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U.S. Department of Health & Human Services

DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES

COPR Alumni

CLASS OF 2012

- Lora M. Church (New Mexico)
- Eileen Naughton (Rhode Island)
- Carlos Pavão (Georgia)
- John W. Walsh (Florida)

Lora M. Church

Term: 2008–2012

Ms. Lora M. Church is a member of the Navajo Nation, Bitterwater Clan born for the Black Streak Wood Clan. She is the Senior Program Manager for the Acoma-Canoncito (To'Hajiilee)-Laguna Teen Centers. These school-based health centers are associated with the University of New Mexico Health Sciences Center and serve youth and families who reside on three American Indian reservations and in two Hispanic communities west of Albuquerque. Her key responsibility is helping define the interface between the primary prevention program and clinical/behavioral health, focusing on prevention and early intervention. She has more than 23 years' experience working in the health and human services field. In a previous position, she managed Native American Community Services, a nonprofit American Indian health and human services agency in Grand Rapids, Michigan.

Ms. Church is a member of the To'Hajiilee Community Action Team and the Pueblo of Laguna Prevention Coalition. She serves as the principal investigator on three research protocols associated with the Navajo Nation Human Research Review Board. She also serves as a trainer/facilitator for J. Dalton Institute in Green Bay, Wisconsin, with a focus on supervisory professional development. She has spoken at several national conferences that address American Indian health and well-being.

Ms. Church has a B.S. from Northeastern State University and is a candidate for master's degrees in public administration and health education at the University of New Mexico. She enjoys running (slow), sewing traditional clothing and pow-wow regalia, and baking bread. She lives with her husband, Casey Church (Pokagon Band of Potawatomi), and their five children in Albuquerque.

Eileen Naughton, J.D.

Term: 2008–2012

Ms. Eileen Naughton was first elected as a Representative in the Rhode Island General Assembly in 1992. As Chairwoman of the House Finance Committee's Subcommittee on Health and Environment, she is very involved with state health policy and regularly meets with a variety of organizations. Ms. Naughton has worked to improve health care for Rhode Islanders by championing affordable and accessible health care and improved care overall. Among other accomplishments, she has been instrumental in developing a Birth Surveillance System, promoted increased funding for HIV/AIDS programs, and created a vision-screening program for preschoolers.

Ms. Naughton has been active in encouraging adult stem cell research in Rhode Island and has represented the state at several meetings hosted by the National Academy of Sciences. She has made efforts to reform science education in Rhode Island by applying advanced technology to create 'hands-on' learning opportunities.

Ms. Naughton was a Council of State Governments Toll Fellow in 2005. She was also a board member of the Northeast Heart Association and served as the Leading Ladies Group Co-Chairwoman. She serves on several other hospital and health-related boards, including Kent County Hospital, the Women and Infants Hospital, and the Ocean State Center for Independent Living and received an award for health policy from Quality Partners. She also serves on the steering committee for NECON, the New England Coalition for Health Promotion and Disease Prevention.

Ms. Naughton is a graduate of the Southern New England School of Law. She and her husband, Dr. William C. Naughton, live on historic Lockwood Brook Farm, where they raise sheep and other livestock. They have two children and six grandchildren.

Carlos Pavão

Term: 2008–2012

Mr. Carlos Pavão is a Training and Technical Assistance Specialist at Education Development Center, Inc. He is responsible for coordinating the delivery of technical assistance and training services on substance use disorders to states and territories, supporting grantees of the Strategic Prevention Framework and Partnership for Success, two initiatives of the Substance Abuse and Mental Health

Services Administration, Center for Substance Abuse Prevention (CSAP). In particular, he offers technical assistance and training to support cultural competency efforts, strategic planning, and evidence-based prevention programs and strategies at the regional, state, and local levels. Mr. Pavão also provides technical assistance to CSAP's Minority AIDS Initiative grantees.

Mr. Pavão has extensive experience with diverse communities, especially newcomer and underserved populations, and he has worked in both clinical and nonclinical settings. His subject and skill expertise includes more than 16 years in community development, evaluation, and public health programming. His interests include examining the cultural experiences of a population rather than race or ethnicity as a framework for developing health promotion tools.

Before joining EDC, he worked as community provider and project manager in HIV, substance abuse, violence prevention, tobacco control, youth development (especially sexual risk behavior), healthy school initiatives, and cardiovascular health and nutrition education.

Mr. Pavão has served as a board member for organizations that advocate for the needs of underrepresented segments of the population, including the Fulton County Commission on Disability Affairs, Georgia Equality, Atlanta Area Evaluation Association, and the Atlanta Lesbian Health Initiative. He presently serves on the institutional review board for Emory University and Morehouse School of Medicine. He has also been Commissioner of the Massachusetts Governor's Commission on Gay and Lesbian Youth.

Mr. Pavão received a master's degree in public administration from Bridgewater State College in 2004. He speaks English and Portuguese fluently, as well as conversational Spanish. Mr. Pavão resides in the historic section of Grant Park in Atlanta, with his partner James H. Doster and two dogs. In his spare time, he enjoys reading, theater, traveling, spending time with family and friends, and exploring the South.

John Walsh

Term: 2008–2012

Mr. John Walsh was diagnosed with alpha-1 antitrypsin deficiency (Alpha-1), a rare genetic disorder, in 1989. He is the co-founder, President, and Chief Executive Officer of the Alpha-1 Foundation in Miami, Florida. Under his leadership, the organization has become internationally recognized and has invested more than $35 million to support Alpha-1 research and related projects, which includes funding grant awards to more than 60 academic institutions in North America and Europe. Mr. Walsh is also co-founder and President of AlphaNet, Inc., a not-for-profit health management services company providing comprehensive care exclusively for individuals with Alpha-1. AlphaNet provides services to more than 2,500 individuals with Alpha-1 in all 50 states, Puerto Rico, and the Virgin Islands. Because of the infrastructure and support provided by the Foundation and AlphaNet, several companies have drugs in development for the treatment of Alpha-1.

Mr. Walsh has an extensive background in business management and government relations. He served three terms on the Advisory Committee on Blood Safety and Availability, is a member and past Chairperson of the National Health Council's Board of Directors, and was the Presidential Appointee to the American Thoracic Society's Board of Directors. He is a member and past Chair of the American Thoracic Society Public Advisory Roundtable (ATS-PAR).

Mr. Walsh is also co-founder and President of the COPD Foundation, which addresses the needs of those living with chronic obstructive pulmonary disease (COPD). In addition, he has held leadership roles with the Center for Genetic Research Ethics and Law (CGREAL) at Case Western Reserve University, the Foundation of the American Thoracic Society, and the International COPD Coalition. Mr. Walsh is a member of the U.S. COPD Coalition's Executive Committee and immediate past chair of the International COPD Coalition.

In 2002, Mr. Walsh's contribution to pioneering collaboration in orphan drug development was recognized by the U.S. Food and Drug Administration with the Commissioner's Special Citation.

He and his wife live in Coconut Grove, Florida, and have an adult daughter.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES (COPR)

JUNE 8, 2012

COPR MEMBERS PRESENT

DONNA APPELL, R.N.
GARDINER LAPHAM, M.P.H., R.N.
JORDAN P. LEWIS, M.S.W.
GREGORY R. NYCZ
LYNN M. OLSON, Ph.D.

COPR MEMBERS NOT PRESENT

STEPHANIE AARONSON
SUSAN GOEKLER, Ph.D., C.H.E.S.
AMYE L. LEONG, M.B.A.
LEO WILTON, Ph.D.

NIH PARTICIPANTS

MARIN ALLEN, Ph.D., Deputy Associate Director for Communications and Public Liaison, Office of the Director, NIH
JOHN T. BURKLOW, M.S., Associate Director for Communications and Public Liaison, Office of the Director, NIH
LAWRENCE TABAK, D.D.S., Ph.D., Principal Deputy Director, NIH

WELCOME AND DISCUSSION

DR. TABAK: All right. So, I am assuming we are live for the cameras since you have all already had a chance to chat briefly.

I am Larry Tabak. I am the Principal Deputy Director. I am here today because Dr. Collins is in London, of all places, not London, Ontario, but London in the UK. He does send his regrets, but he is looking forward to hearing a summary of what has been discussed today.

I know you have already begun discussions about the COPR origins and the various ways that people receive and share and, importantly, act on information. Over time, obviously, all of those modalities have evolved and have changed.

So, the internet, for certain, has had a profound impact on our society. I am told social media does, too, although I confess that I am not up-to-date on any of that.

But, certainly, we are always looking, regardless of what the technology is, we are always looking at better ways to broaden public engagement. And so, it seems opportune to sort of pause and say, how can we, going forward, gather and consider input from the public in the

broadest possible way?

This morning I understand you heard from a number of folks, Jon Carson from the White House Office of Public Engagement, where I hear they bring in -- how many people a day?

MR. BURKLOW: A hundred and fifty every day.

DR. TABAK: A hundred and fifty every day? Boy, that would be quite a challenge.

And then, Justin Hermann from the GSA's Office of Citizen Services and Innovative Technologies. And I saw Debra Lappin as she was departing, and then Michael Manganiello, who are both former members of COPR. And then, I guess Greg Albright. So, you have heard from a broad range of people. No doubt, they each had their own perspectives.

So, what we want to do now, going forward, for the rest of the meeting is to focus on how we can adapt the structure and, most importantly, the function of COPR to reflect some of these changes in communication strategies and how the public expects to engage.

And so, this way, I think we can move forward with a COPR that has a maximum effectiveness that carries out or meets the expectations of the IOM recommendation, which

was to ensure transparency, public input, and engagement.

So, we are not going to do anything final today. This is just sort of brainstorming. The idea will be to develop a broad range of suggestions and next steps. If at all possible, we would like priorities from you because what typically happens in these types of sessions is you have 137 things, and, okay, which is the most important? And it gets lost. So, we would rather have fewer in a priority order. As you think through things, please let's think about what the most important ones are.

Obviously, we continue to be grateful for the service of the COPR members. You have exercised extraordinary patience with us as we sort of work through these growing pains. Really, your commitment to improving the agency's ability to engage with the public is appreciated enormously. So, we do thank you.

The list of questions, at least to get you all started, is here on the screen. How should NIH seek broader public input? What is the role for a COPR member? You have heard over and over and over again during your tenure as members, you know, leave your specific interest at the door. Beyond that, what should the role be? Are you, I guess the

terminology is, amplifiers of messages? I am learning all this new lingo. How do we measure COPR's success? What are the benchmarks, the goals that you would want to put in place for yourselves and for those who come in the future?

The next question is a really important one. How do you balance what is obviously the sort of gold standard of face-to-face meetings with this new social media stuff, in which I am luddite. I freely admit it. I have no idea what Twitter is. I don't use Facebook. So, okay. But the whole rest of the world does. I know everybody is laughing at me.

Actually, I lied. I go to Facebook for one reason. My grandson's pictures are all there, because my miserable son and daughter-in-law don't send us pictures. They put them on Facebook.

(Laughter.)

And then, finally, what is your opinion as to what the next steps for NIH and COPR should be?

Then, we could add to this list, if you want. But this is just a starting point. I think, from that, I will join you back at the table, if that is okay.

MR. BURKLOW: Yes. Yes, that would be great. Thank you very much, Larry.

Again, we will have a conversation style.

Emily, you will be able to type ideas up on the board, so we can keep track of them, and erase them as you need to, depending on if you have changed your minds about something.

(Laughter.)

But thank you very much.

DR. TABAK: Okay.

MR. BURKLOW: And really, as Larry said, these can kick off a conversation. Don't feel limited to these questions. But I think some of it we have talked about already this morning. It is just to get us going. At the end of the discussion, they have a list, more or less a priority list, of suggestions for next steps.

DR. TABAK: So, somebody has to start.

MR. BURKLOW: Yes, somebody has to start. It looks like Lynn has her hand up.

DR. TABAK: Right. Perfect.

DR. OLSON: Well, I will just start with the first bullet point there. I think this morning, which was very helpful, you know, hearing from experts and people with different experiences. So, on the first one, I think there

were quite a few places it was brought up that that question itself is probably too broad. It is, how should NIH seek broader public input on...?" And unless there is some specificity to that "fill in the blank" -- so, you need to know what the issue is and you need to know what the audience is before you can really develop a meaningful strategy.

I would also say that I will raise the question, and now this is related to what is the role of COPR going forward. I think that, at least the way I remember it, it is that COPR has been looked at with the communication possibly both ways. So, it is getting input, advising on that, and, also, advising on pushing information out, which I think is a different question which might use different strategies. So, I think that is part of the question on the table here: what is the role?

DR. TABAK: So, information in versus information out?

DR. OLSON: Right.

DR. TABAK: Obviously, they are not mutually-exclusive, but they are different.

DR. OLSON: Exactly, and it gets back around to that specificity issue. Because if we are not clear about

what the message and the audience is, it is hard to be useful.

MS. LAPHAM: I agree with what you said. I think, how should NIH seek broader public input? I think the conversation this morning was really mostly social-media-focused, the first two presenters, and they offered a whole sort of arsenal of options, like some really innovative, cool ideas.

I see COPR as just sort of one piece of that. Like social media is not going to replace COPR, and COPR is not going to replace social media, right? It is just like we have more tools now to use.

But I guess the question you have posed is really, now in this new age of social media, how is COPR, then, different?

MR. BURKLOW: How does COPR use social media?

MS. LAPHAM: How does COPR use social media, which we have never used media? We have never even like used our web presence.

MR. BURKLOW: Just to be clear, it doesn't have to be even COPR going out as COPR.

MS. LAPHAM: Right, and it doesn't need to be

COPR.

MR. BURKLOW: It is just, how does NIH use social media to engage the public?

MS. LAPHAM: Right. So, that is one question. How does NIH use social media to engage the public? And then, the other question is, what is COPR doing? So, there is this fundamental issue of what COPR's role is. And they are two very different questions, I guess is what I am saying. Whether it is information in, like just giving advice, versus spreading it back out, your membership might be very different.

DR. TABAK: Let me ask you to elaborate a little bit about pushing the message out. Because I appreciate input in is in some sense member-specific.

MS. LAPHAM: Uh-hum.

DR. TABAK: You can have certain input. You can provide certain input. If you have a sufficient number of people, you eventually get a very broad range of input. That is great.

But pushing information out, is that also member-specific or is that a more generic possible function or role? I mean, I am just asking. I don't know the answer.

MR. NYCZ: I want to try to give an example for that. So, as a Community Health Center Director, I know enough about NIH -- I had done some research earlier in my career -- where I want to be a good consumer of research results. Well, that is fine for me, but I have 1200 colleagues. We are in every state, every territory, 8,000 sites, and we are growing.

And I know there is an interest in NIH in closing the disparity gap, health disparities, that we want Discovery to be used by all Americans, not just some of them.

DR. TABAK: Right.

MR. NYCZ: So, there is a natural partnership there.

You guys have been producing information that is useful to us in the field, but sometimes we don't know about it. Sometimes there are barriers other than just ignorance why we are not applying it.

So, what I would hope to do, like within my constituency, is try to work with NIH to say, how can you take a look at what our goals are in the field, you know, 8,000-site strong, 20 million low-income people being served, and what your discoveries are, and matching some of those up.

So, I know your background with dental. So, I will give you a dental example. We know that periodontal disease, if you have it, they said it is like the sixth risk factor for diabetes. If you have periodontal disease untreated and diabetes, you are likely to have difficulty controlling your blood sugar. So, there shouldn't be a health center out there that is not making sure that all their diabetic patients are getting dental care, and yet there is.

And so, I see pushing information is to say, you know, we need to use these discoveries that we are investing in as a nation, and we need to put it to work in our clientele. That is one way I would see COPR collaborating.

We all have our own, you know, and let's put that information to work and let's find ways of collaborating better across these associations and to get that information out in usable form.

DR. TABAK: Right. Let me push you a little further, though. I think that is a very outstanding example. Get a little bit more into the weeds for me. So, here is the information. You review it. You know it is germane to the Community Health Centers around the nation. So, then, what

happens?

MR. NYCZ: What I might recommend, as a member of COPR, is that the Director or the Director's designee potentially work across agency lines to HRSA and talk with the Director of HRSA about you guys have created this wonderful network of primary care delivery out there. You have embraced dental and behavioral health as primary care. You are providing grants to all these folks that touch 20 million lives. Here is some information that we learned that ought to help you improve the quality of your services to those 20 million Americans.

So, what we might want you to do, HRSA, is consider having that as a criteria. Now, if it is a criteria, all of a sudden, however many diabetics there are in 20 million are getting that care.

DR. TABAK: So, in this case -- and again, I am not disagreeing with you; I am just trying to summarize what the approach is -- in this case, the COPR member is drawing to the attention of NIH the potential added value of disseminating information to a specific group and recommending an approach, in this case speaking to a sister agency, to effect that dissemination. I mean, that is the --

MR. NYCZ: Right. Is that the kind of input that the Director would value, for example?

DR. TABAK: Right. Well, the short answer is "Of course." But now I am going to keep pushing you, okay, because you said "dental"? So, I figure I am allowed to do that.

(Laughter.)

So, how do you now insert a COPR member, one of you -- be careful -- into a more active role of doing the push? Is that feasible?

MR. NYCZ: Oh, certainly. I mean, I am on the Hill Policy Committee at the National Association. I am on the Research Committee in that. So, internally, within the Association, which is another way of organizing health centers -- one way of organizing is through the government grants. Another way to organize is our own Association --

DR. TABAK: Right.

MR. NYCZ: -- which, as we heard this morning, what was the term that they used again? The circle --

MR. BURKLOW: The circle of trust.

MR. NYCZ: The circle of trust. So, you trust your Association.

DR. TABAK: Right.

MR. NYCZ: So, then, I would be saying I would be lobbying within that Association to get a push from the Association that would make it receptive to a presence coming from the agency.

MR. BURKLOW: And, Lynn, you had a comment?

DR. OLSON: Well, related to this, yes. I agree with what Greg is saying. I think, though, that the potential value of the kind of folks who have sat around this table is that they are these conduits to the public. So, now I am talking about the pushing information out, pushing findings out.

So, you know, you have had really fantastic patient advocate groups represented. Greg is talking about the Community Health Center. Of course, my myopic world is medical societies and pediatrics.

But you have people -- and I think this has been true for the whole history -- who are experts at understanding those worlds. So, as opposed to its being necessarily just the individual, maybe it is about help in setting up systems and processes that would go beyond any individual.

So, I think what I would have to say about pediatrics probably applies to a lot of medical societies in terms of mechanisms, how things work. So, it is a way of learning from that and amplifying.

I will give what is one of our favorite examples because it has been so tremendously successful. It was the Back to Sleep Campaign, right? We have cut SIDS deaths in half. I mean, this is just the most wonderful public health story.

And that actually was this history of -- it was the group. It was the Academy. It was NICHD and a company, actually Pampers. It was on the diapers.

So, it was a wonderful story of working together from the beginning, taking the evidence and then working out from that in terms of a communication strategy.

Now I realize there are reasons that make that one especially powerful. It was such a clear, specific message. But I think there are lessons from that that can apply to other things.

DR. TABAK: Right. Okay. So, that is helpful.

And again, none of these are mutually-exclusive. They are additive.

MR. BURKLOW: I am curious; Donna has commented before on this whole issue. Donna, can you comment on it, please?

MS. APPELL: Well, just from what we were talking about before, I think that there is so much social media, so many ways that you can get a pulse of the people. I worry, I want to be valuable, too. I want to look for how I am most valuable.

And so, when I think about your biggest needs, personally, having a lot of experience being at NIH, it is that the NIH is terrible at playing their own trumpet. They just aren't really great -- they are humble researchers -- and they aren't really great at getting the message out.

So, my real desire to help is trying to get the message out. Even there is such a wealth of stuff going on at the NIH, and I have a circle of trust and I have these people that, if I send a message out, it is going to be a pebble in a pond; it will go out further.

But I live in a world where people don't even trust research, nevertheless, NIH. Like research isn't even a friendly word in some cultures.

DR. TABAK: Yes.

MS. APPELL: So, we have a lot of work to do with making the NIH palatable, not just in a scientific breakthrough from some enzyme or something, but research in general, and making it user-friendly and huggable and warm, which I know the NIH is.

DR. TABAK: Right.

MS. APPELL: I know that side of the NIH. And I really am struggling to figure out how we can best be most usable to make it seem like the world's friendliest place.

You know, I am thinking stupid things, like it would be great if there were a way for the social media to actually be able to interface with these COPR members. Like wouldn't that be cool if somebody could send an email to me, as a COPR member? I am supposed to be representing the public to the NIH. Does the public have anything, any questions or something that they would like to ask or something like that? And so, making us available to the public; does the public know that the public is being represented?

DR. TABAK: Interesting, yes. That is interesting. Okay.

So, in other words, be sort of beacons. You

know, here we are, if you have any questions or --

MS. APPELL: I am supposed to be representing you, and you know I am here, No. 1.

DR. TABAK: Right, right.

MS. APPELL: And do you have anything you would want me to talk to them about? Or do you have any questions about what the NIH is, about what I am representing? Start there.

DR. TABAK: Yes. Well, that's interesting.

MS. LAPHAM: Just building on that, what you just said, Donna, in the presentation from the man from GSA, he talked about COPR could serve as, we could monitor sort of some of the public feedback that comes in, just sort of sift through and try to distill, a little different take, I think, on what you are suggesting.

MR. BURKLOW: And that is just my idea of it, is that the monitoring or pulse-taking or getting a sense of what is going on that we may not otherwise know, but you would be the filter of it.

MR. NYCZ: I guess the issue for me with the monitoring is, again, we are just a few number of people with only so much time. You guys have lots of folks. So, the

value of the monitoring, if there is a value to the monitoring, it would be that you would have people from our different walks of life who are outside the engine that is here, and that our perspective on that might be a different perspective than your internal folks looking at the same stuff.

DR. TABAK: No question.

MR. NYCZ: And if that is true, then that is where the value added comes in.

DR. TABAK: And there is absolutely no question there is value added from gaining that additional perspective. Because when you live here, you know, you just look at things differently. It is not that it is better or worse, but it is different.

MR. LEWIS: I would just like to add, thinking about all the comments being made, the issue of health literacy, working with tribal communities. Like Donna, you know, I work with a lot of people that don't trust research at all because of past history.

DR. TABAK: Right.

MR. LEWIS: And so, one, educating them about what is NIH. I think at our last meeting we talked about how

do we reach out to the public, through formal presentations? Do we have a PowerPoint that COPR members could give to a community on this is what NIH does; this is what I do? Gathering that community feedback and bringing it back, so I could give a presentation here and say, "Well, I visited 25 tribal communities in Alaska. The top five concerns for health are...."

So, having that kind of an idea and looking at health literacy, not only bringing the information to Alaska, but in a way that where, if I am working with an elder with very limited English, is this very simple?

MS. APPELL: I just want to really say "hurrah" to that because I was in communities, and I was just learning about what their biggest concern is. And then, where do I bring that? It is like, okay, so I am here. I am a COPR member. I did my job. I went and got my communities. I asked them. Their biggest thing is provider prevails. All their medications are being lost. They can't get them. So, I am here and I want to be able to say what the people want and what the issue is.

DR. TABAK: You know, as an aside --

MR. BURKLOW: Jordan just asked me if I would ask

everyone to get close to the microphones.

DR. TABAK: Oh, well, in that case, as an aside, I sit on the Secretary's Tribal Advisory Committee. It meets, I think, quarterly, and representatives of the different nations come to Washington, sit around a table a little bit larger than this one because there are many of them. And they have a conversation with the Secretary and various departmental officials. And I am the one who represents NIH.

From an NIH perspective, I have to say, sadly, we almost never talk about NIH because, overwhelmingly and understandably, their concerns relate to the services. And I get it. But I so much would like to get the conversation about getting young people from Indian country into biomedical research and getting the issues related to health literacy and scientific literacy involved. And there are all these things I want to talk about, and I sort of -- not that I am a bashful person -- but I just sort of sit there, and no one cares that I am there. You know, it's not personal.

(Laughter.)

But it is because it is overwhelmingly concerned about services. So, you have got to have the right venue.

So, the reason I am raising all of this is the right venue is when you are in the village perhaps or when you are with a group, and so forth. And that is portable to any set of issues, but this in particular, where you have communities where service is so dominant in terms of concern and thinking.

So, yes, maybe targeted outreach where you have people's attention, because the venues that we often have at our disposal, it may not be optimal.

MR. BURKLOW: So, just to encourage you to look at the questions. It doesn't have to be in order, either. So, if you see other questions you want to address --

DR. TABAK: Right. You know, it would be very interesting for me if people would comment on face-to-face versus other approaches. Because I am a self-confessed luddite; I already said that. But you are all probably doing this other stuff. So, I am just interested in what you think about it.

MR. NYCZ: Well, I will just say I am with you.

(Laughter.)

And I liked your comment about the gold standard. And we heard that, also, from the White House.

MR. BURKLOW: Actually, you heard it from everyone, including Greg Albright whose business it is to be in social media. He asked of everyone, "Who is on Facebook and Twitter?" And a number of us raised our hands. And then, he said, "Who is very active in the area?" And it is a smaller percentage.

And his point was that everybody is talking as if everybody is totally engaged in social media, and the reality is you may be to certain degrees or not. So, not to look at it as a panacea.

MR. NYCZ: And I would also say that kind of keeping in the eyes and ears thing, we are your eyes and ears in the community.

Part of that is that, since I have joined this, and I have got to see some of what Donna has seen, the commitment and the unified vision and the great logo and saying, and so forth. I become kind of an ambassador, if you say so. I am looking at my normal day-to-day activities there a little differently. I am thinking about NIH.

So, the example I give you, that I have been a little bit of a terror on, is that if I were providing food, if I was a group that provided all this free food to an

agency, and that agency was going out in the communities and handing out that free food to all the communities, everybody would say, "Boy, I really love that agency." And the agency never said who gave them the food. There is a problem with that. And that is what I see.

And so, I come back here and I say I urge you that your grantees should take up the flag and they should help be out there. And that is a natural thing for them to do, rally around. Let's circle the wagons, and we can all grow, if that happens.

DR. TABAK: Well, I know it was a metaphor, but we don't do food anymore, as you know.

(Laughter.)

It is a miracle that you even have --

MR. BURKLOW: We do water.

DR. TABAK: I brought my own, let the record show.

(Laughter.)

Yes, certainly I take your point. This is one of the things that drives me crazy and keeps John up at night, I'm sure, is this lack of willingness to share in the glory, if you will.

You know, the research was done at the University of X, and our great investigators did it because we have this wonderful research facility in the proud State of Y. And, oh, the money -- "And we are wonderful," you know.

(Laughter.)

I'm sorry, go ahead.

MS. LAPHAM: No, I was just laughing.

(Laughter.)

DR. TABAK: Oh. Smile, because I have said this, and I may have said this to this group earlier. I had a conversation a few years ago with a very, very senior Member of Congress. I won't embarrass the person by naming him, but you would know who it was, who, in all honestness said, "Well, I don't see why we need NIH anymore because we have got all this research going on in my District."

And I about nearly fell off my chair because this was somebody who absolutely should know better and did not. So, that problem is real and one that we haven't overcome yet.

MR. BURKLOW: Also, if you want to talk a little bit about what Jon Carson said about his experience with the White House Office of Public Engagement, the role that they

see, their frequent face-to-face meetings, playing in the overall goal of public engagement?

I don't want to talk the whole time. So, I would encourage you all.

MS. APPELL: So, I will help with that.

MR. BURKLOW: All right. Thank you.

MS. APPELL: He was just mentioning that doing social media is certainly where it is at and stuff, but he actually felt that he got more out of it, then, once he has engaged people in social media, to invite them back to the White House for a face-to-face. And it was the face-to-face meeting that actually congealed, that made it all more palpable.

I think that discussion, if I remember correctly, came up when we were also talking about how social media can be difficult and problematic sometimes, certainly in pediatrics where people worry about vaccines or those kinds of things. He was saying that there is a great deal of benefit to bring the people to the campus, let's say, to meet the investigators, to meet the researchers. And that is when they get into this circle of trust.

Did I do that well?

MR. BURKLOW: Yes.

MS. APPELL: Thank you.

DR. TABAK: And I was not aware of the term "circle of trust".

MS. APPELL: That was in "Meet the Parents" first. They keep having to meet the parents.

(Laughter.)

DR. TABAK: But I understand the concept.

DR. OLSON: And I would add, too, what he also said, where they structure it as you take some of the traditional -- I can't remember what term he used, but, you know, like lead agency, so Rotary, right? So, they become partners in planning the activity, but, then, they have found it extremely useful that groups like that are the nexus to more local groups. Right? So, they are the ones that can bring in a representative from every state.

DR. TABAK: Right.

DR. OLSON: So that, it is a way of when you are in partnership and they have ownership, you can really get down to lower levels by working with them on a way you couldn't on your own.

DR. TABAK: Yes. Yes. So, no doubt there is

great value in increasing the granularity of the outreach. I mean, in my former life, I did a fair number of these types of talks, you know, community talks, Rotary-type talks, and so forth.

It is always amazing; you learn. Each time you learn something you never would have thought you were going to learn in that way. You know, it just comes out of nowhere.

And so, I have never had that experience where I went and said, "Oh, gee, what a waste of time." You always at least bring back one seminal idea. And I have been to some pretty interesting places, you know, again, in my former life. I don't travel much anymore.

MR. BURKLOW: I was just going to say one thing Jon Carson said, too, is that he used an industry example which I thought was interesting. One of the websites -- I forget which one -- but they work with a social media site, but, then, McDonald's invites families or parents out to Oak Brook, Illinois. And I was thinking you have the NIH, yes, to peek behind the curtain, and it was the same idea here. People could be invited to NIH.

And we experience that all the time. Anytime we

have either a Member of Congress or a VIP come out, they can't believe -- and this is just a fraction of what we are supporting. But at least it brings up the other point Jon Carson brought up, which was that you can talk on the macro level all you want and people kind of doze off after a while. You have to get into a specific story of what made the difference. And that is what we aspire to do when we tell the NIH story, but I think that is something that we need to do more and more.

Donna?

MS. APPELL: Just to finish Jon, I loved when he was talking about -- and it is something I will consider all the time -- that every observer, or here maybe every visitor, becomes a local reporter, because certainly everybody is Tweeting everything and everybody is taking pictures of everything and sending them all over the place. So, everybody becomes a local reporter.

DR. TABAK: Interesting.

MR. NYCZ: Lynn and I were talking about this a little earlier. When you think about, if we are kind of eyes and ears and we are an ambassador from the public view, what is it we are seeing out there? One of the things that I see

that does great disservice to science, to take you back to one that was a while ago, it was, well, women should get mammograms after age 50. Now they should get mammograms after age 40. No, no, no, it is 50. Now it's 40. And then, the public doesn't see that.

So, we were talking about two examples, one, the fluoridation example, and there is a lot of anti-fluoridation science out there, if I can use that term. And the other one Lynn brought up was immunizations and autism.

Now if you think about the question, in trying to bring input to you, what I would say is think about CDC's role in the fluoridation issue. They are there. They are helping us in the field. In Milwaukee, the Milwaukee alderman, they want to take the fluoride out of the water in Milwaukee right now. This is going on right now.

And CDC is there to help any possible way and they are engaged. We don't really see NIH engaged in those kinds of battles in the same way.

And so, CDC is maybe well-known out there because timing is everything. So, when people are passionate about an issue, you have got a chance to get known. It is an opportunity. And CDC takes those opportunities more often

than I think NIH would.

MS. LAPHAM: They are structured differently.

MR. NYCZ: They are structured differently, yes, but what I am saying is, to me, this is an opportunity.

DR. TABAK: See, in fairness -- I mean, I don't disagree with what you just said; in fact, it is very accurate -- but it is not our mission. See, CDC's mission is to reach out and do the public health outreach. What we do is we support the research that informs the public health approach.

Now, as an aside, a little inside baseball talk, I don't know if it is still true, but for years the dental unit at CDC was supported by NIH.

(Laughter.)

Because there wasn't going to be a dental unit at CDC without NIH support. But that is just inside baseball talk.

But, in terms of the public face, it is because CDC is charged with that responsibility. Now do we do that occasionally? Yes, I think when there are crises. So, for example, related to the bird flu, you know, Dr. Fauci, appropriately so, served as a spokesperson, one of several,

but certainly one of the preeminent spokespersons.

So, there are examples of that, but it is an interesting point, when do we choose to step out and when do we choose to stand behind our mission. So, it is an interesting --

MR. NYCZ: Let me give you another one that involves dental.

MR. BURKLOW: I can't believe it. Dental?

(Laughter.)

MR. NYCZ: The American Heart Association --

DR. TABAK: Yes.

MR. NYCZ: -- just came out as a result of a recent publication in circulation.

You are familiar with that.

DR. TABAK: Oh, yes, of course. I funded the work.

MR. NYCZ: So, NIH maybe should step out on this one. Because the way they came at that made average people and even clinicians think, oh, all that stuff about connectivity, gone, because there is no causal relationship. Yet, there were a couple of people who felt that they had to write a disclaimer on some of this and say it, basically.

So, I am trying to convince our physicians that dental and mental should be integrated for all these good reasons. And then, I get blowback because, oh, the American Heart Association said there is no connection. Well, you didn't read it carefully enough. Let me help you.

DR. TABAK: The general principle that you are raising is a good one. And when does NIH make the decision to step out versus not?

MR. BURKLOW: Perhaps it wasn't a crisis or it is a crisis in a way. The obesity in America and the HBO series, you could argue that, well, we could tell the story without NIH. Well, NIH funds the research that informs all the public health practices and the clinical applications. So, we actually have an extremely important role in it.

And so, we certainly will remain one of the main players in it. So, it is a public health issue, but we were bringing the science behind the health or the science that will contribute to the health. And we do that in other ways, Alzheimer's earlier last month.

MR. NYCZ: But I guess my point is -- and this is getting us back to some of our past -- if you want to select some people from around the communities, and you want them to

come up and give you other perspectives, one of those perspectives, at least from this member, is you do it sometimes; you don't do it a lot of other times. You ought to be broadening it because it is good for science. It is good for all kinds of --

DR. TABAK: Fair point. Fair feedback.

Let me ask another kind of question. Maybe you are all patient advocates, but I distinctly remember you are an advocate for patients and as are you. Maybe some of you are as well, but I remember distinctly.

So, we ask you to do this very difficult thing. We ask you, because you are passionate about the condition that you are concerned about, we ask you to put that at the door. So, how do we thread that needle? Because, obviously, there is not a room large enough to accommodate someone from every patient group.

How have you been able? What are the lessons that you have learned during your experience here which have allowed you to broaden to advocacy, capital "A", as opposed to focusing on the more specific issues that obviously you are very passionate about? It would be interesting to learn from you and anybody else. I apologize if I left anybody

out.

MS. LAPHAM: I will take a stab at that --

DR. TABAK: Yes.

MS. LAPHAM: -- because I think about this issue quite a bit in actually a capacity that is related to Greg, because I do come from the patient advocacy role, but I also serve on the Board of a Federally Qualified Health Center. We are mandated to have 51 percent of the governing board be patients, which is full of challenges.

And we do a very poor job of learning how to receive information from those patients. And then, it doesn't fit, right? It is a bad mix. But we do a bad job of educating them on how to bring their experiences to the Board, and we do a bad job of giving them the skills to govern an organization.

So, I wonder if it is a little related here. Because when you have to fill out your application to be a COPR member, it is right upfront, right? You have to write a little essay as to how you will leave that hat at the door. And that is really important.

So, I knew that coming into this. But I think there could be better maybe conversation about how we do that

as a group. And I wonder, like when we go around the table, when you are here or when Dr. Collins is here, and we have to give our little bit of three to five minutes -- you know, it gets lengthy for some -- that is not leaving our hat at the door, right?

But it gives much more color to the world we come from. So, I kind of struggle with, is that really what we need to be sharing? I think the more sort of focused we can be around a specific topic, whether it is obesity or whether the issue you discussed at the last meeting about race and diversity among researchers, I think it is much easier to leave your hat at the door when we have some kind of topic to ground us on.

DR. TABAK: Right.

MS. LAPHAM: So, it doesn't really answer it, but I think it is a very valid --

DR. TABAK: Well, no, no. No, it actually helps.

Do you have a perspective on that as well?

MS. APPELL: I guess I have a lot of hats. So, sometimes I think Gardiner, for instance, just gave you an example of like, well, I am in epilepsy, but I am doing this.

So, when it comes to organizations -- and I am on

many organizations that I leave my hat at the door, so I understand the whole idea not going to your own agenda specifically. However, when you are with a group of people that come from all different areas, my frame of reference and my knowledge -- for instance, I work a lot with Puerto Rican people and Hispanic people. I am not sure you need me to leave my hat at the door in a way. You need me to bring my perspectives, which is why I came to the table.

So, I understand that I don't want to talk specifically about one particular disease process, but there are some hats that I wear that you actually need to hear from. So, I kind of try to temper that leaving that hat at the door because you really need me, I hope someday. Maybe someday I will prove to be needed in something like that.

So, I think along with not always leaving your hat at the door, I really like to work on projects where we can just kind of get involved and not worry about our hats at all.

DR. TABAK: It is certainly a grounding principle that you raise.

MR. NYCZ: I will just say, for me, I mean, my wife was sick for 10 years. She had heart disease and she

beat it. Then, she had primary pulmonary hypertension. Then, she had a lung transplant, so she was immuno-suppressed. And then, she got cancer and she beat that. And it was ultimately that immuno-suppression.

I wouldn't know what discoveries helped extend her life for 10 years, had her see her son get married and achieve things she wanted to do before she could die. So, for me, it was like NIH has helped in so many different ways; I can't even count them. So, it is easy to think about it is discovery at its core that is important.

MS. LAPHAM: What do you think about the topic?

DR. TABAK: Yes. So, again, I think part of the value added is the unique context that you bring. From the position of the agency, how do we get the right mix? Because, you know, you filled out that application, right? That is sort of what we have to go on. No matter how good you are in filling out that application, you don't really know until you are face-to-face and you listen and hear what you are about, you know.

And so, that is part of the challenge. I mean, sure, the easy way is you need an infinite number of people, but, obviously, it is not possible. So, that is the

challenge. How do you come up with the right mix of individuals? And you do have a great mix here, but I don't know if we should pat ourselves on the back. We may have just been lucky that we picked the right people.

DR. OLSON: And I think this is a really relevant question as you look to the future because there will be a lot of slots to fill.

(Laughter.)

I think it does begin with, I think, some clarity on this issue of what COPR should accomplish. But I guess my observation is that what has been good about this group is that it has had this diversity. And I know I came on, and it was really, personally, being able to -- because I talk with health people all the time, but from a narrow perspective, right, a group of pediatricians mostly.

But what I think would be important to continue to have around the table is this combination of you have gotten great patient advocacy groups of different types. I think it actually depends on the individual, well, with all the members.

I think it is important to have the provider community represented, and the different types. So, I think

community agents, Community Health Centers are really important. And I think people who have expertise in communication strategies, too. So, the important thing is to maintain that mix of peoples who actually -- I mean, I can tell you from like when we have all had dinners together, it is great conversations. So, you see the potential in the synergy there from these people bringing expertise from different arenas.

DR. TABAK: Well, there is no question that each of you is very interesting people. And so, that is part of it.

But, yes, again, there is no algorithm here. We don't have a --

MS. LAPHAM: I thought it was interesting what Debra had to say in her presentation because she was the first class.

DR. TABAK: Oh, okay.

MS. LAPHAM: And she said -- you can correct my history or understanding of this -- but that that current Director brought together 30 kind of experts from all over.

MR. BURKLOW: Yes, it was zero. Dr. Varmus started with 500 applications, then he got down to 70, and

then he got down to 40, I think, or something like that, and, ultimately, 20.

MS. LAPHAM: Right. So, there is the application process piece, right?

MR. BURKLOW: Right.

MS. LAPHAM: There was a shared, it sounds like, responsibility and sort of going through the vetting process. So, that was one interesting piece.

But, then, the other piece about bringing together experts from the field, like to say what should COPR be doing, that is how they defined the mission, is what I understood, which I thought was an interesting way. So, it wasn't this chosen group to come up with what should we be doing, but this much wider external, broader -- I don't know; maybe it is was external and internal, John. I don't know.

MR. BURKLOW: The meeting he actually established COPR --

MS. LAPHAM: Right. Okay.

MR. BURKLOW: -- that is, I think, the meeting that Debra was mentioning.

MS. LAPHAM: They brought in external people.

MR. BURKLOW: Yes, it was a day-long meeting

about what COPR should be about.

MS. LAPHAM: And it really raised like the excitement --

MR. BURKLOW: Yes.

MS. LAPHAM: -- for COPR. And then, it drove, I think, a very good applicant pool.

MR. BURKLOW: Yes.

I know Dr. Tabak has to leave for a meeting at the White House, of all places.

I was wondering, I would like to talk a little bit about the third question: what should be the measurable goals of COPR. I think COPR has wrestled with this for as long as I have worked with the group, trying to define success for COPR.

As I said earlier to several of you, when I have seen COPR make tremendous strides or tremendous success, COPR members have felt inadequate or that they somehow have disappointed the agency. I am trying to explain, no, it actually really helped. And sometimes it is not a direct link that day. It may have surfaced months later. But it speaks to the issue of, what are the measurable goals of COPR?

DR. TABAK: I am actually going to have to excuse myself.

MR. BURKLOW: Yes.

DR. TABAK: Thank you all for being here and for all that you are doing.

MR. BURKLOW: We are going to follow up with Dr. Collins as soon as we all can get together.

DR. TABAK: Great. Okay. Thank you all.

MR. BURKLOW: Thank you, Larry. Thank you.

MS. APPELL: Thank you for coming.

MR. BURKLOW: So, to stick with that question, the measurable goals of COPR, in your mind, how do you see telling somebody, "Oh, COPR is such a success because...." or "We had this impact because...."?

Donna, you're up.

MS. APPELL: The COPR of the past, I saw their goal. I saw their measurable outcomes. They published things. They created things. There was stuff.

And I think that is because they had something they had to do and they had to produce something. And so, I have a hard time answering that question until we figure out what it is that we are doing, for me to figure out what the

measurable goal for that project is. So, that's me; it is a question I can't answer.

MR. NYCZ: As someone who has had his own advisory committee and projects, I mean, part of my measure on that would be for COPR, because Jon said so, I mean, or Francis Collins said so.

The measurement of success of an advisory committee is, did they have input that the people they were advising found of value to help them? I mean, I think it is as simple as that.

We are here to help you. If we are not helping you, then let's not waste our time. If we are helping you, then you just need to let us know. Our time is valuable. I don't need anything more than that.

DR. OLSON: I would like to echo both of the things that have been said.

MR. LEWIS: Yes, I would, too. And then, I know when we first started, an article was published. Like I think it was our second meeting, and it was exciting to see how a discussion started on something important to NIH and became a tangible product, which was then distributed in a prominent journal as well.

And so, I think I would echo what Donna says. It is kind of hard to have goals when you don't have a project yet.

MR. BURKLOW: Okay. Just going back to the questions here, I think we have identified all of them except perhaps the next steps for COPR.

Go ahead, Greg.

MR. NYCZ: Well, I mean, kind of echoing what Lynn was saying, a next step would be to kind of grow the group a little bit, I think. Okay?

MR. BURKLOW: A couple of givens, for those of you at home watching us today who wonder the size of the COPR today.

(Laughter.)

Twenty-one is the capacity. We have hovered around that for a while, but we have gone down and we haven't re-upped, in part because of why we are talking today. I felt that we needed a shift or at least an agreement on where we were going before we brought new members on, especially if who we are looking for might be different than who we may have looked for in the past. And so, we are at a point now where, I mean in the next six months, it is what we would

want to do.

Oh, and that is a great point, too. There are more members than this. It is just that we had to move the date around a couple of times and probably threw several people off. So, we have a larger group than this.

MR. NYCZ: But I actually like the way you conceptualized this when we were talking before about like rearview mirrors or blind spots, and so forth. But it is another guard against that. If that is the kind of thing that would be helpful, then that helps you in determining how to select.

MR. BURKLOW: Yes, to grow the group. We certainly will grow.

We can talk about the types of folks, and I think we have already, the expertise, the background of people we would be looking for to join the COPR.

Also, I think there is a balance of, do you want the expertise to lie within the COPR membership or do you want to be able to reach out to specific experts? And it might be a combination of both.

I mean, it has been great to have Stephanie Aaronson as a communications expert. At the same time, you

may want to call on other outside experts as well.

The other point I think is to come up with at least a sense of the group, issues such as inward versus outward, you know, gathering input versus your role as ambassadors, those types of things. Conveners, one option would be you have decided to hold -- it is almost like you are the planners for those meetings that the White House was talking about this morning. Is that a role of COPR, to plan a series of those types of meetings or one meeting, or something like that? But you have helped design it, figure out who comes, what they are talking about. So, it is not just coming in and giving your individual advice, but you have helped orchestrate or be the architects for another way of getting advice.

MS. LAPHAM: I like that. And would it be possible for the next meeting, between now and the fall meeting, to have a small group come up with two or three options of what COPR could look like and really think through it?

MR. BURKLOW: Yes.

MS. LAPHAM: It is hard to do this.

MR. BURKLOW: Oh, yes. Yes.

MS. LAPHAM: This is actually a nice-sized group.

MR. BURKLOW: Right.

MS. LAPHAM: And I know who that right little group is. And then have a meeting? I mean, I think the point made earlier about this has to be a back-and-forth with the leadership.

MR. BURKLOW: Right.

MS. LAPHAM: And if came up with some options of what this group might look like, two or three different models, and had a back-and-forth on that --

MR. BURKLOW: Yes.

MS. LAPHAM: -- there is more substance there.

MR. BURKLOW: I think it is an excellent point.

MS. LAPHAM: That might be helpful.

MR. BURKLOW: Just because people couldn't make it today, for whatever reasons, they shouldn't be outside the decisionmaking process --

MS. LAPHAM: Oh, yes.

MR. BURKLOW: -- or our choice. But I like the idea of, once we come up with several options, two or three options, to meet with Dr. Collins, Dr. Tabak, Dr. Hudson, and have an exchange about it, so we are all on the same page,

before we recruit people to be on COPR and do all that.

So, one option might be that we end up being a convening group, or at least a portion of the meeting might be devoted to a particular topic you think that the NIH should pay attention to. And we are not defensive about things. So, maybe we have paid attention to something for 30 years, but you feel like it is time for us to pay attention to it again or things have changed. So, we have to be open to whatever you see.

And Larry said -- I didn't write down the phrase -- but he did say sometimes we are so close to it, you know, our perspective isn't as broad as yours. So, you are coming in from the outside. You see things we don't see anymore. It is like things in your house. You know, if you walk by them every day, they become invisible. So, you need to say, hey, look, you have that right there. That is one of the things that I was talking about before, the blind spots. I see an important function of COPR is to point out things that are blind spots.

And a previous Director used to say we can't start believing our own propaganda. I bring that up because sometimes I think NIH needs to be not humbled, but needs to

be brought down to earth and say, yes, you are a great agency, a great organization; however, you still need to pay attention to some of these things. I think that is a role of COPR, to be candid with us.

MS. APPELL: So, I think that is a great idea. To have a focus group before the next meeting would be great, and I agree with that and I would love to be a part of that.

I would also really like to have that PowerPoint slide. I do a lot of public speaking.

MR. BURKLOW: We will make sure you get it.

And part of what we were talking about before about the NIH communications plan, we are going to be putting together a new version of that with some other messages as well.

Yes?

MR. NYCZ: When we heard from the fellow from the White House, the White House doesn't go through all that work without wanting something in return. So, what we might want in return might be a little different than what the White House wants in return, but it would be helpful to try to articulate what it is we would want. Because I could see, at some level, if all you want to do is get the word out on what

NIH is to broader communities and help them, then, get that word out longer, that is one thing.

But if part of it is to say we want to make a change in the uptake or use of new knowledge in partnership with that, then that is a little bit different. And maybe it is a combination of things, but it would be helpful to kind of understand, if we are going to follow that lead, what is it that we are actually looking to get out of that exercise.

MR. BURKLOW: And one of the purposes, I think, is for NIH to be -- I don't know what the term is -- but multi-sensory. So, you are giving another sense to NIH as it moves forward, to have an idea of what is going on in the world and how it can adapt to it, just like we adapt constantly to changes in the scientific world.

So, the consensus is to have a smaller group put together not a series of proposals, but two to three proposals, and then work through the rest of the COPR members, the membership, to make sure everybody has an opportunity to comment on it. Identify a time for whoever can make it or a small group, meet with the NIH leadership here, and settle on where we are going forward, and then move on from there.

Does that capture it accurately? Okay.

As part of the proposal, would this include the types of members we are looking for? I don't see it being tremendously different, but I think that has to be part of the conversation as we look forward.

MS. APPELL: Speaking of the members, I think it was very interesting that Debra was mentioning that it was really important that the people who came to the table at COPR really had a really good understanding of what NIH is. I think that should remain a tenet of the choices of people.

And I only say that because of the fact that we might actually want to perhaps broaden the idea of who should be at the table because we might want experts in social media at the table, or whatever. They might not have a really good working knowledge of what the NIH is.

In order to have the passion, because this group has to be the passion, like the heart and soul of the NIH, to get out there and to be able to present it, in order to have that passion, they really should have the working knowledge of what the NIH is.

MR. BURKLOW: Yes, I think that is an important point. Also, it is much more efficient, too, from a very

practical standpoint, to have people who understand not only what it is about, but the challenges facing it and things that have been done or tried in the past, that kind of thing.

So, okay, any other?

(No response.)

I think we are kind of coming down to a time that is sooner than 3:30, obviously. But we don't want to just talk for talk's sake. So, does anyone else have any final comments or questions?

Greg?

MR. NYCZ: I feel a need to update the folks who weren't here and get them on the same level that we are at. There should be some process that we go through to make sure that that happens.

MR. BURKLOW: Good question. Good question.

And Pat has been taking minutes the whole time. So, we will have those available. But we should have a followup call with all the COPR membership before we do the proposals, before we do the meeting with the leadership.

So, process-wise, yes, that is a great idea. So, we will set up that. We will set that up and give people enough time, because I know we are getting into the summer

months and vacations, so to make sure you are available.

But it is a good point. It has to be planned when we are ready. That is the only thing. I know, yes, that is true. It is true. It is true, right. Yes, and by that time, you can invite the new members.

Greg?

MR. NYCZ: I was just going to say, it has to be kind of, I mean, if you miss the fall meeting, you have got, from what I can see here at least, three -- I don't know if we have four or three --

MR. BURKLOW: Another option that somebody mentioned earlier, you could ask people to stay on, too. So, you don't automatically -- it is not that the mafia is at your door, you know, in the fall.

(Laughter.)

You can stay on longer.

MS. LAPHAM: If we really want to bring on a new crop in the fall, then maybe this discussion needs to happen sooner than the fall.

MR. BURKLOW: Oh, this discussion, oh, absolutely, is going to happen.

MS. LAPHAM: Oh, okay. I was thinking that, come

the fall, we would sit down with the leadership.

MR. BURKLOW: Oh, no, no, no. I am seeing it all in the summer. I would like to get it all done by August.

MS. LAPHAM: Okay.

MR. BURKLOW: Yes.

MS. LAPHAM: Okay.

MS. APPELL: Speaking as a member of the class of '14 -- (laughter) -- I really think it is important, because of this history and because of what we just listened to, and because of the kind of growing pains that we are having, I vote for keeping the class of '13 longer. I just want to put that out there.

MR. BURKLOW: There is probably a good chance of that.

MS. LAPHAM: What is the status of the current application process?

MR. BURKLOW: We have applicants. I mean, we have applications from a number of people from before. And, yes, we can go through them and, also, if there are new -- well, you would certainly go through that pool, even if you had new elements that you were looking for in the COPR members.

MS. LAPHAM: But there hasn't been a call for new applicants?

MR. BURKLOW: Correct.

And you may be sticking around.

Okay. Well, thank you very much.

Oh, sorry, Pat reminded me of a good point. This is the part of the meeting where we have public comment, if anybody wanted to make public comment.

(No response.)

Going, going.

And there are some that have come in. If they have come in in a written form, they will be in your materials and they are on the record as well.

Well, thanks again. Actually, I thought this was great. I mean I thought it was a very helpful discussion. I really enjoyed the presentations this morning.

And thank you for your patience, your enthusiasm, your candor. Can't get enough candor.

We will have a very different meeting come fall.

And I am such an old-timer, I have worked with them. So, we can bring in people from other generations, and I have probably worked with them.

So, anyway, thanks again, everyone, and have safe trips home.