disparities. We have an army of folks out  
13 there in the Community Health Center program  
14 that are engaged in trying--trying to change  
15 that. So that if you were going to target,  
16 what would you target us with?

17 And so the advice is, you know,  
18 part of the advice is to say that we all have  
19 these continuance where we can bring a little  
20 bit to the table on that. But the general  
21 themes that evolve are saying let's take a--  
22 take a lesson from the private sector, who've

1 made a lot of money targeting specific clients  
2 based on their preference. And we can look at  
3 the constituencies that are out there and say  
4 how do I convince my colleagues, as a health  
5 center director, that you have something to  
6 offer us and that you can make us better.

7           And so I need to work with your  
8 folks to figure how that--my community can be  
9 targeted. And in targeting it, if we pick up  
10 and use that data more, the value to the  
11 taxpayer of the research investment at NIH  
12 grows with every additional use of the results  
13 of that research.

14           CARLOS PAVÃO:       As I'm hearing  
15 what you're saying, Greg, and--and I'm hearing  
16 what you're saying, Dr. Collins. And I have to  
17 acknowledge (unintelligible) as an undergrad  
18 and I have heard numerous times from John  
19 Burklow and (unintelligible) all the great work  
20 that they're doing. And I'm always in awe of  
21 the different levels of outreach that's  
22 happening to different media outlets. But one

1 of the questions that I'm always asking myself  
2 is what's that gold standard, how do you know  
3 it when you get there, how do you measure it.

4           STEPHANIE AARONSON: And--and I  
5 think that's a big question to be, you know, to  
6 be asked and I'm sure a lot of folks ask that  
7 question. But I think to--let's--I always--  
8 when looking at public health, you know, we  
9 start with the risk, you know, what--what are  
10 the risks and you focus on the risks but you  
11 forget all the positive and protective factors.  
12 Starting off with what's been done so far is  
13 amazing.

14           The question is, is how do we  
15 fine-tune that to become either more  
16 measureable or more targeted but also setting a  
17 gold standard. And also, what I've heard from  
18 the community, is that the different ICs,  
19 sometimes, they have different messages. And--  
20 and they brand themselves a little differently.  
21 So how do we coalesce that together and coming  
22 up with one central way of doing that. And

1 that's the question that I've heard from  
2 different folks.

3 I think that there's a couple of  
4 different levels of input we could have, as we  
5 talked about in the YES working group. And  
6 then specific to your question. But when  
7 you're--when you have a goal or objective, I  
8 think that you can look at the expertise in  
9 this group and say this is what we want to  
10 accomplish, let's pull together an advisory on  
11 it, let's looking at strategic level. And  
12 there's a lot of people that have information  
13 based on the constituency you're looking for.

14 And so I think that sometimes we  
15 can provide a role as a group and sometimes you  
16 should pull us specifically in for other  
17 meetings and other brainstorms. And then  
18 specific to the group in what you feel like  
19 you're looking for, and it's building a little  
20 bit on what they were saying, but, you know,  
21 what is--what is a group you're trying to  
22 influence, what do you want them--what do you

1 want that behavior to look like, what does  
2 success look like and then let's start  
3 building--and some of us can help you with  
4 this, a map to reach them.

5           And we need to break it down  
6 because the notion of NIH trying to say we just  
7 need to reach everybody fast is never going to  
8 work. So looking at the specific groups you  
9 feel like are the most influential that you  
10 really want to impact right away and building a  
11 map to them. There's actually, like, a Harvard  
12 program that Nike has used when they're looking  
13 at their stakeholder groups to say, these are  
14 the groups we need to influence. Whether  
15 they're consumers or whether they're NGOs in  
16 communities where they've got plants, what do  
17 we want them--what's the behavior we want from  
18 them and how are we going to find the points of  
19 influence to get to them?

20           And they've got (stammers) several  
21 different mapping units and that would be a  
22 commercial industry example of trying to bite

1 it down. And then you've got the roll-out  
2 effects. So I think a lot of us here would be  
3 helpful in looking at that, you know,  
4 otherwise, it's just an example of connecting  
5 you with people at Nike who have done it and  
6 done it really well, so that's one thought.

7 DONNA APPELL: I love listening  
8 to Stephanie because she's just got so many  
9 brilliant ideas and plans and stuff, so I'm  
10 going to be the real simplistic little  
11 Pollyanna, you know, token rare person on this  
12 group and say I'd like to apply my little  
13 thought process into her big plan. So I look--  
14 so this is going to be really, like, weird to  
15 think of NIH like this. But I work with  
16 Hermansky-Pudlak Syndrome. Nobody the heck  
17 knows about what Hermansky-Pudlak--and so all  
18 of my life, I've been climbing the mountain,  
19 trying to get name recognition.

20 Which is exactly the same place as  
21 the NIH is right, trying to get name  
22 recognition. So in a way, it's kind of like

1 NIH is like a rare disease, nobody knows what  
2 it is and I was just kind of trying to make an  
3 analogy here. So I'm blushing and embarrassed.  
4 But anyway, so think of it as a rare disease  
5 and you're trying to get it out to the world.  
6 And I really know, very closely, scientists  
7 that work and dedicate their lives to the  
8 betterment of mankind.

9           And they are inept at blowing  
10 their own horn. They cannot tell the world how  
11 unbelievably super they are. So where I would  
12 like to see you utilize COPR better, in  
13 Stephanie's major plans, is we are the face of  
14 NIH. We are the face of NIH because  
15 researchers tend not to be very good at being  
16 their face. So we are their horn-blowers. We  
17 can toot their horn, we can show the world,  
18 through large, great ideas but to consider us  
19 your cheerleaders. We are your inspiration and  
20 your cheerleaders and that's what you need to  
21 use COPR for.

22

1                   GARDINER LAPHAM: Well, we need to  
2 be all piggybacking on one another. When I  
3 first came on COPR, realized that there are  
4 other people that I had known on COPR. And  
5 COPR, in fact, has a 19-year history at NIH,  
6 which means that in every year, there have been  
7 quite a few people on board. So we have a--we  
8 have a good repository since 1992, I believe,  
9 of people who have not been tapped after  
10 they've come off of this table, if you will.

11                   And so the platform that we are  
12 suggesting through LinkedIn, would be your  
13 instant access, either individually or as a  
14 group to us. It is hard to keep all of us  
15 updated twice a year around this table.  
16 Utilizing technology, we believe, is the best  
17 way of doing that, just to keep each other  
18 informed and keep the work of COPR going. But  
19 we also believe that it is an important tool  
20 for you to use to get in touch with us to find  
21 out what you want to know about.

22

1 All of our backgrounds have been  
2 vetted, quite frankly. We were selected by  
3 your teams because of the diversity, the  
4 geography the variance. But in addition to  
5 that, when we came together as a COPR, we have  
6 found that we've influenced one another, so  
7 that one person's individual opinion may or--  
8 may, most likely, get changed because of the  
9 interaction of other experts and professionals  
10 and people with experience in this room who  
11 represent different consumer points of view.  
12 So individually and collectively, there is a  
13 wealth of information. The dynamics of that  
14 interaction in COPR is very, very important and  
15 it can be accomplished through this platform.

16 So I see my role as advising you  
17 but I need to know what areas you want advice  
18 on. And to give us time to do appropriate  
19 interactions, so that we can come up with a  
20 view that makes sense from a consumer  
21 perspective. To speak to--a way to decrease  
22 the rare disease of NIH in terms of trying to

1 get the word out, to me, it's about reputation.

2 Those of--those of us who either have  
3 benefitted from NIH or are on the payroll of  
4 government through NIH know it and get it.

5           There are so many others that  
6 don't understand it. And so much about  
7 reputation is connecting the dots so it becomes  
8 human, that there's a personal touch. So help  
9 me understand what a genetic genome means to me  
10 as someone who may have a predisposition for  
11 rheumatoid arthritis. And to do it in a way  
12 that says, wow, aren't you glad, as a person  
13 who just heard this 30-second spot either on  
14 the radio once a week, some new spot that  
15 brings that translational side of biomedical  
16 research, to touch a human being. That  
17 connects the dots without saying, this is what  
18 NIH is.

19           It provides that human side of the  
20 story. There have been hundreds of examples  
21 currently on TV and on radio that make that  
22 connection and there's lots of examples of that

1 I would love to see NIH make that, you know,  
2 one for every day on the radio would be great.

3 LYNN OLSEN: In partial answer to  
4 your question, I wanted to point to one of the  
5 suggestions that have been made here and that  
6 is to pair individual COPR members with some of  
7 the OPLs. And our idea there is that it's a  
8 way of building direct connections and it's a  
9 way of building models, perhaps, examples. So  
10 that what you have here are different groups  
11 that might be important targets for  
12 communication, whether it's legislators or  
13 lawyer groups, patient groups or, in my own  
14 example, professional medical societies. That,  
15 by working together, we can think of examples  
16 and then they might be applied to, you know, 50  
17 other groups.

18 But we will better learn  
19 communication strategies through that way. So,  
20 for example, I can tell you a lot about, at  
21 least, how pediatricians communicate or don't  
22 communicate. I suspect it's similar with other

1 physician groups. We know, for example, from  
2 our own recent surveys, that if you think  
3 you're going to rely on social media strategies  
4 to reach pediatricians for professional reason,  
5 it's just not true. They're really not using  
6 social media yet for professional applications,  
7 personal, yes.

8           And I'll just, you know, one  
9 example that always comes to mind, the best I  
10 know of in modern public health and education,  
11 was something the academy did with NICHD, using  
12 the science, developing the Back to Sleep  
13 program. And, in fact, also bringing in as  
14 partner Pampers. So it was an incredibly  
15 effective communication strategy, you know,  
16 that we know has really dropped SIDS deaths  
17 tremendously. So I think by--that was our  
18 (stammers) the idea there that we could build  
19 better models and examples.

20           CARLOS PAVÃO:       I love this  
21 question about, sort of, how do we better get  
22 the NIH brand out and how to have folks

1 understand what NIH is all about. But when I  
2 sit here--and I do work in the Caribbean, I do  
3 work in the U.S. and we cover tribes and we  
4 also cover the Pacific jurisdictions. But I  
5 think it's--my first question is, who is your  
6 audience? And I'm trying to think of, like, an  
7 appropriate an example, piggybacking on what  
8 Donna was saying about sort of how do you make  
9 this kind of real and applicable to--how do you  
10 do this?

11           When you look at, like, the state  
12 of Florida and how they market themselves, they  
13 market themselves kind of incrementally, I see,  
14 you know, as a vacation spot, whatever the case  
15 is. And they market on one of their best  
16 attributes that people can really tag into,  
17 saying I can relate to this. When I look at  
18 NIH and I can see a lot of great things. My  
19 question becomes kind of--and there's different  
20 forces going on. You have social policy  
21 forces, you have sort of what consumers are  
22 ready to sort of digest, is maybe kind of

1 taking a scale back and say, you know what,  
2 let's just focus on not one, you know,  
3 institute or division but let's focus on a  
4 cross-trans NIH theme that cuts across  
5 different aspects.

6           One might be health disparities.  
7 I don't know. And then kind of figuring out,  
8 how do we market that but also bring in  
9 (unintelligible) NIAAA and NIMH, slowly. And  
10 this way, you're--you're getting sort of an  
11 anchor versus trying to say, here is not the  
12 (word?) but here is the store and all the  
13 different components in the mall, whatever you  
14 want to call it, and digest it. I know for  
15 some of us, I know for me when I came on, I was  
16 overwhelmed with all the acronyms and all the  
17 different institutes and what they meant and  
18 how they overlap.

19           So the question is, is how to find  
20 those kernels across. And I think that's, for  
21 me, sort of the nugget there and how do we  
22 maximize on that, so...

1                   AMYE LEONG: I think also, you  
2 know, if the question is who are your audience  
3 and there's multiple audiences but then once  
4 they're identified, I think we also need to  
5 take a look at the sensitivity of the messages  
6 that would be sent to the audiences or the  
7 subpopulations within that particular  
8 population. And I'll give you an example. For  
9 many cultural groups or within the Native  
10 American population, sometimes the sensitivity  
11 of that particular topic or subject may not  
12 want to be presented or discuss, some may call  
13 it denial, but others, there's the cultural  
14 aspect or the teachings of--we don't want to--  
15 we don't want to speak about that particular  
16 subject because that may bring about the onset  
17 of that disease or the health condition.

18                   And so, you know, we want to--in  
19 some cases, they may say, we don't want to have  
20 that discussion at this particular time. So we  
21 also, you know, have to think about the  
22 appropriateness of how do we send that health

1 message out. I think, again, the National  
2 Institute of Arthritis and Musculoskeletal and  
3 Skin Diseases are really taking a look at that  
4 through this qualitative research of working  
5 with multiple--multicultural groups in  
6 designing and developing those cultural  
7 (stammers) culturally-appropriate messages to  
8 get that message out but that recognizes the  
9 sensitivity and the appropriateness of how to--  
10 how to design that message.

11           So, you know, yes, it's very  
12 important but even within subpopulations, there  
13 may be a generation of let's say the ledgers  
14 that say, you know, our teachings--our  
15 teachings say this. Maybe the younger  
16 generation says, yes, it is important to hear  
17 this. So you have to, even within my, you  
18 know, within my tribe or within my population,  
19 I have to kind of maneuver a way to where I can  
20 get the message out but, yes--but also I'm  
21 cognizant of who is my audience.

22

1                   FRANCIS S. COLLINS:    So this is a  
2 helpful conversation.  I want to follow-up on  
3 what Carlos said and then we should come to the  
4 (stammers) YES program in a minute here, about  
5 the importance of having a theme.  Because I  
6 think sometimes it does help these  
7 conversations if it's not about everything but  
8 it's about something.  One of the things that's  
9 deep concern to anybody's who looking at the  
10 state of health in our nation, which represents  
11 a threat to the gains in longevity that have  
12 occurred over the last many decades and might  
13 actually result in our children and  
14 grandchildren having less life expectancy than  
15 we do, is obesity.

16                   And all of the efforts that we  
17 have been making in research to try to identify  
18 causes, and there are many, and interventions  
19 that--and there are some that actually work,  
20 have not resulted in a change in what continues  
21 to be a really frightening trend across the  
22 country.  Particularly so in certain geographic

1 areas and certain groups, with--predicted \$150  
2 billion this year going into healthcare that's  
3 directly a result of obesity. Where as NIH is  
4 spending less than a billion dollars on  
5 research on obesity because we have what we  
6 have.

7 Connection to diabetes is a hugely  
8 important part of this. We know interventions  
9 that could be very valuable here if implemented  
10 but most--it seems most of the public has yet  
11 to fully embrace the need to take action or  
12 finding taking that action very difficult. I  
13 notice you have Let's Move there in front of  
14 you, so certainly the First Lady has made an  
15 enormous contribution to this issue by putting  
16 her own credibility out there. But focusing  
17 particularly on childhood obesity, which is a  
18 very appropriate focus, because that's where  
19 maybe the greatest fears are that 17 percent  
20 now of kids are actually medically obese.

21 But there's a third or more of  
22 adults who are obese and our interventions

1 there, perhaps have not been very successful.

2 So I'm just wondering, as a theme, as an

3 example of something, that if we were going to

4 really try to energize our relationship with

5 COPR around something and seek your advice

6 about, okay, what's the public's reaction to

7 this campaign to try to bring this attention?

8 And what should we, NIH, be doing both in terms

9 of maybe additional research we haven't thought

10 of to try to figure out how--how to influence

11 health behaviors in a more effective way.

12 And how can we make sure that what

13 we are doing and have done in research is

14 actually getting distributed to the point where

15 people can take advantage of it. It's just an

16 idea. So what's the response there?

17 EILEEN NAUGHTON: (unintelligible)

18 as a point for, to me, a very useful and

19 meaningful document produced by NIH with its

20 partners, which had the benefits of practices

21 that were effective, contained in that and

22 would provide the framework for us to start a

1 mapping, if you will, to actually get those  
2 around us in society. To make sure the social  
3 determinacy, the world around us was  
4 reinforcing those principals. Vending  
5 machines, etcetera, were all reinforced. Bring  
6 employers in, bring industries in and also to  
7 review our entire food policy in the state.

8           The strategy for agriculture and  
9 also the food deserts in our inner cities where  
10 we're seeing too many children with adult-onset  
11 diabetes. And we're coming up with very  
12 creative solutions and this is only March that  
13 this was available to us. We're talking about  
14 mobile type vans, like blood centers might use  
15 to bring farmer's markets into inner cities,  
16 bringing them fresh produce. And also having  
17 the farmers be able to grow the produce that  
18 various ethnic groups really like and would  
19 enjoy.

20           We've been--so it's a whole food  
21 strategy, including development of a food  
22 council, so we're starting to get the

1 infrastructure, the support mechanism in the  
2 wider community, reviewing state laws about  
3 various food chains, about calories, about  
4 what's in--making partners, as the First Lady  
5 has done with Walmarts. Which is providing  
6 fresh fruits, vegetables, whole grains to the  
7 public that really could not afford these in  
8 the past. So, you know, I want to say that  
9 this is your diagnosing test for diabetes,  
10 followed up the strategy information in that  
11 release.

12           There are still some outstanding  
13 questions for us to deal with on ethics of  
14 determining someone might be subjected to  
15 having diabetes and what kind of consequences  
16 our insurance companies, not just healthcare,  
17 our life insurers, etcetera, put those  
18 individuals immediately at high risk, making us  
19 not really employ that as a tool. Because  
20 people are hesitant that if they are diagnosed  
21 with this, that they wouldn't be able to have  
22 reasonably-priced insurance and be motivated to

1 take those actions that will, in fact, and have  
2 shown work.

3 So we have a whole host of society  
4 things going on that don't really reinforce a  
5 lot of the good things we're doing. So your  
6 federal partners are important, even beyond the  
7 HHS network to see that this--these things  
8 happen. But this is a wonderful positive  
9 direction that NIH is in now.

10 SUSAN WOOLEY: Thank you. I  
11 wanted to draw on the--what you're talking  
12 about, translational sciences and think about a  
13 way that we can perhaps work together in  
14 thinking about translation as broadening the  
15 concept of translation, not only from getting  
16 something from the lab to clinical but  
17 translating--we think about language and  
18 culture, but I think we also translate across  
19 systems. So even the word translating, in the  
20 medical community might be one thing, in  
21 linguistics community means something very

22

1 different and another community, it means  
2 something different.

3           So are we communicating well? The  
4 other thing is that we may need NIH's help in  
5 the research end of implementation. Program  
6 implementation. You know, what is effective in  
7 getting something not only to a clinical place  
8 but to--to scale? You know, how do we get--  
9 what are the--what are the tools that are  
10 effective? And I don't know that we have the  
11 research base behind a lot of that and that  
12 might be something really great for this center  
13 to think about.

14           I think that there are other  
15 agencies that could use that research to help  
16 get things disseminated. As a--and as an  
17 example, since my field is in the school field,  
18 what we may need is in research that NIH is  
19 supporting related to children and youth that  
20 encourage their measures on school achievement  
21 that are included in NIH studies. Because  
22 that's going to be convincing to the

1 gatekeepers in schools to adopt programs or to  
2 look at health issues. And that might not be a  
3 priority, necessarily, of the health agency,  
4 but in order to get your programs implemented,  
5 it might be an important piece of the research.

6 So I think those are things that  
7 we can, perhaps, help with--with, is bringing  
8 some of these things to NIH's attention.

9 STEPHANIE AARONSON: I just want  
10 to get back to the idea of a theme--resonates  
11 really well with me, something to ground all of  
12 our work around and to coordinate more  
13 deliberately with OPL around. Makes a lot of  
14 sense. I like obesity because it's cross-  
15 cutting and I think it's something that all of  
16 our various skill sets and experiences can  
17 somehow speak to. I think it's a very good,  
18 broad topic (unintelligible) because I was  
19 listening to you earlier talk about the other  
20 advisory groups that report to you and the--  
21 they ACD (unintelligible).

22

1           Are there any synergies there  
2 between their work and what could be going on  
3 here? And might obesity be an example where  
4 you might benefit from both and, you know,  
5 working together from different perspectives.

6           FRANCIS S. COLLINS: There  
7 certainly could be. At the moment, they've not  
8 focused on this particular issue. There is a  
9 trans-NIH obesity research working group that  
10 is trying to coordinate amongst the institute's  
11 research in this effort because it involves a  
12 lot of different ICs. But perhaps,  
13 particularly, the Diabetes Institute and the  
14 Heart, Lung, and Blood Institute, but many  
15 others also have a stake in this. I mean,  
16 heck, cancer is more common in obesity and we  
17 don't know why. We really don't know why.

18           So that kind of research  
19 discussion goes on in terms of basic questions  
20 about what are the factors involved. But so  
21 far, I've (stammers) asked the ACD to sort of  
22 turn their attention to this as a research

1 advisory group. I guess COPR's input, though,  
2 I think, would be particularly helpful in  
3 understanding what's the public's response to  
4 this sort of increasing drum beat of why this  
5 is important. Are we--are we getting that  
6 message out there in a way that is actually  
7 constructive or are people feeling uneasy and  
8 perhaps even a little bit offended by this  
9 focus on the fact that a lot of us are  
10 overweight.

11 CARLOS PAVÃO: With all due  
12 respect, Dr. Collins, as I'm thinking about a  
13 theme--and I love the fact of obesity and  
14 healthy living and I think it (stammers) really  
15 cross-cuts across different cultures or  
16 different groups. But when I think about that--  
17 -and I live in Atlanta. And the agency that  
18 really has taken the lead on this is CDC. So  
19 as I think about that, I'm thinking, you know,  
20 what is--and I'm going to be very honest with--  
21 this is all with due respect.

22

1           Is that what can NIH bring to the  
2 table when CDC has been doing a lot of work  
3 with this and has really done a lot of  
4 community mobilization around this. And  
5 especially with HERSA (unintelligible) moving  
6 forward to expanding federal qualified health  
7 centers. And I'm thinking I love the word  
8 theme but let's think outside the box and think  
9 about maybe trans-federal theme. And I  
10 actually participated in a webinar last week  
11 and it was a powerful webinar. And it's the  
12 power of peers, how social groups can drive  
13 behavior change for health.

14           And it's this woman, I can't think  
15 of her name, but I think her last name is  
16 Freedom--Freedman, and she basically has  
17 studied why people make choices. Because she's  
18 studied it from an international context and  
19 she's studied about how people access health.  
20 And I think there's a lot to be learned. And  
21 the weird part is, is this is geared towards  
22 folks who are working at CDC and

1 (unintelligible) looking at social behavioral  
2 health models and how to move that forward.

3           So the questions becomes--and I'm  
4 going be kind of black and white, is I think  
5 CDC has value to be bringing to the table and a  
6 lot of knowledge. I think NIH has the research  
7 to support what they're doing and I think HERSA  
8 can be the vehicle to do that. And I think  
9 that is, in this era of, you know, money is  
10 tight. It might be an opportunity to really  
11 make a lot of impact with little dollars.

12           FRANCIS S. COLLINS: No, I think  
13 your point's very well-taken because this  
14 clearly does cut across many different  
15 agencies, not just in the federal government  
16 but also in other places. We do have at NIH  
17 maybe some resources that could be thought  
18 about to address some of the lingering research  
19 questions. So we now have this HMO research  
20 network that we're funding, which collectively  
21 follows 13 million people. They all have  
22 electronic medical records already. These are

1 the Kaisers and the Marshfields. I'm sorry,  
2 Greg has left. The Geisinger, all of these  
3 very forward-looking HMOs that have a pretty  
4 good system in place.

5           So if you wanted to try to collect  
6 information from patients about the obesity  
7 problem and the interventions that are  
8 available, trying to find out what public  
9 attitudes are, as well as what has public  
10 receptivity been to various interventions and  
11 what's worked and what hasn't. We have a  
12 pretty good laboratory for doing that. We also  
13 have the CTSA, so its 55 clinical centers that  
14 all have community outreach programs that also  
15 could also be brought to bear on this. Nobody  
16 has so far sort of tried to figure out how to  
17 put all of those resources to this problem.

18           And I'm just thinking out loud  
19 about whether that would make sense and whether  
20 COPR, as a connection to the public, would see  
21 that as a reasonable thing for us to put some  
22 focus on or whether (unintelligible).

1 CARLOS PAVÃO: I would just add  
2 that CDC has the last piece as prevention.

3 FRANCIS S. COLLINS: Yes.

4 CARLOS PAVÃO: And that's what  
5 people remember. NIH does not. So--and I  
6 think that's--when you're looking at weight  
7 and--and I'm being very honest with you because  
8 it's about doing things that have a meaningful  
9 impact, so I'm done. (all talking at once)

10 MICAH BERMAN: Yeah, I mean,  
11 there's a--there's a lot of prevention  
12 research, yeah. I mean, there's, I mean, the  
13 Framingham Heart Study has now been  
14 (all talking at once) applied towards new  
15 findings on obesity and how obesity has--  
16 spreads through social networks and so forth.  
17 Just to respond to your question--and I think  
18 your instincts are right, that there is a  
19 significant public communications issue  
20 surrounding the issue of obesity. I've--I've  
21 dealt with this on the tobacco control side and  
22

1 now that I'm moving more into the obesity  
2 issue, as well.

3 I think it's everyone's first  
4 instinct is that this an issue of personal  
5 choice and that's the end of the story and  
6 there's not really much to say beyond that.  
7 And all of the research is suggesting that  
8 that's not the case at all. There's--besides  
9 just the medical side, there's social and  
10 cultural and environmental and economic factors  
11 that are very well-documented, they go into  
12 that. So I think, you know, the research that  
13 NIH is doing is so important in helping to  
14 change the way people think about the issue.

15 Because I really think obesity is  
16 not an issue that we're going to be able to  
17 tackle until we change the way that people  
18 think about it and conceptualize the issues.  
19 So I don't necessarily have good answers but I  
20 think that is a good issue that COPR could dig  
21 into more and think about how some of the  
22 findings can be communicated in a way that will

1 change the way that people start to think about  
2 this.

3           STEPHANIE AARONSON: So about two  
4 or three years ago, I engaged in this exact  
5 project for public broadcasting, public media,  
6 where we essentially recognized there was a  
7 problem. We were asking--we were asking to  
8 help, we did a really aggressive deep dive, we  
9 started looking at all of our resources and  
10 assets across the entire system in 360  
11 communities. And then did an even further deep  
12 dive of what we had existing. Because when we  
13 talk about budgets, of course, I'm in the--  
14 we're in the same boat.

15           And it was a really great exercise  
16 to work across all of our stations, see what  
17 assets were available, pull stuff together, see  
18 where voids were in the marketplace. And then  
19 even dive deeper to see what can media do, how  
20 is it different, you know, what are we  
21 learning, what's working and not. So you ask--  
22 it's a great question. I think it could take a

1 lot of work. I don't know if it's something  
2 that just COPR could take on. I think a lot of  
3 us are really interested in the topic.

4           So I feel like there's an approach  
5 to go about it for NIH and then--I know you say  
6 I look at the big picture. Then just  
7 tactically--I do feel like there's messages for  
8 different people. You know, visualizations can  
9 do a lot. Sometimes it's the research that  
10 does a lot. Every person's going to respond to  
11 different things and I think that it's going to  
12 take a village. What, it took us 30 years to  
13 get here, right, and it's going to probably  
14 take a long time for us to reverse everything  
15 around us.

16           Whether it's policy, whether it's  
17 the environments, whether it's individual  
18 attitudes. And as soon as we change the  
19 attitudes, can they actually react to it? One  
20 of the things that we've learned a lot, it's  
21 about--for a lot of kids, it's about the  
22 proactive story. So not about--it's not a

1 lecture of what you shouldn't be doing but,  
2 wow, look what you can do. If you have  
3 broccoli in your body, look at the physical  
4 reactions you have differently. Now, you'll  
5 win that soccer game or whatever.

6           So we've really spent a lot of  
7 time just trying to show the positive side of  
8 what the goal is, which is playing soccer or  
9 reading or whatever--how it helps your brain.  
10 And I think that's made a lot of difference.  
11 But it's--we want to test that. We'll try to  
12 take our content to, and look at, over time, if  
13 people are actually reacting to it and how  
14 they're changing their behavior. And, you  
15 know, that would be ideal. But I think that it  
16 would be a really rich, deep dive for us to  
17 collect all of our stuff and then figure out  
18 how we work with the resources you have here.

19           MICAH BERMAN:       I know we were--  
20 oh, go ahead, Dr. Collins. I was going to say  
21 I know there's not enough time to discuss it  
22 fully but the other question Dr. Collins posed

1 was feedback and how, you know, COPR's advice  
2 on getting the public's feedback on NIH  
3 programs, activities, plans.

4           AMYE LEONG: Just one last piece  
5 in terms of translation. Another element is  
6 translating the scientific findings into a  
7 plain language. And considering that. And  
8 also another segment of translation is how do  
9 you translate scientific findings into plain  
10 language and then even translate that into  
11 other languages. And, you know, Navajo is a  
12 very descriptive language and how do you--so  
13 it's considering that--that there's multiple  
14 definitions of translation but I also want to  
15 just underline the fact that we need to also  
16 consider the plain language piece.

17           MICAH BERMAN: We only have a  
18 couple minutes, so I also wanted to make sure  
19 you have a chance to respond to the YES  
20 workgroup, too, if you want to  
21 (unintelligible).

22

1                   FRANCIS S. COLLINS: I wanted to  
2 go there. I was feeling badly that we have not  
3 focused enough on what has been currently an  
4 example of a specific theme. So I appreciate  
5 the work that this working group has done in  
6 the phases one through four that were outlined  
7 by Susan. It does seem like a pretty ambitious  
8 list of next steps. And again, just as we were  
9 talking about with the idea of working on  
10 obesity, there's obviously a lot of players out  
11 there in terms of youth science education, that  
12 we want to be sure are being fully tapped into,  
13 as far as partners.

14                   And again, I would just urge you,  
15 as you're going forward, to focus specifically  
16 on sort of the larger question of giving us  
17 advice about how to put in place the kinds of  
18 programs that will have an impact on youth  
19 science education. And not, perhaps, to feel  
20 as if the sort of one-off conversations that  
21 you might be able to have are really the main  
22 responsibility. Because I think if we're going

1 to be successful here, it has to be on the  
2 basis of outreach on a broader scale than any  
3 individual can possibly accomplish by those  
4 one-on-one conversations.

5           Even though that may be useful in  
6 information gathering, I guess, again, I'm  
7 urging that you look at this on the larger  
8 scale. So I will look forward to hearing how  
9 you move this forward and I'm aware that you're  
10 working closely with the Office of Science  
11 Education and SEPA, which is soon to be sort of  
12 reorganized a bit. And this will be also  
13 helpful to get your input about how we should  
14 be using our resources. I mean, you may know  
15 that NIH, unlike NSF, has not had a strong  
16 congressional mandate to focus on science  
17 education.

18           We're kind of sneaking around a  
19 little bit to do this but we believe it's very  
20 strongly justifiable on the basis of other  
21 mandates that we have. But it's not as if this  
22 was a program that's specifically mentioned in

1 statute and a budget is specifically given to  
2 it. We are doing this because we think it is  
3 critical for the future. But that means we  
4 have to be really thoughtful about how the  
5 resources get expended. And that's where we  
6 could really use your help as this project  
7 moves forward. If you see other areas that we  
8 should be thinking about or if you see things  
9 we're doing that just really don't seem like  
10 they're all that useful, that's helpful, too.

11 MALE FOUR: Permission to find a  
12 camera.

13 SUSAN WOOLEY: I just want to  
14 appreciate--I appreciate what you're saying. I  
15 think that we struggled with the working group  
16 on sort of the charge. And felt that we could  
17 bring advice but I think we felt, from the last  
18 meeting, we were sort of asked to come up with  
19 something we could do. And so what you said  
20 just now actually felt like it was in a  
21 direction that we would like to go and  
22 (stammers) take some of the burden off us, a

1 feeling that we had to be the ones doing the  
2 implementation.

3           Because we--we felt, I mean,  
4 you've got the resources, why should we be  
5 doing it? But we felt that's what we were  
6 being asked, so I do want to thank you for  
7 clarifying that.

8           FRANCIS S. COLLINS: Okay, got  
9 it. Other comments? Well, I see we're at  
10 3:27, so maybe it's not a bad thing that there  
11 seem not to be a lot of hands up or people with  
12 their microphones on. Again, I just want to  
13 say thank you to all of you for the time and  
14 effort you put into this. I think you can  
15 appreciate that this is still sort of an  
16 evolving process of our trying to figure out  
17 how best to utilize this group of talented  
18 people.

19           And we appreciate your forbearance  
20 as we keep trying various ideas and we'll  
21 probably try more in the future. But it is  
22 extremely valuable to have your input and we

1 want to make the most of it. So thank you all  
2 very much. (all talking at once)

3 JOHN: Dr. Collins, the--Micah  
4 and Carlos both went to (unintelligible).

5 FRANCIS S. COLLINS: Sure.  
6 Totally happy. Do we have a camera?  
7 (unintelligible) they're bringing it right now,  
8 okay. Well, very good. Other than that, are  
9 there--is there other business?

10 FEMALE ONE: You just have to bang  
11 the gavel to officially end the meeting.

12 FRANCIS S. COLLINS: Oh, well I  
13 always (all talking at once) I now declare the  
14 meeting adjourned.

15 [end of tape]

16

17

18

19

20

21

22

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NATIONAL INSTITUTES OF HEALTH (NIH)  
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November 4, 2011

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Y.E.S. Working Group  
Carlos Pavao, M.P.A. Co-Chair,  
Agenda Working Group

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1

**WELCOME**

2

MR. PAVAO: Welcome, everyone.

3

Thank you very much, Dr. Tabak, for being here

4

today.

5

We have a very, very good presentation for you

6

that's going to tie in from last time to today and the

7

work that we've done but before we actually dive into the

8

work we wanted to spend a couple of minutes if we go

9

around just briefly, state our names and where we're

10

from, what state you're from, and also just talk about

11

any observations that you've noticed when it comes to

12

biomedical and behavioral research lately in your

13

communities that you think that NIH needs to hear about.

14

So with that said I want to turn to Lynn.

15

**INTRODUCTIONS**

16

DR. OLSON: So thank you. I am Lynn Olson. I

17

am the Director of Research at the American Academy of

18

Pediatrics and so live in the Chicago area. I guess the

19

observation I would make are a couple of very recent

20

things.

21

One was just last week. It was the closure of

22

comments on the advanced notice of changes to the Common

23

Rule and to my mind related to that was an IOM report,

1 workshop report that came out last week on public  
2 engagement in clinical trials.

3           And what these both represent to me is an  
4 ongoing indication of a need for public engagement in  
5 research and for public engagement in understanding what  
6 it means for people to participate in research but what I  
7 was struck with in both of these things is that there is  
8 really such a lack of what I call research on research.  
9 In other words, you know, there's--in both of these a lot  
10 of experts and good thinking people trying to think about  
11 how can we better engage, how can we make consent better,  
12 how can we engage but a lot of it is experts talking to  
13 each other.

14           We really have very little data from people  
15 themselves. Why or why don't you participate in trials?  
16 What does it mean to you once you have? How do you  
17 understand the consent process? What about these new  
18 issues related to biological samples and using them over  
19 time? We really have very little information on how  
20 people really feel on these things and it's kind of  
21 remarkable, you know, in the big scientific enterprise we  
22 have how little information there is on these key points  
23 from the participant's point of view.

1           There were 1,000 comments I think on the Common  
2 Rule changes. I think a lot is going to be said and I  
3 think a lot will have to do with we don't really know how  
4 participants themselves think.

5           So I just thought those were really great  
6 examples of the important need for continuing to  
7 understand the public perception.

8           MS. NAUGHTON: I'm Eileen Naughton. I'm from  
9 Rhode Island, the smallest state in the union.

10           And I think it's important to let you know that  
11 my husband is a dentist and he very much likes the fact  
12 that you're deputy director.

13           One of the things I strive for is to integrate  
14 the whole human body, which has been quite a challenge in  
15 our health system applying the knowledge that's generated  
16 from NIH. And we strove to develop a patient centered  
17 medical home model expanding on what the pediatric  
18 community has developed and we did an 80,000 person pilot  
19 project with highly successful results, recognized  
20 nationally, and it is now into the community health  
21 center model. In fact, they just received distinction as  
22 an example of a national model.

23           This is the Blackstone Valley Community Health

1 Center. They have electronic health records. They serve  
2 uninsured and underinsured population. They only have  
3 about ten percent insured population with other payers  
4 and their results because they have the outcomes, they  
5 are doing quality control-- their results rival the best  
6 system anywhere for private care patients. So this can  
7 be done following some of the prototypes envisioned, I  
8 guess, in legislation and what we're attempting to do  
9 with patient outcome centered research, translational  
10 science.

11 Now the community health center could assist  
12 the NIH and their grantees in clinical trials and be a  
13 real important member of this community.

14 MR. LEWIS: Hi. I'm Jordan Lewis. I'm a  
15 research scientist with the Center for Alaska Native  
16 Health Research at the University of Alaska, Fairbanks.

17 What I've been observing is we're seeing an  
18 increase of NIH funding in Alaska, specifically on  
19 biomedical research looking at genetics of obesity with  
20 Alaska Natives, as well as behavioral health, and as a  
21 result of this we're seeing more appropriate  
22 interventions being developed, programs and services.  
23 And it's my hope that we can get more Native students

1 involved in this research.

2 MS. LEONG: Hello, Dr. Tabak.

3 I'm Amye Leong from Santa Barbara, California.

4 I serve--I do consulting in patient advocacy and  
5 communication and translation of research and I for the  
6 last ten years have been serving as the international  
7 spokesperson for the United Nations Bone and Joint Decade  
8 and so at the National Institute of Arthritis,  
9 Musculoskeletal and Skin Diseases I work very closely  
10 with Steve Katz and his wonderful team.

11 The area of biomedical research has for me  
12 personally been very, very beneficial. I mean I used to  
13 be wheelchair bound and now I'm not because of the  
14 advances in research. I have been asked quite a few  
15 times this, particularly once at the 25<sup>th</sup> anniversary of  
16 NIAMS for which Dr. Collins was a keynote speaker at and  
17 I also spoke at, to talk about what those benefits are  
18 and how they actually translate to the human function or  
19 getting people back to work, getting someone like me off  
20 of Medicare disability back into a functional taxpaying  
21 citizen role. So very, very important. Also, the other  
22 conferences are two national summits. One on  
23 musculoskeletal disparities because of the access to care

issues for people of underserved and people of color and racial disparities particularly in musculoskeletal disorders. And then also the value of musculoskeletal care.

What we see is the translation of biomedical research into the important role of what care does but what is the value of that care from the economic and human perspective, and particularly with lessening budgets these days.

What I also am observing is that NIH is playing an important role in the development of the Health and  
12 Human Services strategy/strategic plan on multiple  
13 chronic conditions. And because I'm one of those people  
14 I know now the next stage is to begin reviewing that to  
15 see how that is implemented. So, as some of my  
16 colleagues have said, the public engagement of that--I  
17 think we're here--we definitely are here for you to do  
18 that and would like to be a part of that.

19 Thank you.

20 MS. CHURCH: Good afternoon. (Indian language  
21 not herein transcribed.) I am Navajo and I am from  
22 Albuquerque, New Mexico. A change that has occurred is  
23 that I am no longer working for the New Mexico--

1 University of New Mexico but I have taken a position with  
2 the New Mexico Public Education Department in the School  
3 and Family Support Division. A couple of things that I  
4 wanted to share with you--today I'm--the hat I'm wearing  
5 today is a community member.

6 A couple of things that I wanted to share with  
7 you and just express my appreciation. Number one is  
8 congratulations to NIH for the National Library of  
9 Medicine's 175<sup>th</sup> anniversary and for featuring the Native  
10 American, which is my background, my culture, my  
11 traditions and my world view, in expressing health and  
12 wellness and healing. And a thought to that was looking  
13 at--you know, there's two realms that I see. You have my  
14 Native world view, our Native world view, and then you  
15 have the scientific process for discovery and really  
16 taking a look and challenging NIH to look at how you  
17 would respectfully integrate those two realms.

18 I think the benefits that would come out of  
19 that is, number one, a diversified workforce; number two  
20 is the innovation to discovery, especially when you're  
21 looking at encouraging young American Indian scientists;  
22 and then the third, of course, is just strengthening the  
23 stakeholders' engagement into that process. I think

1 that's important.

2 Another piece that I wanted to share in my  
3 appreciation to NIH as a student because I just recently  
4 received my Masters of Public Administration and Masters  
5 of Science and Health Education, a double masters from  
6 UNM, and just the wealth of resources that are available  
7 from PubMed and how that really assisted me in my  
8 graduate work when I looked at health education work and  
9 studies for the Native American population. And so on  
10 behalf of myself as a student, thank you very much.

11 DR. TABAK: Thank you.

12 MS. APPELL: Thank you, Dr. Tabak. It's lovely  
13 and wonderful to be here certainly in this room with  
14 these very talented consumers. I am Donna Appell and I  
15 am the founder of the Hermansky-Pudlak Syndrome Network.  
16 Hermansky-Pudlak Syndrome is probably the number one  
17 genetic disorder of Puerto Rican people and I do a lot of  
18 work in trying to help in Puerto Rico and it's certainly  
19 an area that needs more attention.

20 When we talk about biomedical research I just  
21 really want to take a minute. You know, I mentioned that  
22 we are a genetic disorder and I have to celebrate the  
23 NIH. I love it dearly and I have to, you know, say that

1 the genetic research is applauded this month because of  
2 Family Health History Month. And I am a registered nurse  
3 myself so I practice, you know, speaking with families  
4 very often and we are now really making great strides in  
5 having people understand and connect the dots between  
6 their genetics and their own health. The story of their  
7 parents and their grandparents and their health and how  
8 they really understand that it relates to a personal  
9 health and how they can make changes. So I have seen  
10 over the years how genetics has impacted people's  
11 personal lives and I think they understand so much more  
12 and I applaud the NIH for all its efforts on behalf of  
13 National Family Health Month.

14 MS. LAPHAM: Hi. I'm Gardiner Lapham and one  
15 of the--one of my interests is epilepsy. One of the  
16 things that I've been very encouraged to see lately in  
17 the news and to see more research on is head injuries in  
18 sports as well as there's an increased look at the number  
19 of vets that are coming--returning to the U.S. who have  
20 head injuries, especially post traumatic epilepsy. So  
21 I'm encouraged to see there is more public discussion  
22 about that but also more research in those areas not only  
23 at NIH but across other agencies within the federal

1 government.

2 Thank you for that.

3 DR. WOOLEY: I'm Susan Wooley. I started a new  
4 job this summer as the executive director of the  
5 Director's of Health Promotion and Education, whose  
6 members work in state health departments on health  
7 promotion, health education and health equity, and really  
8 take a systems and environmental change approach to  
9 health.

10 I remember when I was in high school hearing an  
11 NIH researcher give the results of a study of tobacco and  
12 the effects of it on human health, which was not--it was  
13 a long time ago. And what I want to comment on is that  
14 over the years we've held the basic science but now NIH  
15 moving also into the behavioral sciences research is  
16 important because just because we have the biological or  
17 biomedical science doesn't mean it translates into what  
18 people do in their health.

19 And then the need now for being cross  
20 disciplinary and, as I said, systems and environmental  
21 change, recent research that I have heard was that of all  
22 the tobacco consumed in this country 30 percent of that  
23 is by people with mental illness. So what are the

1 connections between mental illness and substance abuse  
2 and how people make decisions and are--you know, and so  
3 often we are siloed so that we are not looking at those  
4 cross connections and how those might impact the nation's  
5 health.

6 MR. NYCZ: Hi. I'm Greg Nycz. I run a large  
7 community health center in North Central Wisconsin in  
8 partnership with Marshfield Clinic and we have a very  
9 large Dental initiative going on and our last fiscal year  
10 we served over 41,000 individuals through our dental  
11 clinic, our expanding network, and that activity caught  
12 the attention of one of the NIH funded bench researchers  
13 by the name of Yiping Han and I have the tremendous good  
14 fortune to be able to hear her present some of her work.  
15 And she presented to our provider community and our  
16 research community but also some of the people like me  
17 who aren't scientists but run programs. And I have to  
18 say as a non-researcher she had me at the edge of my seat  
19 because she was basically telling a very interesting  
20 detective story.

21 The point that I want to make is she made a  
22 difference in decisions we will make going forward in  
23 trying to give better care to pregnant women. And you're

1 going to hear from our team here about how we could maybe  
2 scale that up to make a much bigger difference  
3 nationally.

4 MS. AARONSON: Hi. I'm Stephanie Aaronson,  
5 Fairfax, Virginia.

6 Right now I am doing some communications  
7 consulting and helping get a website off the ground  
8 called Citizen Jane which is getting young women involved  
9 in politics and making sure they vote.

10 As a mom and a very involved family member, I'm  
11 really excited that the obesity working group is finally  
12 pulled together and working across agencies. One of the  
13 key things that having worked in obesity in public media  
14 to look at what's happening in the community at the local  
15 level, what are the factors of influence and actually  
16 getting NIH to come forth with some research to know why  
17 this is happening and how we can change it because I have  
18 seen a lot of money being thrown into communities and the  
19 evaluations have not been great nor are they telling any  
20 kind of solution stories. So with your capabilities I'm  
21 sure you'll turn it around with all the research you do.  
22 So that will be exciting to see.

23 MR. PAVAO: And finally Carlos Pavao. I'm

1 actually from Atlanta, Georgia, and my expertise is HIV,  
2 substance abuse and mental health, looking at the  
3 intersections of that. And I actually work with states,  
4 Tribes and jurisdictions around those issues.

5 One of the things that I've noticed is that  
6 there are controversial public health topics for certain  
7 states or certain regions are a little more conservative  
8 in looking at it and what I've noticed where I'm from is  
9 that anything to do with reproductive health, HIV,  
10 anything to do with sexual health issues tends to get the  
11 attention of the local legislature. Especially if they  
12 are public universities that actually has a drastic  
13 impact on funding, local funding.

14 One of the things that I've noticed--and this  
15 has been playing out already in the media in Georgia--is  
16 that researchers--and also their partners--are not  
17 necessarily well prepared to deal with that kind of  
18 controversy. So what that does is it creates sort of a,  
19 you know, why are we spending these dollars on X, Y and Z  
20 and, you know, should we be doing this.

21 And another topic could be also stem cells and,  
22 you know, there's a lot of those controversies.

23 So what I would love to see--and I know there's

1 a lot of great work here at NIH--is how to sort of  
2 increase the capacity of local researchers and their  
3 partners to think proactively about sort of, you know,  
4 crisis management when it comes to issues in the public.

5 **DIRECTOR'S UPDATE**

6 DR. TABAK: Well, thank you all.

7 I have to say each of you said something that  
8 resonates with me. It's a little bit of a cognitive test  
9 so I'm going to start with the last comment first and  
10 we'll see how far I get but certainly on a federal level,  
11 as I'm sure you're aware, on occasion organizations will  
12 call into question why there is federal funding for  
13 certain types of research activity. And actually John  
14 Burklow and his outstanding team together with folks  
15 within the institutes and centers are very proactive in  
16 being able to explain why the science is, in fact, so  
17 important.

18 I'll give you one example that I personally got  
19 involved in. In fact, there's evidence of my involvement  
20 because it was on NPR radio and my son called me very  
21 early in the morning and said, "Was that you on NPR?"

22 So somebody took issue with a study involving  
23 nail clippings. They thought this was the silliest

1 funniest thing. Why would NIH spend hard earned taxpayer  
2 dollars on nail clippings? Of course, it was a biomarker  
3 study to measure tobacco exposure. And so when you put  
4 it into that context, into the scientific context, it  
5 didn't seem so silly anymore.

6 And so we all need to be quite vigilant and it  
7 starts with communications and John and his colleagues  
8 are able to help us as scientists craft a message in a  
9 way that is readily understandable but is, you know, true  
10 to the science and that's a real art. So, yes, I can  
11 appreciate that this is occurring on the local level but  
12 it also occurs on a federal level.

13 All of you who mentioned dentistry, thank you  
14 so much. It's so rare that I--you know, I don't get to  
15 do that anymore but thank you all so very much.

16 I think your comments about mental health and  
17 addiction or substance abuse is one of the reasons why  
18 NIH is moving towards a recommendation that the  
19 Scientific Management and Review Board made to create one  
20 single entity at NIH to study substance use, abuse and  
21 addiction research. And on the table and, in fact, as we  
22 speak in real time is the analysis of the portfolios of  
23 all institutes and centers from across the NIH and things

1 like tobacco cessation, that is the addictive qualities  
2 of nicotine are very much going to be part of this new  
3 entity, whatever the final name really is. So that--I  
4 mean you said it better than I've been trying to say for  
5 months and months now so I do thank you for that.

6 I think, you know, the whole issue of getting  
7 people of all backgrounds into the biomedical research  
8 workforce--I'm going to speak to that more formally in a  
9 few moments but this is so, so important and this is  
10 something that NIH has been trying to do for over 30  
11 years and we are falling way short of where we need to  
12 be. And whilst I know that we need all of your help, we  
13 need all of your public input on so many, many different  
14 things, that question is probably one of the foremost  
15 ones that we need your help with. And I'll show you some  
16 data which I think will prove the point.

17 So I think we--oh, and then I can't help but--  
18 see I'm having all this fun stuff here. So you mentioned  
19 head injuries and, of course, there's a tremendous  
20 emphasis on our men and women who are coming home from  
21 their service duties but, you know, young kids in sports.  
22 I was a basketball official for many, many years and you  
23 might think that basketball and head injuries are not

1 really synonymous--okay, so now you all know why it is.  
2 It gets transmitted up through the jaw and, you know, so  
3 it's real. And for years , you know, we've tried to  
4 convince young kids to wear mouth guards playing  
5 basketball because it dissipates the force. But, of  
6 course, their coaches yell that you can't communicate.  
7 Until we taught them some sign language and so at least  
8 one point guard in the early 2000's worth a mouth guard  
9 and was able to communicate with his team just fine into  
10 the state second round championships. My younger kid.

11 (Laughter.)

12 So anyway, okay.

13 And to everybody else, sorry, I couldn't make  
14 connection but do resonate very strongly with your  
15 comments.

16 Okay. So let me, if I may, give you sort of a  
17 quick update on several issues. I have heard--is that  
18 right? Am I--yes. I'm just following my cues. I'm  
19 going to go up there.

20 (Slide.)

21 I understand that John Burklow covered a couple  
22 of things this morning related to NCATS so when we get to  
23 those slides they are going to be really familiar and I'm

1 going to fast forward, which will give us a little more  
2 time for some of the other issues that perhaps he didn't.  
3 But if you see something that you've already heard today  
4 just raise your hand and we'll fast forward.

5 So I just wanted to do a quick environmental  
6 scan. I will fast forward through NCATS. I do want to  
7 spend a fair amount of time on the discussion about  
8 diversity and the biomedical research workforce because  
9 we really do need all of your help, all of your input.  
10 And then talk a little bit about economic impact unless  
11 John covered that as well.

12 So the scan. This graph depicts the  
13 appropriation of NIH from 1998 through the current fiscal  
14 year. Now, of course, we don't have a budget yet so  
15 really we should just sort of have a big question mark  
16 here. The dark bar represents the actual dollar  
17 appropriation and so beginning around 2000 or so you see  
18 the start of the so-called NIH doubling and that was such  
19 a spectacular time and so many opportunities were  
20 realized. And then we unfortunately sort of leveled off  
21 through the 2000s and then in 2009 and 2010 these light  
22 bars designate the miracle known as the Recovery Act.  
23 And it really was a miracle, an infusion of \$10.4 billion

1 into NIH, which allowed us to do so very, very many  
2 things. And what I think the data and analysis will  
3 ultimately show is that infusion, that investment will  
4 reek benefits for many, many, many years to come.

5 Just early this morning we were hearing about  
6 some high throughput cold genome sequencing projects that  
7 are ongoing. Some in the cancer field, some in the  
8 cardiovascular field, several in the mental health field.  
9 Most of that was fueled by the Recovery Act dollars and  
10 we're just now beginning to have access to this very,  
11 very rich dataset. Again I think we'll derive benefits  
12 from this for many, many years.

13 And then we sort of got back down to reality  
14 again but what is more of concern is that the yellow bar  
15 are our appropriations indexed against 1998 dollars. So  
16 this is our real buying power and so whilst our absolute  
17 dollars have increased and have sort of leveled off and  
18 then had this amazing jump and now have leveled off  
19 again, what you see in terms of buying power is we're  
20 sort of back to where we were in 2002 or so.

21 And, of course, we still don't know what our  
22 fate is for this fiscal year and, indeed, we are already  
23 knee deep in contemplating what 2013 has to offer and

1 beyond. It's not a pretty sight and I'm not revealing  
2 anything that's not in the lay press each and every day.  
3 We have super committees and all sorts of triggers and,  
4 frankly, given the actual buying power and given the  
5 ambiguity and uncertainties going forward is there any  
6 reason to question why young people when they're  
7 contemplating career choices think, gee, should I really  
8 go into biomedical research or should I take any one of a  
9 number of other opportunities?

10 Now, I guess the only good thing about our  
11 401Ks becoming 201Ks is that very few of our young people  
12 are going to Wall Street anymore but apart from that  
13 advantage, you know, there are many other career choices  
14 that young people can make and this is partly, you know,  
15 why I think they are making some of the choices they are.  
16 They see their professors struggling. They sort of  
17 wonder, gee, is this really what I am looking forward to  
18 doing for the next 30-40 years of my life?

19 (Slide.)

20 So I'm going to fast forward through this only  
21 to say that if you have not had an opportunity to read  
22 this policy piece in Science Translational Medicine you  
23 might want to because it's beautifully written and it is

1 written in a way that I think lays out the logic of what  
2 the NIH is trying to do with the creation of this  
3 National Center for Advancing Translational Sciences.  
4 Apart from the cool acronym, I do think that the logic,  
5 you know, is irrefutable. And again the center's  
6 activities are going to complement and not compete with  
7 what's going on in the private sector.

8           Early on there was a bit of a misperception  
9 that somehow NIH was going to move all translational  
10 activities across the agency into this new center and,  
11 indeed, that's not the case. The National Cancer  
12 Institute will continue to do its translational efforts  
13 and so forth. All the institutes and centers will  
14 continue to have a very robust presence in this space but  
15 we hope that this proposed new center is really going to  
16 be catalytic and help all of the translational efforts  
17 both within the agency as well as in the private sector.

18           (Slide.)

19           So a good part of that is going to be NCATS's  
20 emphasis on catalyzing partnerships because what we have  
21 learned as we analyzed, you know, with some rigor the  
22 whole translational sciences space, what you very quickly  
23 understand is that NIH alone can't pull this off. We are

1 obligated if we have any hope of succeeding to engage all  
2 of these groups as partners. So the advocacy groups are  
3 equally important to pharma, biotech is equally important  
4 to the not-for-profits, international efforts are equally  
5 important to academicians and let's not forget our sister  
6 agency, the Food and Drug Administration. So all of  
7 these partnerships are going to be crucially important.

8           And whilst individual institutes and centers do  
9 this, and some of you alluded to this in your  
10 introductory comments earlier, we need to do more of it  
11 and the hope is that NCATS will serve as a fulcrum for  
12 new and additional opportunities of this type.

13           (Slide.)

14           So if you go to the NIH homepage of which this  
15 is a screen shot, there is a button towards the bottom of  
16 the homepage, "advancing translational sciences," and if  
17 you click on that it will give you a great deal of  
18 information about translational activities in general  
19 across the agency.

20           (Slide.)

21           So this is really what I wanted to spend the  
22 majority of my time speaking to you about. Some recent  
23 studies on the diversity of the biomedical research

1 workforce.

2 (Slide.)

3 So on your left is a pie graph which depicts  
4 the census of our nation in 2010. And it may be a little  
5 difficult to read the legend but let's focus on the 16.3  
6 percent of our population that is Hispanic or Latino and  
7 the 12.6 percent of our population that is Black or  
8 African American, and then the 0.9 percent American  
9 Indian or Alaskan Native, and then the 0.2 percent of  
10 Native Hawaiian or other Pacific Islanders. Those are  
11 the individual groups that are underrepresented in  
12 science and so the question becomes how underrepresented.

13 And by comparing the race and ethnicity of NIH  
14 principal investigators on research project grants from  
15 across the agency--so this is aggregated data--it doesn't  
16 take higher math to observe very quickly that Black or  
17 African Americans are woefully underrepresented, 1.1  
18 percent versus 12.6 percent, those of Hispanic or Latino  
19 background are woefully underrepresented, 3.5 percent  
20 versus 16.3 percent, and frankly the numbers of American  
21 Indians and Alaska Natives and Native Hawaiians and other  
22 Pacific Islanders are so tiny amongst our principal  
23 investigators that there is no--there is nobody there.

1 It's just too small a number.

2 Now, there are many, many, many reasons why we  
3 have this disconnect from the general population to an  
4 NIH principal investigator. Some would argue that it  
5 begins prior to kindergarten. Others would say the issue  
6 is K-12. Others will--you know, so--and every one of you  
7 if I went around the room--every one of you could list  
8 five or six or ten reasons why we have this extraordinary  
9 disconnect. But just because we can each describe why  
10 it's occurring doesn't mean that we shouldn't begin to  
11 address how to redress this issue because what typically  
12 happens is, oh, it's K-12 and then there's a bunch of  
13 hand waving and then you move on to the next issue. And  
14 we can't do that anymore and I'll elaborate as to why  
15 not.

16 (Slide.)

17 Just to give you a sense of the magnitude of  
18 the problem, this is a part of the pipeline that is  
19 closer to the NIH mission, if you will. Now, just to  
20 preface K-12, my wife has been a second grade teacher for  
21 over 25 years. Trust me I understand how important  
22 elementary education is. All right. But I think you  
23 would all agree that individuals in the Baccalaureate,

1 Ph.D., post-doctoral positions are closer to what the NIH  
2 mission is. So let's just focus on that for a moment.

3 Underrepresented minorities make up a third of  
4 our college age population and that's pretty good because  
5 25 years ago that was not the case. But they only make  
6 up 17 percent of the young people who earn a  
7 Baccalaureate in science or engineering. So there's this  
8 tremendous drop off and further drop off occurs at the  
9 level of earning a Ph.D. in science or engineering.  
10 They make up only seven percent. So only seven percent  
11 of this group actually goes on. And it's a constant  
12 distillation.

13 (Slide.)

14 Now, let me show you numbers to underscore the  
15 challenge that we're facing. And let's just focus on the  
16 Ph.D. total for a moment. These are Ph.D.s awarded from  
17 2000 to 2008 in the biological sciences, chemistry and  
18 physics to citizens and permanent residents by U.S.  
19 institutions. So again this is aggregated data.

20 Each year our nation is only producing about  
21 400 new Ph.D.s amongst underrepresented minorities in  
22 these categories. So think about that for a moment.  
23 Only 500 each year to fill all the positions that one

1 could imagine an individual filling with a degree in  
2 biology, chemistry or physics.

3 We could give--if I could wave a magic wand and  
4 give everyone of these young people an NIH grant today we  
5 would still be woefully underrepresented relative to  
6 those two pie charts that I shared with you a couple of  
7 slides ago. So even if we could fix it and every one of  
8 these young becomes an NIH grantee, we're still woefully  
9 underrepresented.

10 (Slide.)

11 So we are thinking that one place that NIH  
12 might be able to make a difference, and this is a  
13 question mark because we really don't know, is the  
14 transition from the Baccalaureate to the Ph.D. , non-  
15 underrepresented minorities make that transition, about  
16 10 percent of those who receive a Bachelor's degree  
17 ultimately receive a Ph.D. but underrepresented  
18 minorities only receive that at a five percent rate.  
19 That means that we need to at least double, at least  
20 double the number of underrepresented minorities making  
21 this transition to maintain the current proportion of our  
22 population.

23 Why emphasize that? Because, as many of you

1 know, by 2042 minorities in this nation become the  
2 majority. And we are beginning to enter a perfect storm.  
3 If you go into any laboratory in this country and say,  
4 "Do you have a diverse laboratory workforce?" I  
5 guarantee you people will say, "Yes, I do. I have  
6 someone from Korea. I have somebody from India and I  
7 have somebody from China." And that's about as diverse  
8 as you can get. And it's reflex. I mean they are not  
9 trying to be glib. So in that context, yes, biomedical  
10 research is very diverse but that's, of course, not the  
11 diversity we're speaking about.

12 So if you have a nation where the minorities  
13 are going to become the majority certainly within many of  
14 your lifetimes, you have a circumstance now where the  
15 economies around the world are booming except here so  
16 that it is becoming increasingly difficult to recruit the  
17 scientific talent of other nations to come to the U.S.  
18 and, indeed, once they are here more and more difficult  
19 to retain them because more and more of these young  
20 people are repatriating. You can see that we're going to  
21 have a circumstance where unless we are very, very  
22 proactive who is going to make up our biomedical research  
23 workforce in the future.

1           So I asked scientists around the country  
2     imagine a circumstance where we do not have a seemingly  
3     endless supply of foreign research talent coming through  
4     our nation and underrepresented minorities are not going  
5     into the sciences, we're doing a horrible job of  
6     recruiting them and encouraging them and enabling them--  
7     and, oh by the way, they're going to become the majority  
8     of the population within the next 30 years or so--who is  
9     going to replace, you know, the fast aging, you know,  
10    boomer generation? This is a perfect storm. It gets  
11    even more challenging.

12           (Slide.)

13           So in mid August a paper was published in  
14    *Science* magazine entitled "Race, Ethnicity and NIH  
15    Research Awards." Now, I want to emphasize to you that  
16    this was an NIH commissioned study. Wally Schaffer  
17    continues to work at NIH and Raynard Kington, who is the  
18    senior author, the last author, was my predecessor's  
19    deputy director. So this is very much an NIH study.  
20    This was not, you know, an uncovering something. This  
21    was an NIH sponsored study.

22           But what this study did was it uncovered racial  
23    disparities in our grant awards. So putting this into

1 context, I've already told you we don't do a great job of  
2 recruiting under representing minorities into the  
3 pipeline. What I'm now going to tell you is the very,  
4 very few that are in the pipeline, we're not doing such a  
5 great job of rewarding them through grant awards.

6 (Slide.)

7 So here is the study at a glance. For  
8 statistical reasons only Ph.D. investigators were  
9 studied. Now think about that for a moment. For  
10 statistical reasons. That means there were an  
11 insufficient number of M.D. researchers who are  
12 underrepresented minorities to have sufficient power to  
13 include in this analysis. So we're only looking at  
14 Ph.D.s. The trends are the same for the M.D. researchers  
15 but again for the purpose of the statistical analysis  
16 only Ph.D.s were looked at.

17 So they looked at 40,000 or so Ph.D.  
18 investigators from the year 2000 to 2006. Those  
19 individuals contributed 83,188 R01 applications. That's  
20 our gold standard application. It's sort of a yardstick  
21 by which most places measure the quality of their faculty  
22 and research efforts.

23 Of those 40,069 unique Ph.D. investigators,

1 1,149 were from Black Ph.D.s. That is from the 83,000  
2 applications, 1,149 were submitted by Black Ph.D.s. And  
3 I'll stop for a moment. Of 83,188 applications, only  
4 1,149 were submitted by Black applicants. If Black  
5 applicants would receive awards at the same level of  
6 success as White applicants you'd expect them to have  
7 received 337 awards. Only 185 awards actually went to  
8 Black applicants. Again that's all things equal. Okay.

9 So these data are trying to take into account  
10 from statistical means all manner of issues that you  
11 would expect might influence whether or not somebody  
12 would be able to receive an NIH grant award.

13 (Slide.)

14 Now, there's some additional not so great news.

15 Award probability is correlated with NIH  
16 funding rank of an applicant's institution. What that  
17 means is, is that if you were at a top 30 organization in  
18 terms of NIH total funding you are more likely to get an  
19 award than if you are an organization that is 31 through  
20 100. And in data that's not displayed here if you're at  
21 an organization 101 through 200 you would be here and if  
22 you're at an organization that's 200 or less, meaning  
23 this is a very--a non-research intensive environment--

1 you'd be sort of down here. And there's sort of this  
2 straight line correlation.

3 Now, some people think, well, sure, that's why  
4 they are top 30 organizations. When other people look at  
5 those data their heads explode. I mean why should  
6 somebody at a top 30 organization enjoy this much of a  
7 difference in award probability than somebody from 31  
8 through 100?

9 But in each rank group Black Africans have the  
10 lowest award probability. That means that even if you  
11 are at a top 30 organization, if you're Black or African  
12 American, you are still not receiving award at the same  
13 rate as your majority colleagues. And that persists at  
14 all of the rank levels.

15 Now, curiously if you're at a top 30 and you're  
16 Black you're doing better than a majority individual at a  
17 31 through 100.

18 So this is very complex stuff and we could, you  
19 know, come up with all kinds of ideas as to why this is  
20 or why it isn't but the fact of the matter is that the  
21 disparity, the differential success rate, persists even  
22 at the very finest institutions in the country. So it's  
23 not a simplistic, well, the majority of Black African

1 American applicants are at less research intensive  
2 environments, they don't have the infrastructure, you  
3 know. No, even if you're at a top 30 there is still this  
4 discrepancy.

5 The only thing that seems to matter--the only  
6 thing that reduces the disparity for Black Africans is  
7 their citation record. That is how well their work is  
8 received by the scientific community as measured by other  
9 people's citing their work or prior review committee  
10 experience. Now that is a conundrum. Some of you are  
11 very familiar with the NIH system. Others perhaps less  
12 so.

13 So basically you don't get to be invited to  
14 review grants until you, yourself have a grant. The  
15 conundrum is you don't really learn how to write a grant  
16 until you review a grant. Hmm, now what do we do?  
17 Right? So, you know, have you ever seen a dog chasing  
18 its tail? I mean, you know, it's--so I'll share with you  
19 one approach that we're using to begin to help redress  
20 some of this and it has to make more accessible the  
21 opportunity to serve on review panels.

22 It turns out that if you participate in some  
23 sort of form of NIH training or career development, that

1 has a positive effect. But for reasons that we don't  
2 understand, it helps Whites more than it does Blacks or  
3 Asians.

4 So we have the data now. And so the question  
5 is what are we going to do with this? Now, I will tell  
6 you when we shared these data with members of the Black  
7 academic community, many of them looked at us and said,  
8 "I could have told you that. That has been going on for  
9 years." And even though the data say that there is no  
10 difference between White or Hispanic investigators, many  
11 Hispanic or Latino investigators will say, "Now wait a  
12 minute. You're lumping all Hispanics and Latinos  
13 together. If you look at Mexican Americans you would see  
14 the same type of disparity." And obviously we don't have  
15 enough in the way of numbers to even make a statement  
16 about American Indians, Alaska Natives. Those groups are  
17 just so small there are no numbers of this type but no  
18 doubt the same disparities are present. Otherwise we'd  
19 have a much greater percentage as principal  
20 investigators.

21 (Slide.)

22 So in that same issue of *Science* Dr. Collins  
23 and I offered this policy forum and in this we laid out

1 our plan of action because the reaction of most people  
2 when this all came out was either, well, I could have  
3 told you that a long time ago or, oh, my goodness, what  
4 are you going to do about this or something in between.  
5 So these are the things that we're doing about it and I  
6 wanted to share this with your group because no doubt you  
7 will be able to think of additional things that we should  
8 be doing about it. That's the whole purpose of  
9 discussing with members of panels like this.

10 (Slide.)

11 So the first thing we're going to do is we're  
12 going to increase the number of early career reviewers.  
13 The Center for Scientific Review, which is responsible  
14 for roughly 70 percent of the reviews that are done at  
15 NIH, across the NIH, now has this Early Careers Review  
16 Program and what they have done is they have reached out  
17 to a much broader diversity of institutions.  
18 Institutions that are much less research intensive,  
19 institutions that typically we don't have many reviewers  
20 from and, interestingly enough, many of those  
21 institutions are very enriched in a much more diverse  
22 workforce. So think for example HPCU. Think for example  
23 Hispanic serving institutions and so forth.

1           Now, in addition to this outreach, there is  
2           also the opportunity for people to self nominate. And so  
3           if any of you know of a bright scientist who has not yet  
4           received an NIH grant but you think is at a point in his  
5           or her career where they would be able to make a  
6           contribution as a reviewer, please if you could get that  
7           information to them that there's a way of self nominating  
8           or send the information to me and I'll connect them that  
9           would be an enormous help for us. Particularly those of  
10          you who are at institutions that we are typically not  
11          reaching out to.

12           Now we are going to look at the grants review  
13          process for bias because even though we don't want to  
14          believe that in 2011 there is still bias, we have no  
15          choice but to consider that as one possibility. Again,  
16          for those of you who are not as familiar with our grants  
17          process, when a reviewer gets a grant application there  
18          is no indication on the application that the reviewer  
19          sees of the applicant's race or ethnicity. But so much  
20          of our review criteria are steeped in the individual's  
21          prior experience to ascertain whether they are or are not  
22          capable of conducting the research proposed that you  
23          include bibliographic information. And so in many

1 instances based either on a surname or where an  
2 individual has trained it is possible to infer race or  
3 ethnicity of an individual.

4           And I don't know if any of you have run across  
5 Project Implicit. It is a consortium project looking at  
6 unintended, unconscious bias. If you just Google Project  
7 Implicit on the web you'll find it. They take--they have  
8 a series of anonymous tests that you can take. I have  
9 done this. I will tell you the results are unbelievably  
10 sobering. At least they were for me. So it might be  
11 something you want to do some rainy afternoon.

12           We need to improve support for all of our  
13 applicants. You know, in the good old days--I'm  
14 beginning to sound like all those old people that I swore  
15 I would never become but here I am, I'm there. In the  
16 old days when you were a member of a department, your  
17 departmental chair never let your grant application go  
18 out until he or she reviewed it, made comments, and then  
19 you followed the recommendations and only then did you  
20 send it out. I think that the pressure on investigators  
21 today is so much greater than it was in the good old days  
22 that increasingly less and less of that mentorship is  
23 occurring. So I think NIH needs to partner with

1 applicant organizations to figure out ways of bolstering  
2 our mentorship work for grant applicants.

3           And then this last piece, that's why we're  
4 here--I mean one of the reasons why we're here--to try  
5 and get the best advice from you all as to the types of  
6 things that we should be doing. Now, again what I've  
7 described is a problem that is multifactorial and has  
8 many, many levers that one could potentially adjust to  
9 help redress things. This most recent discussion--that's  
10 at the very, very, very far end of a pipeline. People  
11 who make it through everything, apply for a grant and,  
12 sadly, things don't work out the way they should. So we  
13 need to redress that.

14           But way back here, and again I'm not being  
15 dismissive of K-12 but even if we just start at the  
16 Baccalaureate to Ph.D. transition we have far, far, far  
17 too few kids from underrepresented groups who are even  
18 taking that pathway.

19           Now, I mentioned earlier I was a basketball  
20 official for many years and I can't tell you how many  
21 times I would see a kid in what they now call middle  
22 school, we used to call it junior high school, who  
23 decides not to take algebra. Well, once you decide not

1 to take algebra the game is over. And it's not that we  
2 shouldn't have historians and lawyers and artists. I  
3 mean that's all wonderful. But once you decide not to  
4 take algebra you are not going to get a Ph.D. in physics  
5 or engineering unless something remarkably happens along  
6 the way. So we have got to figure out what else we can  
7 do to redress this.

8 (Slide.)

9 Okay, so I'd like to just quickly finish up and  
10 to share with you some numbers. The last time this group  
11 met I thought--as I recall there wasn't a discussion  
12 about economic impact.

13 (Slide.)

14 This is just some of the more recent things  
15 that people can point to. So there is this increased  
16 life expectancy, reduction of deaths because--from these  
17 various diseases and conditions, increased survival rates  
18 for a number of forms of cancer. This translates into  
19 over \$3 trillion a year according to the economists. I'm  
20 not sure how you put a price on a life but that's where--  
21 in terms of productivity and so forth.

22 Cardiovascular disease death rates have fallen  
23 greater than 60 percent.

1           HIV therapies--now this is the most remarkable  
2    thing. The National Institute on Aging is now talking  
3    about what they should do research-wise for individuals  
4    with HIV/AIDS. Think about that for a moment. I mean if  
5    you think back to 1979 when this all first--we became  
6    aware--would anybody have thought that the National  
7    Institute on Aging would be--so that's a victory of  
8    sorts. It doesn't mean we're there yet but it is quite  
9    remarkable.

10           And then, of course, cancer rates keep falling.  
11   And every time it falls one percent, it saves the system  
12   \$500 billion. So this is nontrivial.

13           (Slide.)

14           And the additional good news is people are  
15   living longer but their quality of life also continues to  
16   improve. You know, living longer with a poor quality of  
17   life is no picnic. But if you are living longer with  
18   increasingly less disability, and that is the case, that  
19   is--everybody would sign up for that.

20           (Slide.)

21           Now, in terms of the sort of local NIH  
22   supported research on the economy. In 2010 we supported  
23   just under 500,000 jobs. That's a pretty good economic

1 engine. \$68 billion in new economic activity is twice  
2 what gets put in. I know if I could find something that  
3 would give me twice what I put in I would definitely sign  
4 up for that. Actually I'd take 1.1 percent if I put in  
5 money. And there's this foundation that NIH serves for  
6 in terms of the whole medical innovation sector, you  
7 know, it's over a million people when you count up  
8 everybody. \$84 billion in wages and salaries, export of  
9 \$90 billion. So that's a pretty good investment of \$30  
10 billion at least by my calculation.

11 (Slide.)

12 So I just would like to just finish up with  
13 this quote from Jim Shannon who was the eighth director  
14 of the NIH. It's a quote about basic research because,  
15 you know, everybody is so very convinced that NIH needs  
16 to do more in the way of tangibles and we need to do a  
17 better job of translation, and all of that is true but we  
18 really do need to continue our investment in basic  
19 research as well. "The hope of major advances lies in  
20 sustaining broad and free-ranging inquiry of all aspects  
21 of the phenomenon of life, limited only by the criteria  
22 of excellence, the scientific importance, and the  
23 seriousness and competence of the investigator."

1           We can track back virtually every blockbuster  
2 pharmaceutical, great discovery which has increased life  
3 expectancy, great discovery that has reduced disease,  
4 burden of disease, to some--at the moment it was  
5 discovered--some seemingly arcane scientific finding that  
6 at the time most people would look at and say, "Well,  
7 that's really nice." We are not really understanding why  
8 it was so profoundly important and we need not lose sight  
9 of that.

10           So whilst we have to do a better job  
11 translating and we have to do a better job capitalizing  
12 and exploiting all of the great discoveries that emerge,  
13 we can't lose sight of this piece as well.

14           So with that I will stop and if people have any  
15 comments or questions or suggestions I am all ears. I'm  
16 going to go back to the table.

17           DR. WASHINGTON: Just really quickly before we  
18 start since we have gotten a little agenda. We'll spend  
19 about ten minutes on questions. If you can please keep  
20 your questions concise. And if you have multiple, ,can  
21 you just do one at a time just to make sure we at least  
22 give everybody who has a question an opportunity. And  
23 then we're going to break at 2:45 to do the photos and

1 then if there's additional discussion we can do it at  
2 that time.

3 So I'll let Stephanie and Carlos--you can  
4 manage their questions.

5 MR. PAVAO: A couple of suggestions. One is as  
6 you're looking to increase diversity don't forget--and  
7 this comes from some of the dental pipeline studies as  
8 well as some studies in medicine--that with increasing  
9 cost of education we should not forget what they call LI  
10 populations, low income. You can get minority  
11 populations who are not low income populations. And so  
12 keep that going and recognize that the work that you've  
13 got going in the K-12 is a major impetus towards that.

14 And then, secondly, the pilot--you know, most  
15 people, I think, feel that in order to get an R01 you  
16 can't just come out of the box with it. You have to have  
17 pilot studies done on that.

18 And have you looked at the extent to which some  
19 of these institutions may be doing a better job  
20 supporting the pilot work and that could be part of the  
21 problem here?

22 DR. TABAK: Yes. So with regard to your first  
23 comment you are absolutely correct. You know, I'm scared

1 for the current generation of young people. I'm old  
2 enough to have been privileged to grow up at a time in  
3 New York City when a college education was free. I went  
4 to City College and if not for City College and the  
5 tuition being zero I would not have gone to college. You  
6 know, full stop. And if I had not gone college I  
7 probably wouldn't be sitting here today. A pretty good  
8 bet. And, unfortunately, those options don't exist for  
9 the most part anymore.

10 Now, a place where a lot of great work is being  
11 done is in the community colleges. I was just down at  
12 Dade College in Miami a few weeks ago and they are doing  
13 some spectacular things with young people. Many Hispanic  
14 Latinos but people--you know, all backgrounds.

15 With regard to the second point, you know, we  
16 are seeing the disparity in the top 30 institutions so  
17 it's not just resources but it may be that there are a  
18 subset that do a better job than others. It's something  
19 that we need to think about.

20 MR. LEWIS: Thank you for your presentation.  
21 One suggestion--you were talking earlier about the really  
22 low rate for American Indians and Alaska Natives in the  
23 pipeline. I wasn't sure if you guys do any work with the

1 Association of American Indian Physicians. I know they  
2 have a summer internship program for college students  
3 that are interested in the biomedical or health fields.

4 DR. TABAK: Yes, so the short answer is we do.  
5 And everybody has an anecdote of the one young person  
6 that they have either mentored or interacted with who has  
7 done well and gone on. But when you roll up all the data  
8 we're still falling way short. I kid people. I say, you  
9 know, "The plural of anecdote isn't data." And sadly in  
10 this case that's true.

11 We have--you know, here at NIH we've got great  
12 summer opportunities. We virtually never get a young  
13 person from Indian country. Now part of that is because  
14 of the costs because there are some inherent costs but we  
15 get very few--we get even very few inquiries. We can't  
16 even have a conversation about what might or might not be  
17 possible.

18 So somehow we've got to do a better job of  
19 getting the word out that there are these opportunities.  
20 Some people have said we have got to do more to support  
21 the local activity where it's more likely that young  
22 people from these groups would, you know, participate.

23 DR. OLSON: So thank you so much for that great

1 presentation. I will definitely take you up on your  
2 offer of going back and looking at my network to identify  
3 minority candidates to be reviewers.

4 I also just want to make a suggestion going  
5 back to the discussion on the translational park. You  
6 have that diagram there with the wheel of the different  
7 groups involved. I think there's one group that I would  
8 argue should be there that isn't. If we're going to take  
9 translation to the bedside because ultimately unless the  
10 providers are involved in changing behavior it doesn't--  
11 it's not going to matter. So I think they need to be  
12 part of that wheel, the health care providers.

13 DR. TABAK: A fair point and thank you.

14 MS. CHURCH: Thank you, Dr. Tabak.

15 (Crying.) The presentation just really strikes  
16 me when you say who is going to make up our biomedical  
17 community. It's all of our communities. But coming from  
18 my world time and time and time again the American Indian  
19 population is too small. It's not statistically  
20 significant. I hear that over and over and over again.  
21 As a recipient of this message and as the recipient of  
22 that statement that strikes me.

23 So number one is taking a look at the

1 statistical calculations of how we make that significant.

2 Number one.

3           Number two, you say NIH needs to do a better  
4 job and maybe--you know, I'm going to go out with a bang  
5 because this is my last official meeting. NIH has to  
6 step out of the gates of NIH. You have to go down the  
7 road to Indian Health Service. You have to talk to Dr.  
8 Yvette Roubideaux to say how can we work in partnership.  
9 There is a lot of Native communities that have a strong  
10 tie to Indian Health Service so there is your neighboring  
11 partner.

12           Another neighboring partner is the American  
13 Indian Science and Engineering Society. Another one is  
14 the National Indian Education Association. Another one  
15 is the U.S. Department of Education--Indian Education.  
16 Another one is the National Congress of American Indians.  
17 And another one is the American Indian Tribal Colleges  
18 and Universities.

19           I am not sure if anyone remembers but I'm going  
20 to remind you that one of the former COPR members was Dr.  
21 Cynthia Lindquist Mala. She was a Tribal president from  
22 North Dakota. She is another resource that understands  
23 COBRA, that understands and can allocate how we can help

1 increase the numbers of the Native scientists and get  
2 involved in biomedical research. I know it's important  
3 and that's why my passion is here. I have to speak up.  
4 I have to just say why it's so important and that we have  
5 to spread the word to our young people but as well as  
6 also understand that we look at the scientific world and  
7 how does that correlate and support the Native world  
8 view.

9 I gave an example yesterday in our meeting when  
10 you look at even the consent forms there are some  
11 correlations with the consent forms that support my world  
12 view. When you look at the teachings of honesty,  
13 kindness, sharing and respect. When you look at the  
14 teachings of honesty there is your transparency. When  
15 you look at the teaching of kindness look at your methods  
16 in your protocol. When you look at the teaching of  
17 respect there's your privacy and confidentiality. And  
18 the last is your sharing is your dissemination.

19 I am throwing that on the table to just have  
20 NIH really take a look at the scientific aspects and  
21 really start integrating how that fits into the Native  
22 world view. Don't just showcase Native American health,  
23 wellness and healing in the library. I am very--you

1 know, I'm so appreciative of that but let's go further  
2 and beyond and look at the 27 institutes and centers that  
3 can really help promote this. We have to make a change.  
4 Things are happening in our U.S. population that is  
5 changing the dynamics of our country. We have got to be  
6 ready and we've got to be ready to meet those challenges  
7 with our young people.

8 I'm a mother of five. You know, I value  
9 education. My husband values education. We keep, you  
10 know, pushing our kids to just excel in school, excel in  
11 sports, excel in the Junior ROTC program. We're doing  
12 many things in that way and I just feel like that message  
13 has to be so much integrated with the NIH language that's  
14 an institutional language of how you integrate Native  
15 American health, wellness and healing in the scientific  
16 parameters of NIH and beyond, beyond the gates.

17 I'm sorry but I just had to express that  
18 because that message speaks so much to me and I will just  
19 carry that message on to these other organizations that I  
20 mentioned. I don't think we do enough of communication.  
21 I don't think we do enough of having to set  
22 conversations. You know, having an academic journal  
23 article here is important and I'm thankful for that, that

1 it is being disseminated but I think we need to have that  
2 conversation and I challenge NIH to start having these  
3 conversations with these organizations.

4 If it is then continue that conversation  
5 because we have to make a difference on behalf of not  
6 only the Native American population but all other  
7 underrepresented minorities because the world is changing  
8 and we have to change with that world.

9 Thank you.

10 DR. WOOLEY: In a way this follows up on what  
11 Lora was saying, although maybe not with the same  
12 passion. I think that part of the reason in my  
13 experience, and I've worked in a Historically Black  
14 College--I--where I'm working now we're doing a lot of  
15 work on health equity. There are many of the underserved  
16 populations who feel that a lot of biomedical research in  
17 the past has exploited them, that they as a community  
18 don't benefit from that and they are taken advantage of,  
19 and that contributes to the workforce issues. So we're  
20 not going to address all of those until we can build  
21 trust in communities that have been negatively affected  
22 in some ways.

23 I'm wondering if there was any examination of

1 the content of the application of the research studies  
2 and whether in terms of discrimination if they address an  
3 issue that brings a different cultural perspective,  
4 whether it's Native American or African American  
5 perspective, and whether this is viewed negatively by the  
6 reviewers who might tend to come from a different  
7 cultural background?

8 DR. TABAK: So, in fact, an analysis has been  
9 done about the field of study because that was one of the  
10 first things that people thought might help explain the  
11 findings. So using study sections as a surrogate, for  
12 example, looking at the study sections that review health  
13 disparities research, there is a disproportionate number  
14 of individuals who are Black or African American. There  
15 was no difference in the success rates.

16 What was telling was the reverse. There are  
17 virtually no Black or African American applicants  
18 submitting grants in basic science. Virtually none.  
19 It's stunning. So there's a disproportional  
20 representation in health disparities research, in  
21 behavioral and social sciences research in general, in  
22 clinical research, and again none of that is bad. I mean  
23 that's all wonderful that people are applying for those

1 fields but it is stunning that there were virtually no  
2 Black or African American scientists submitting NIH  
3 grants in basic science.

4 So, yes. Do I want to see underrepresented  
5 minorities redress health disparities? Of course. But  
6 I also would like to see some of these young people  
7 getting degrees in biophysics.

8 DR. LEONG: Dr. Tabak, you can see that this  
9 obviously is a very passionate subject for us who  
10 represent our various diverse communities from wherever  
11 we come from. We spent yesterday--a great deal of  
12 yesterday and the previous meeting really drilling into  
13 the depths of what Tony Beck (ph) talked about in terms  
14 of the science and education program getting down to  
15 really elementary school levels and moving it forward.

16 There are many programs that are beginning to  
17 address this and, like as you said and implied, this  
18 doesn't happen overnight. The problem didn't happen  
19 overnight and the solutions are not going to happen  
20 overnight.

21 My company is called Healthy Motivation. It is  
22 talking about how we motivate people with the right kinds  
23 of incentives to move them into certain areas.

1                   I refer you to the Small Business  
2 Administration. When you want a grant from the  
3 government in opening up a business and continuing a  
4 business, if you are from a diverse background, if you  
5 have a disability, if you are female, you are a triple  
6 whammy in my case, but there are extra points, if you  
7 will, that are given. Not to say that we should apply  
8 this kind of model to workforce issues and granting  
9 issues but to at least look at it and see how we might  
10 incentivize those kinds of areas.

11                   The other piece is that the National Institute  
12 of Arthritis, Musculoskeletal and Skin Diseases--the fact  
13 that I can say that in one breath is actually pretty darn  
14 good--actually has for the last year-and-a-half, of which  
15 Lora and I sit on as members, along with many other  
16 individuals from throughout the country who represent  
17 very diverse populations, are helping NIAMS develop and  
18 improve their outreach of NIAMS related information to  
19 the diverse populations. This is a wonderful group of  
20 targeted--all five of the targeted diversity areas to ask  
21 these same groups to take a look at the study section  
22 issue, to take a look at the workforce issue in those  
23 particular institutes. We have expertise in those areas

1 and so it is a readily available group of experts who  
2 could be available to further their research in this  
3 area.

4 MS. NAUGHTON: Hi. Dr. Tabak, we are seeing  
5 progress. In my small state we have a minority woman  
6 heading up the Dental Society. The Medical Society has  
7 female minorities. They were entering the medical  
8 schools in the '90s. We had--Brown University had a  
9 woman president that made unprecedented steps in the  
10 biolife sciences and working with a public university.  
11 We have worked in the K-12 grades in the '90s. Those  
12 kids coming up that attend most likely the community  
13 college. We have worked with Brown and the University of  
14 Rhode Island and others as part of the state network to  
15 have those students that are showing promise in the  
16 science, including physics, be able to have access to the  
17 physics lab at Brown, et cetera. However, they need  
18 funding.

19 The Affordable Care Act has a provision that  
20 the states can elect to remove middle management in the  
21 Pell grants and in other programs. Much of that has not  
22 been actually effected. So that there would be more  
23 funding through that system but it's also under pressure

1 from congress to not even exist.

2           So I think that again you have to reach out to  
3 U.S. Department of Ed and to the land grant colleges.  
4 That system includes the American Indian system as well.  
5 And work to see that that Pell grant stays stable and  
6 that there is some incentives for the states to utilize  
7 instead of having this management cost--put it more into  
8 having the students be able to go into the sciences.  
9 There could be fees for the science labs at the advanced  
10 schools. And also the labs mean less time for a job to  
11 help pay for the school.

12           So you--and they need to have the grades to go  
13 into the dental schools, the medical schools, et cetera.  
14 So you want to have them be able to show the promise of  
15 their intellectual and passions and not be diverted from  
16 just trying to have a subsistence living. So you have  
17 that complex but the Pell grant and utilizing that fund  
18 is one way that we could maybe make this really happen.

19           DR. TABAK: As a private citizen, of course, I  
20 can tell you my thoughts about Pell grants but as an NIH  
21 employee that's not what--

22           MS. NAUGHTON: No. And, for instance, for  
23 students to apply for a Pell grant you need a Ph.D. they

1 are so complex. We have smart technologies that we could  
2 make available to help minorities be able to apply  
3 because they are most likely not going to be fulfilling  
4 that application.

5 MR. PAVAO: Dr. Tabak, our last question comes  
6 from Gardiner.

7 MS. LAPHAM: Thanks. This is clearly a  
8 compelling issue. Just one suggestion. NIH is not in  
9 this alone obviously. There are so many private  
10 foundations and organizations around the country that are  
11 funding young investigators and trying to get them in the  
12 pipeline for NIH funding. I would think if you all can  
13 play a leadership role in pulling these other  
14 organizations into this conversation and these strategies  
15 for how we can work through them as well to, you know,  
16 diversify their grantee pool.

17 DR. TABAK: We have and we are reaching out to  
18 organizations of that type. We're not in this alone. It  
19 has to be a partnership but the partnership has to be  
20 very broad.

21 DR. WASHINGTON: Okay. Now that we're done  
22 with the questions we're going to take a quick break.

23 If I could have the COPR members convene over

1 in this corner so we can do the group photo as well as  
2 photos with some of our retiring members, and let's start  
3 back up about five minutes after 3:00 to begin the COPR  
4 presentation for recommendations.

5 (Whereupon, a brief break was taken.)

6 **RECOGNITION OF RETIRING MEMBERS**

7 MR. PAVAO: Some of us are leaving, myself,  
8 Lora, Eileen and we had John Walsh, who could not be here  
9 today, out of the Alpha One Foundation--he actually had  
10 to travel to the Far East to do a presentation.

11 But I also wanted to take this time to  
12 recognize Jim Wong. He did come in as one of our cohorts  
13 and he did pass away from cancer. And he was a  
14 courageous public health warrior. He actually was very  
15 involved with the American Congenital Heart Defect  
16 Association and he was from California. So I just wanted  
17 to make sure at least we recognized Jim for all of his  
18 contributions to COPR but also that we're leaving with  
19 him in our hearts today.

20 With that said, we turn to Stephanie.

21 **COPR PRESENTATION**

22 MS. AARONSON: Thank you.

23 Thank you, Dr. Tabak. That was a great

1 overview earlier today and we very much appreciate the  
2 discussion on diversity.

3 (Slide.)

4 So the presentation that we put forward today  
5 is really a summary of the work we've been doing.  
6 Specifically, Dr. Collins had said that science education  
7 and obesity were real important to him. He really wants  
8 to dive deep into those two issues. So we spent  
9 yesterday with those two teams giving an overview of  
10 where they are, our feedback, discussion about next steps  
11 and how we might be more involved.

12 (Slide.)

13 That said, the Power Point was done this  
14 morning and it's not fair because your Power Point was  
15 very slick, had lots of picture, graphs. So if I just  
16 did this the whole time it might make our presentation  
17 better. I was looking at it and I was like it's so hard  
18 for me with a media background not to have images and  
19 video and comparing it to yours.  
20 Anyway, get with the simplicity with which we go over our  
21 findings.

22 Also I wanted to--coming off your discussion a  
23 couple of themes that we--that resonate from each of the

1 presentations, each of the discussions that we had with  
2 the different teams at NIH. And the first four really  
3 relate to the issues of diversity that you were talking  
4 about in education and in trials.

5           They have to do with the translation of  
6 promotional materials and applications for diverse  
7 audiences and how uniquely different some of the  
8 different audiences are. It has to do with changes in  
9 outreach paradigms. Some many activities have been going  
10 on for a long time, traditional structures, resources are  
11 short, extending the resources of different communities,  
12 and we're kind of saying we just need to do more with  
13 less, and we can't. So I think we need--some of the  
14 things we need to kind of break away from the old  
15 paradigms of distribution and start thinking differently.  
16 It's not going to take a lot of work.

17           Engage rural communities and engage ethnically  
18 diverse organizations and diverse professional groups.  
19 Lora was great in listing those. And to attest to--  
20 obviously those organizations that Lora mentioned she has  
21 mentioned at every COPR meeting, in every meeting at  
22 every presentation, and again I think there's a rich  
23 resource that a lot of people at COPR can bring

1 connections to organizations that would help you reach  
2 the communities more efficiently than trying to go to  
3 them one by one directly.

4           And then just other--you know, some other big  
5 picture stuff is headlining your stories to all state  
6 groups and any time you talk, you know, what's the impact  
7 of the work NIH is doing. You gave a great presentation  
8 today and at the end you talked about the impact its  
9 having on the economy and the environment. You know,  
10 bring us in right away with the relevance. I think  
11 that's great and a lot of other presentations are not.  
12 Brand consistency and metrics. When you guys are setting  
13 out what you want to do think across all programs. We're  
14 seeing a lot of improve and increase but from what to  
15 what, what does it really look like. It's hard for us to  
16 give you feedback on communities if we're not shown point  
17 A to point B. So I just wanted you to think of those  
18 themes through it.

19           (Slide.)

20           So at the last meeting we did a pretty robust  
21 presentation on science education and how we might engage  
22 in that. We also began talking about new COPR  
23 communication tools. Yesterday we also in light of the

1 *New York Times* study we are working with John and his  
2 group to talk about ways that COPR could be supportive in  
3 brainstorming how to get in front of stories when we're  
4 looking at transparency and public trust and what that  
5 means for our group and how to help you all when you're  
6 hitting those conflict of interest issues that happen  
7 frequently.

8 (Slide.)

9 So for science education recommendations--am I  
10 going too fast? Okay. Previous recommendations have  
11 already been completed, which is great. There's  
12 obviously progress and we like to hear there's some  
13 contribution from COPR. Working across NIH, in preschool  
14 programs, engaging other children in the programs, and  
15 there are actually even high school kids who mentor  
16 middle kids, integrate curriculum with common core  
17 standards, and that is being looked at. And then we had  
18 also recommended last time and want to continue this  
19 recommendation--and, hopefully, we can move forward--  
20 incorporating a member of COPR into working groups and  
21 review boards across the--getting more engaged in  
22 science. And we encouraged last time more public and  
23 private partnerships around education, from industry to

1 Department of Education, National Science Foundation and  
2 CDC.

3 (Slide.)

4 And then some new recommendations.

5 So this--again thinking along the themes I  
6 mentioned before. Thinking about how the work you are  
7 doing is in the public interest and it's a showcase of  
8 how government is working. There is a great story to be  
9 told about this work, it's impact in the economy,  
10 opportunities for careers, accomplishments to date, and  
11 then creating objectives that really are measurable and  
12 that help us tailor our input according to where you are  
13 and where you are trying to go.

14 Tony gave a great example of a map of where  
15 local programs are--local CIPA (ph) programs are and the  
16 overlap geographically with COPR members. And at our  
17 lunch and dinner last night we were talking about  
18 programs that we are engaged with that might match really  
19 well with some of the CIPA programs or encouraging people  
20 to apply for CIPA grants and maybe that would also feed  
21 into some of the diversity goals. And then again rural  
22 and Tribal communities raise again access is key and of  
23 course not limiting it to those two groups but those were

1 certainly raised as two groups that are not being met  
2 right now in terms of outreach.

3 (Slide.)

4 We can't do more with less. We talked about  
5 this. You know, buying less is costly and  
6 limiting. We have no money to buy lists for each teacher  
7 so let's really think about how we're spending that money  
8 differently because we're just going to hit a wall. And  
9 we need new distribution methods for reaching more users  
10 so the money can be expanded and can go further.

11 There are a lot of additional influence of  
12 groups and these use the resources beyond teachers, local  
13 policy makers, health community agencies that want to use  
14 these resources that have been built for the classroom or  
15 to engage kids in their own groups.

16 Eileen was talking about an example where she  
17 has completely mined the website and found great  
18 resources to share with other people in her building, her  
19 and her community.

20 And then as you are looking forward let's think  
21 about the future of diverse work force. As you said,  
22 what does that look like for the needs in medicine and  
23 healthcare and what does it look like in terms of career

1 path, support and modules?

2 (Slide.)

3 I'm going to jump ahead to obesity. So then we  
4 also sat down with the Obesity Research Task Force. And  
5 as Amye (ph) mentioned in her remarks, I think the entire  
6 team is really excited about the work that's underway.  
7 We've got a lot of people  
8 interested in this issue and a lot of people are already  
9 working on it. So we're looking forward to  
10 continuing dialogue at the biennial meetings as well  
11 as updates from the group on ways that we can contribute,  
12 including putting a representative of COPR on the working  
13 group task force.

14 We believe that the team is--the working group  
15 objectives should stay on target with the intervention of  
16 heavily populated areas, clearer metrics would help for  
17 moving from point A to point  
18 B in understanding where NIH can go with this,  
19 recognizing environmental and community factors is key.

20 And then looking at other organizations you  
21 want to gain--bring into the fold because there are so  
22 many people out there. I know you're working with the  
23 Robert Wood Johnson Foundation, Kellogg, local community

1 groups, public health organizations are involved. There  
2 are more organizations at the community level that are  
3 heavily interested in this area and it could be an even  
4 more rich discussion.

5           There is also interest in news alerts about the  
6 research as it unfolds. It's a five-year research.  
7 There can be information coming out of it that people who  
8 are following this issue consider doing emerging science  
9 and education, which we call ENR, to community health  
10 professionals to find out how they can apply research  
11 that's unfolding and news that's unfolding in their daily  
12 practice. Again, the diversity of translation and  
13 materials is  
14 key. And we look forward to continuing to work with this  
15 group.

16           (Slide.)

17           So those were two areas that we deep dove into  
18 according to Dr. Collins' interest and I'm going to go  
19 back to public communications.

20           And this goes to our interests in increasing  
21 communications among COPR members, among OPLs with the  
22 Director's Office and something we put on our own agenda,  
23 and so we had a brainstorm with some of the OPLs this

1 week and we want to figure out how we can expand  
2 consistency in working with them, as well as some ideas  
3 that we have for different challenges they're having.

4           So one of the ideas is to make sure we have a  
5 liaison with each OPL. We have also offered to review  
6 some of the parameters around best  
7 practices in engagement for research. OPL--several OPL  
8 members have been great about reinforcing the need to  
9 have COPR members in NIH working groups and we hope that  
10 will continue. Two examples right now is Donna is part  
11 of the Clinical Trials website development and Lynn is  
12 part of the Down Syndrome  
13 Consortium. And those are examples of actually OPLs  
14 saying we should go get a COPR for public input as part  
15 of this working group.

16           And then we hope the OPLs will increase the  
17 participation at these meetings biennially so we can have  
18 a great exchange. Some of the things that we considered  
19 for them is morning electronic news  
20 briefs, helping them with the diversity of materials  
21 like Lora was saying in terms of speaking to diverse  
22 audiences and what that looks like, and using more common  
23 language and simplicity in materials and applications.

1           And then in terms of promotion--you know, we  
2 did talk about this. I think when you are dealing with  
3 stakeholder groups, you know, what's the headline, you  
4 want to give them about where all this work is leading.  
5 Making sure the communications is consistent across NIH  
6 for everything from social media to branding.

7           We had an example of a colleague who was at a  
8 conference where there was an exhibit space and there was  
9 probably 12 institutes exhibiting there all spread out  
10 and there was no common thread to know that these groups  
11 were from NIH and representing NIH. And what we're  
12 saying is it's really asking too much from the end user,  
13 especially when you go on line, to determine what's the  
14 common thread here.

15           And then resource is transportable, especially  
16 in our digital age where everyone has their own Facebook  
17 page, newsletter, blog, twitter feed. Stories that are  
18 transportable, widgets, principles, downloads allow  
19 people to actually list stories and insert them into  
20 their own forums, blogs, newsletters, websites. And that  
21 might help actually brand some of the efforts you have as  
22 well as extend the information.

23           There is--we spoke a lot about what's on the

1 web and that it would be great if NIH had a seal of  
2 approval on information that's emerging because if you go  
3 online you are often getting conflicting  
4 information whether the research is real or not  
5 real or status of it. So it's great if you see the NIH  
6 logo when there is new information and are really holding  
7 true to that.

8 In terms of outreach all the OPLs, stakeholder  
9 groups, professional organizations,  
10 state legislators, grantees, these are really engaged  
11 audiences. Use those as influencers to  
12 reach the larger public rather than trying direct to  
13 consumer. It will ease the drain on the staff, the cost,  
14 because there's a lot of groups that we  
15 can engage. And again the rural community outreach is  
16 key. Greg has done a lot of work in that group and feels  
17 it would be very responsive to clinical trials given how  
18 their response was in other  
19 scenarios.

20 (Slide.)

21 In conclusion, it would be like me to change  
22 the power point presentation in the middle of it.

23 Okay, so our next steps. I had mentioned that

1 we would like to be more engaged with CIPA in the Office  
2 of Science Education and their working groups and review  
3 boards. We'd like to have a COPR member more engaged in  
4 the Obesity task force as well as continuing to engage  
5 with them on a biennial basis. And if we could identify  
6 a role for COPR in the HHS plan on multiple chronic  
7 conditions. I understand NIH has a portion for that.  
8 We'll be integrating more COPR members into OPL  
9 activities and recaps and reports. We have a liaison  
10 there.

11 As a working group we'd like to implement a  
12 progress report in terms of what was asked of us, what  
13 our contribution was, what really is actually more  
14 information so there is more a tracking of give-and-take  
15 between NIH and COPR. And we've actually implemented  
16 monthly calls, thanks to Sharia, and I think we'll start  
17 outlining specific  
18 issues with subject area experts across NIH so we're  
19 getting really robust updates between the annual meetings  
20 so we come in with a lot more information and previous  
21 dialogue.

22 Communications for the Director's Office is  
23 working with the OPLs and stakeholder engagement

1 planning. So that is something that is big on our agenda  
2 next. And we'd also like to offer guidance on new ways  
3 NIH can get more public feedback on a regular basis from  
4 a larger group of public. That would be great.

5 And I just want to add based on Dr. Tabak's  
6 comments today that the interest in diversity is  
7 something we can add to our plate and  
8 consider a really robust kind of discussion with your  
9 leads on that issue to start drilling down and reaching  
10 specific communities, what that looks like, putting  
11 metrics against it and making sure we're actually seeing  
12 some results.

13 Thank you.

14 Any questions?

#### 15 **DISCUSSION**

16 DR. TABAK: Did anybody else have  
17 other things to add because I know this is a group  
18 effort. No?

19 Okay.

20 So the common theme--and I know you were trying  
21 to make a pun but things went by a little quick but the  
22 common theme appeared to be communication which is not  
23 surprising. So if you could just rewind a little bit and

1 elaborate on the science education piece. So as you--so  
2 where you do see the key tipping point here for where  
3 COPR is uniquely positioned to help us make a difference?  
4 Is it overlap, the fact that you engaged at the community  
5 level or maybe if you could just elaborate a little bit  
6 on that.

7 MS. AARONSON: I think that some of the--the  
8 recommendations are kind of overarching based on our  
9 experiences working with communities and what that looks  
10 like and when we've had similar experiences trying to  
11 reach into various communities. I think from the  
12 expertise of the group they are dealing with a pretty  
13 diverse population at their level and they are in the  
14 field on the ground understanding how people learn, how  
15 they want to be engaged.

16 And I'm just going to go back to Lora's again  
17 because it is great. In terms of how to speak to  
18 different communities, if you want them engaged in a  
19 science, you think of you've got the different  
20 stages of life, you've got your Pre-K, you've got K-12,  
21 you've got the post graduate degrees, you've got post mom  
22 career changes and potentials, you could have people at  
23 different stages and you've got the extra layer of

1 diversity. And you've got people who are either engaged  
2 in trying to have one issue communicated in their  
3 community to different communities that might learn  
4 lessons from or you've got someone who represents very  
5 strongly a specific community who can tell you exactly  
6 how to speak to them at the different levels. So I think  
7 that will provide a lot of the richness when you are  
8 looking at the materials.

9 DR. TABAK: So that helps.

10 MR. NYCZ: One of the things I want to do when  
11 I get home is talk to the people who do after school  
12 programs or out-of-school programs. They're less  
13 structured than the school and have the people that we  
14 really want to turn on. They are from lower income  
15 families generally, you know, and there is a whole  
16 network of out-of-school programs nationally. So I don't  
17 know to what extent this is all plugged  
18 in but I'm going to approach our folks and if they go,  
19 wow, they didn't realize all these resources are out  
20 there, then you want them to talk to their national  
21 organizations or statewide organizations.

22 DR. TABAK: And the other part which I confess  
23 to being a Neanderthal about are social media. So you

1 went through a whole host of social media. Only a small  
2 fraction of which I even know what those things were.

3 MS. AARONSON: (Not at microphone.)

4 DR. TABAK: Well, you mentioned a whole--I mean  
5 I--I kind of know what twitter is because John has been  
6 desperately trying to teach me but they are a whole other  
7 bunch of things that I have no idea what you were even  
8 talking about.

9 MS. AARONSON: How much time do I have?

10 (Laughter.)

11 So obviously technology--everyone can create  
12 their own newsroom. I mean you certainly recognize that  
13 even a twitter response--something can go viral.  
14 Everything is a wire story now. You've got mom having  
15 her own blog, you've got so and so teacher having a  
16 listserv that they created, and maybe New Mexico or a  
17 certain community, you know, people are trying to use  
18 technology to make it faster and easier to communicate in  
19 the middle of the night whenever they have time.

20 So as you are creating materials it is hard to  
21 remember there is different levels for each person but  
22 it's going to be hard to get people to do extra work on  
23 behalf of NIH to share their story but you give them

1 content for what they're already  
2 creating it makes it easier to spread the word and tell  
3 stories. So consider each of these things pieces of  
4 contents that are flexible enough to meet different  
5 technology expertise and levels.

6 (Simultaneous discussion.)

7 MS. AARONSON: Of course. So some people have  
8 a newsletter or a blog. Some people only tweet, like  
9 Sharia.

10 MR. PAVAO: Eileen has something to say.

11 MS. NAUGHTON: Yes. I have something.

12 What we did trying to get into using social media with  
13 health access and messaging is the HIV site developed a  
14 widget which had a zip code connection.

15 And we were able to have that widget and then promote  
16 that widget via all kinds of means and L'Oreal is a huge  
17 international supporter for HIV education and they have  
18 hairdressers all across the United States. So they  
19 promised that they were going to pick this up and make  
20 this available to  
21 all their clientele across the country. And L'Oreal as a  
22 partner also brought their teachers. They have educators  
23 in the hair sciences and they brought them to New York

1 and they did a huge promotion on HIV and how to get  
2 people to understand about getting a baseline screening,  
3 et cetera.

4 So the widget served as an easy test for people  
5 to plug in their zip code and know where the resources  
6 were proximate to them to get scientific, medical, you  
7 know, social assistance.

8 DR. BURKLOW: We have used widgets for  
9 everything from H1NI to peanut butter scares and  
10 sometimes we call them badges and widgets.

11 (Laughter.)

12 DR. BURKLOW: I may even make up a name  
13 and act like it's a real one and see if you buy it.

14 (Laughter.)

15 DR. : Which is what I thought  
16 you were doing with widgets but I said fine, excellent.

17 MS. APPELL: Just as another utility  
18 for content pieces, in my community everybody is  
19 legally blind. So it's easier for me to take a piece of  
20 content from the NIH very branded by the  
21 NIH and send it to my people who can zoom text it and do  
22 what they want, rather than disseminate a news letter to  
23 them. So the piece in social

1 networking is extremely important.

2 DR. TABAK: I just want to mention one thing as  
3 you are talking about all these things that I know so  
4 little about. This past--this week, earlier in the week,  
5 I was fortunate to speak to a group of people who won the  
6 NLM competition for apps. So you all know what this  
7 stuff is, right?

8 What do I know? Anyway--so on their website--on the NLM  
9 website you find the description of these apps and some  
10 of them might be very useful at the community level.

11 So, for example, one is this powerful search  
12 engine that pulls health data from  
13 everywhere. It was remarkable. I mean I saw this demo.  
14 It was remarkable and also based on zip code and so  
15 forth. So--and this is all free and  
16 you can download it or do whatever you want with it.  
17 So you might want to check that.

18 MR. PAVAO: I think we have no other  
19 comments. Questions?

20 DR. : (Not at microphone.)

21 DR. BURKLOW: We don't have any public  
22 comments at this time? Oh, yes, we do. Okay.

23 Would you like to go to the microphone?

1 MS. DUPREE: Okay. This is just a comment.  
2 I'm Erica Dupree. I'm a student at the UDC David A.  
3 Clarke School of Law in D.C. I am currently in the  
4 administrative law class and  
5 part of our assignment was to come out to a government  
6 agency and come to one of their hearings, and here I am.  
7 And it was very interesting that this group was  
8 discussing diversity among minorities  
9 in the sciences.

10 I actually wanted to, I guess, share my  
11 experience with that because as an undergrad I was in  
12 biology and philosophy, and I had a few students who  
13 were--oh, I went to Swarthmore College during undergrad  
14 and there were a few of us who were in science, African-  
15 American students in the sciences. I have a best friend  
16 right now who is in medical school, and I remember  
17 varying experiences in the sciences at Swarthmore and I  
18 guess I just wanted to point out some of the issues that  
19 I experienced, which I think went along the lines of  
20 income and preparation through high  
21 school.

22 So just seeing students who came from low-  
23 income backgrounds having a bit of a harder time in the

1 sciences and I know at Swarthmore there were different  
2 departments. Our biology department had a  
3 great reputation for being supportive in general, which  
4 wasn't the case for the other departments which played a  
5 role in that. And for some of the  
6 Students--I also have a friend who is Native American,  
7 and for her things were difficult but she actually  
8 pressed through--she actually stayed another year to get  
9 her bachelor's in chemistry and now she's in medical  
10 school. But it was an extra year she put in. It was  
11 like deciding whether  
12 do I continue on this path or not for her.

13 So I guess all that to say when you're looking  
14 at how to bring more minorities into the sciences to  
15 consider issues like support and low-income backgrounds  
16 because those factors play out in such interesting ways.

17 For example, not seeing other students who had  
18 parents who were professors, you know, and  
19 were well-versed in academia and how that works  
20 versus students who didn't.

21 So thank you.

22 DR. BURKLOW: Thank you very much.

23 Donna?

1 MS. APPELL: I just want to say that  
2 we talked about people post graduate when you were  
3 speaking but certainly-and your comments were from the  
4 heart and lovely and I mean I thought about  
5 them deeply and it shows that the CIPA program is so  
6 important, that what Dr. Beck is doing is really,  
7 really important and we've got to really bring it down to  
8 young, young people. And I think that it's not going to  
9 be an instant fix but certainly that's where a lot of  
10 attention needs to go.

11 DR. TABAK: Your comments sort of  
12 underscore another little piece of the puzzle. So while  
13 we are seeing gains in the numbers of underrepresented  
14 minorities in professional schools,  
15 actually mostly medical school, dentistry is  
16 basically flat, the decision tree--do I go into a  
17 professional career, medicine, or do I go into a career  
18 in biomedical research?

19 The decision tree is very much skewed towards  
20 clinical endeavors. It's very, very much skewed towards  
21 going to medical  
22 school. And part of it, I'm reminded by Vivian Penn,  
23 because I asked her about this. I said what--you know.

1 She said, "Well, back in the '70s when  
2 we increased enrollment in schools of medicine around the  
3 country we specifically did so under the imprimatur of  
4 getting more people to go back to their communities to  
5 treat the underserved and  
6 that has stuck.

7 And so, so many individuals from  
8 underrepresented communities sort of have that as their  
9 focus. And again it's not a bad thing. It's a great  
10 thing but we'd like just to have a few of  
11 those people come into biomedical research. And for some  
12 of the reasons that you alluded to, financial. Do I go  
13 down the academic pathway where I may or may  
14 not be funded, where I may or may not get tenure or do I  
15 become a physician where obviously the opportunities  
16 might be a little bit more stable? So we have that  
17 little piece of the puzzle also that we  
18 need to deal with.

19 DR. OLSON: I just have to add you made all  
20 good points. I just have to say though so we know--I  
21 know in pediatrics and I think it's similar across  
22 medicine over the last 20 years there has barely been any  
23 increase in underrepresented minorities. And then there

1 is all these decision trees as you say and then there's  
2 the decision when you have finished your primary care  
3 training do you go to subspecialty work, and that's often  
4 where the clinician scientists are. And we do see  
5 probably fewer minorities then taking that path. So it's  
6 all so complicated and important.

7 MR. PAVAO: How much time do we do have? I  
8 just want to do a quick time check.

9 DR. WASHINGTON: We have until 3:45.

10 MR. PAVAO: 3:45. Okay.

11 Eileen?

12 MS. NAUGHTON: Just to emphasize as much  
13 as possible that the CIPA working with K-12 isn't  
14 really a waste of time. These kids take what they  
15 learn immediately and use it. They use it among their  
16 parents at the grocery store. So all of your emphasis in  
17 working with obesity and all of the these things and  
18 exercise and choice are really impacted by the K-12. So  
19 kids do not wait. They use it.

20 MR. NYCZ: And I just wanted to suggest a long  
21 term strategy to try to get at that point  
22 and that is the investment, for instance, in a dental  
23 PDRN and other kind of practice management stuff, if we

1 look for bridging between bench  
2 researchers and clinical researchers in the field and  
3 then we mix in a little--students in that mix, some of  
4 them will get turned on to the bench research. It's a  
5 way of reaching out in the communities to get people from  
6 those communities engaged even if the first ones go out  
7 in clinical. If they then tie in back with the academic  
8 health science centers and they get turned on by that,  
9 throwing some students in the mix may help  
10 generate more.

11 DR. WOOLEY: I also want to suggest a  
12 program that I was involved in as an undergraduate.  
13 I actually had an undergraduate grant to do  
14 research. It was funded by NSF. It was a long time ago.  
15 And I actually worked for two summers and the year in  
16 between during college in a research lab.  
17 And there is a difference between--I mean an internship,  
18 which is a short time sort of one-project kind of thing,  
19 and actually the experience  
20 of working through a grant, and I don't think that--the  
21 undergraduate research grant I really haven't seen in a  
22 long time those opportunities. It doesn't cost a lot and  
23 it might pay off benefits particularly if you were

1 targeted to the minority  
2 serving institutions.

3 DR. TABAK: These are ideas that many  
4 suggest. Part of it relates to what are the boundaries  
5 of the NIH mission? And some would argue you shouldn't  
6 have any boundaries. Okay. And that--but then others  
7 would say, look, finite resources, you have got to make a  
8 choice someplace. And so we are always trying to strike  
9 this balance. And I have to say again I absolutely  
10 understand the  
11 benefit of elementary education and exposing young  
12 kids to science and math but relative to other  
13 agencies we do so very little of this--again because of  
14 the way our mission is crafted--and so one of the things  
15 NIH has to come to grips is, you know, should we expand  
16 it or shouldn't we expand it?

17 You know, how do we be more strategic in it and  
18 so forth? Or is there--so, for example, some people have  
19 argued--you know, NSF and Department of Education and  
20 other organizations are really dealing with K-12. Why  
21 don't you all begin--if you're going to work down the  
22 pipeline, why don't you start thinking about community  
23 colleges which now for so many, many low income

1 individuals is the only option. I mean there are no  
2 other options except for the local community college  
3 where tuition tends to be somewhat reasonable.

4 And we actually have on campus a community  
5 college summer program now which--and I met with those  
6 young people last summer. They were amazing. Okay.  
7 They are just a tremendous group of kids.

8 So it's a question of where do you pick your  
9 intervention but this is all interesting to factor into  
10 the equation.

11 I see hand signals here.

12 MS. NAUGHTON: Thank you. I'm squeezing in  
13 here but I wanted to bring up some other models from non-  
14 traditional sources. NASCAR, the pit was responsible for  
15 a lot of innovations in the OR and also team approach to  
16 healthcare. The other samples might be the--we just had  
17 an exciting baseball season, great, especially game six  
18 and seven. But those teams have farm leagues and they go  
19 all the way down into the kids. And they would not have  
20 the caliber of players that they have and the system they  
21 have but for the interconnections that are there. So  
22 what you are proposing to do and connect with other  
23 entities you shouldn't do alone. You should do in tandem

1 because it really has shown  
2 effectiveness in a whole host of other areas.

3 **NEXT STEPS**

4 DR. BURKLOW: Okay. With that, the next steps  
5 is Dr. Tabak will talk to Dr. Collins and report back and  
6 I'll join them as to all that has been discussed here.

7 Our next steps I think would be to schedule a  
8 call for December to talk about all  
9 the things that you have listed out here as far as  
10 the next steps and who is doing what. And then--

11 DR. TABAK: I want to formally thank the  
12 members whose term is now concluded. It's not a life  
13 sentence.

14 (Laughter.)

15 Carlos, Eileen, and Lora, and one individual  
16 who was not able to be here. We do thank you very much.  
17 We know that you are all very busy people and yet you  
18 have found the time and energy to help us in many ways,  
19 and we are really greatly appreciative. So thank you  
20 all.

21 DR. BURKLOW: And we don't have a gavel  
22 for you, Larry, but when everyone is finished, unless  
23 Stephanie or Carlos have other things to say, we'll

1 pretend you have a gavel and then you have to officially  
2 adjourn the meeting.

3 DR. : (Not at microphone.)

4 DR. BURKLOW: I know, yes. But, you know,  
5 budget cuts.

6 (Laughter.)

7 DR. TABAK: We're adjourned.

8 (Whereupon, at 3:42 p.m., the proceedings were  
9 adjourned.)