

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 sever

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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NATIONAL INSTITUTES OF HEALTH

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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-11.41 -3.384 Td y

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
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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 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.

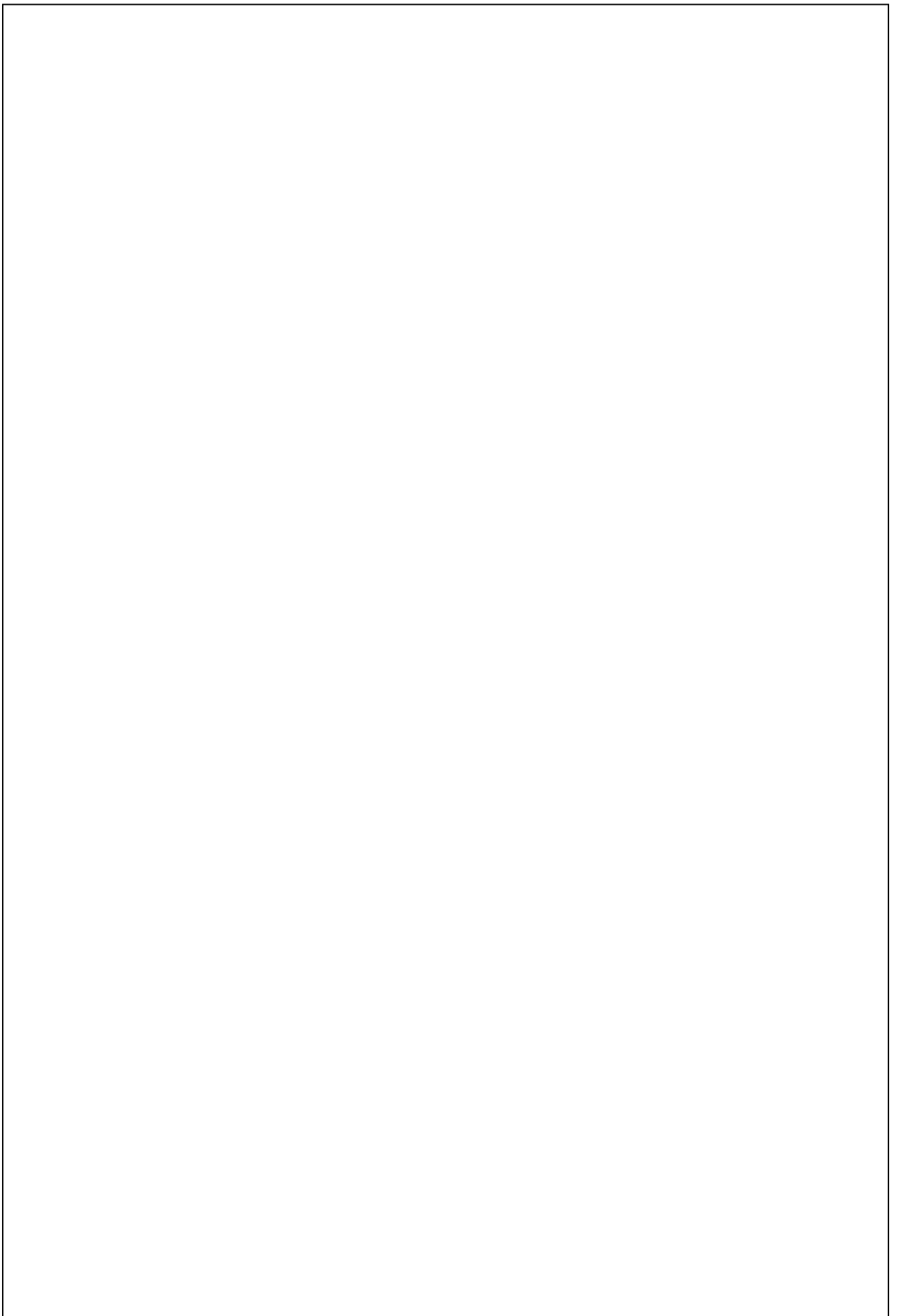
10 Because many of the folks who go
11 there regularly for information on rural health
12 are probably not really aware or fluent on how
13 to access some of the resources at NIH. I
14 spoke with Marin Allen and she said that's in
15 process, trying to bring those together. So
16 that's a whole new community 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 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.

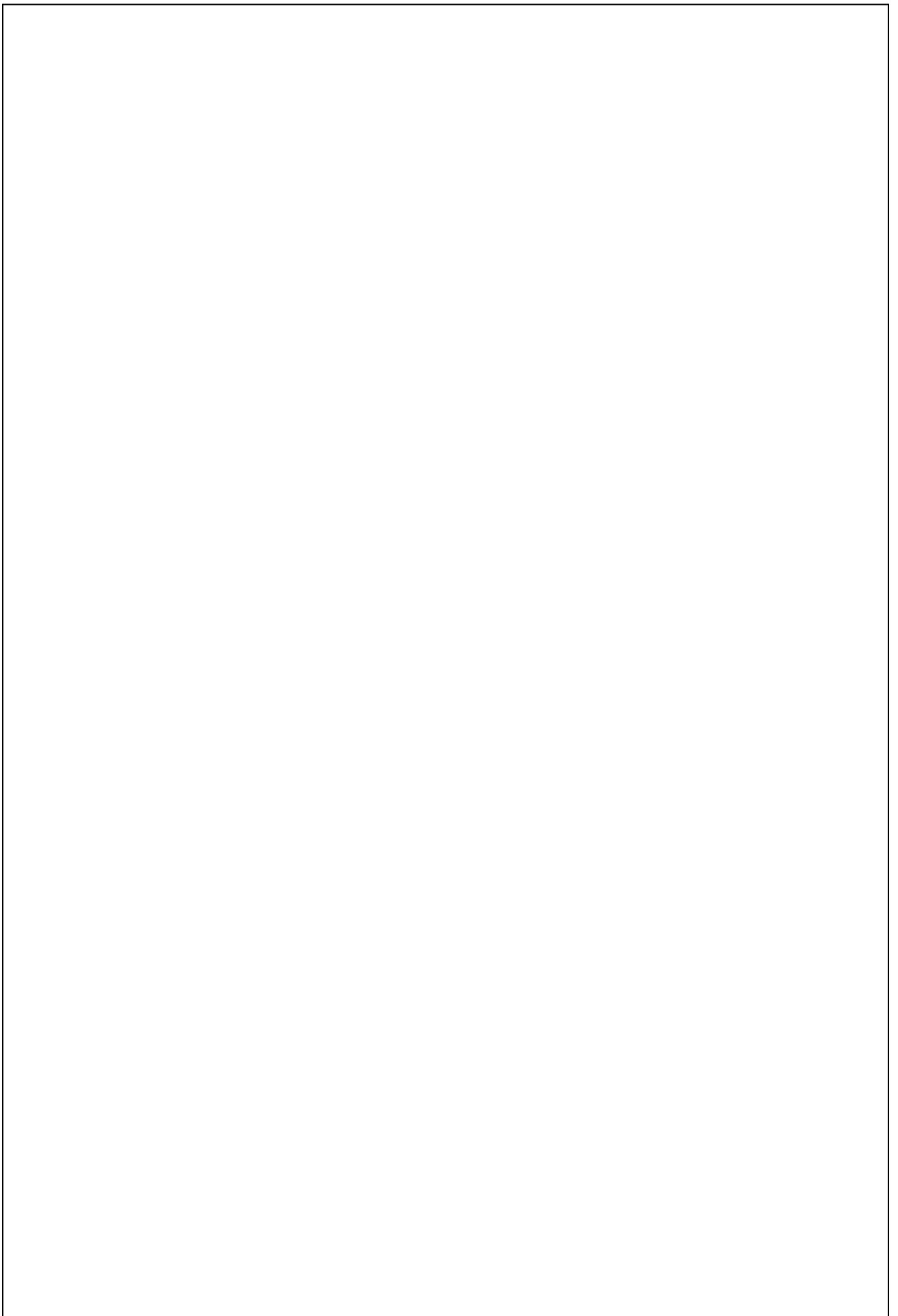
16 Because I'm in the transition
17 right now, it's been a lot of shutting down and
18 starting up, so I haven't done a lot of new
19 things. But I did complete, during this
20 transition time, a chapter in a book by the
21 American Public Health Association on
22 children's safety, the part on school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

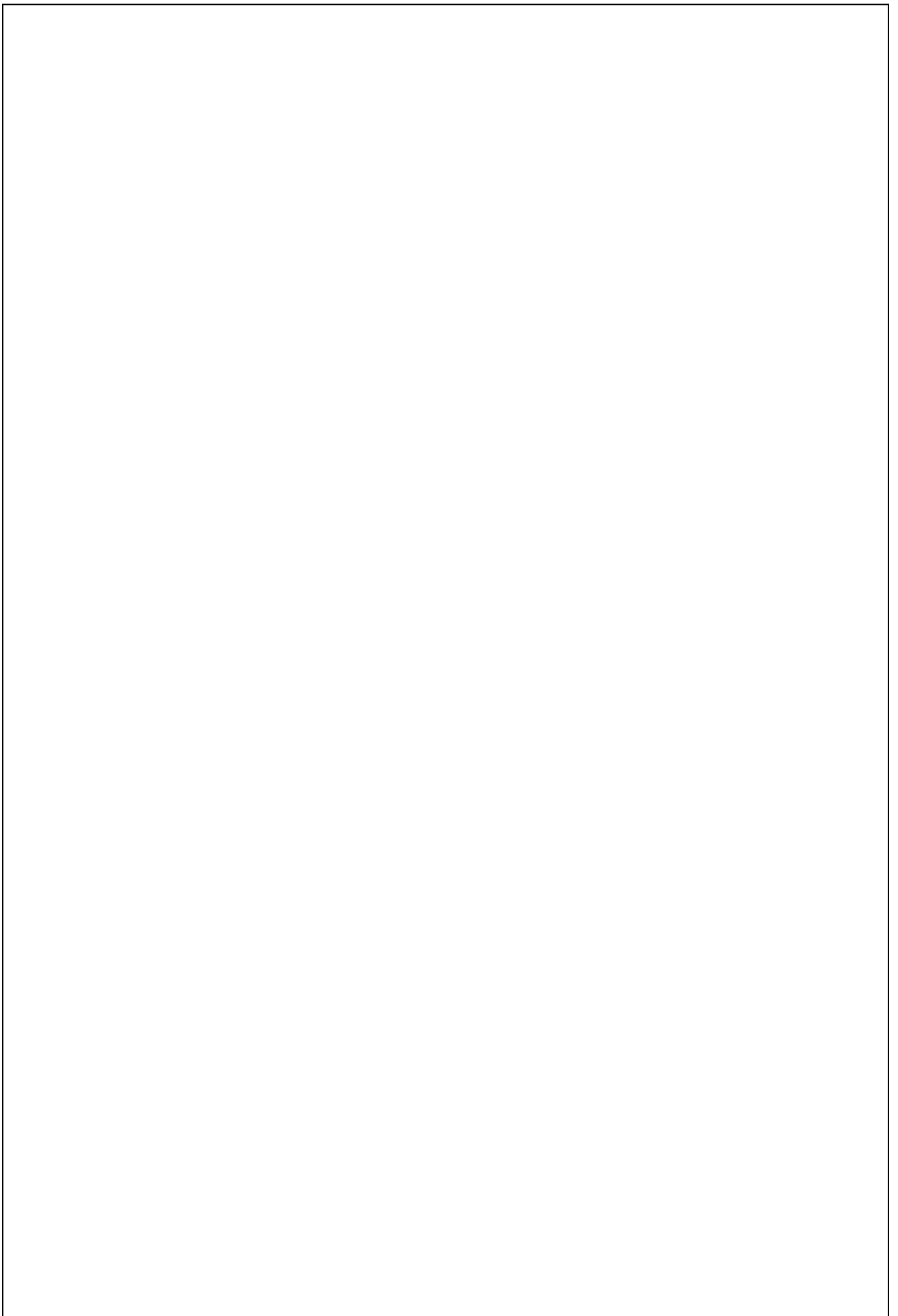


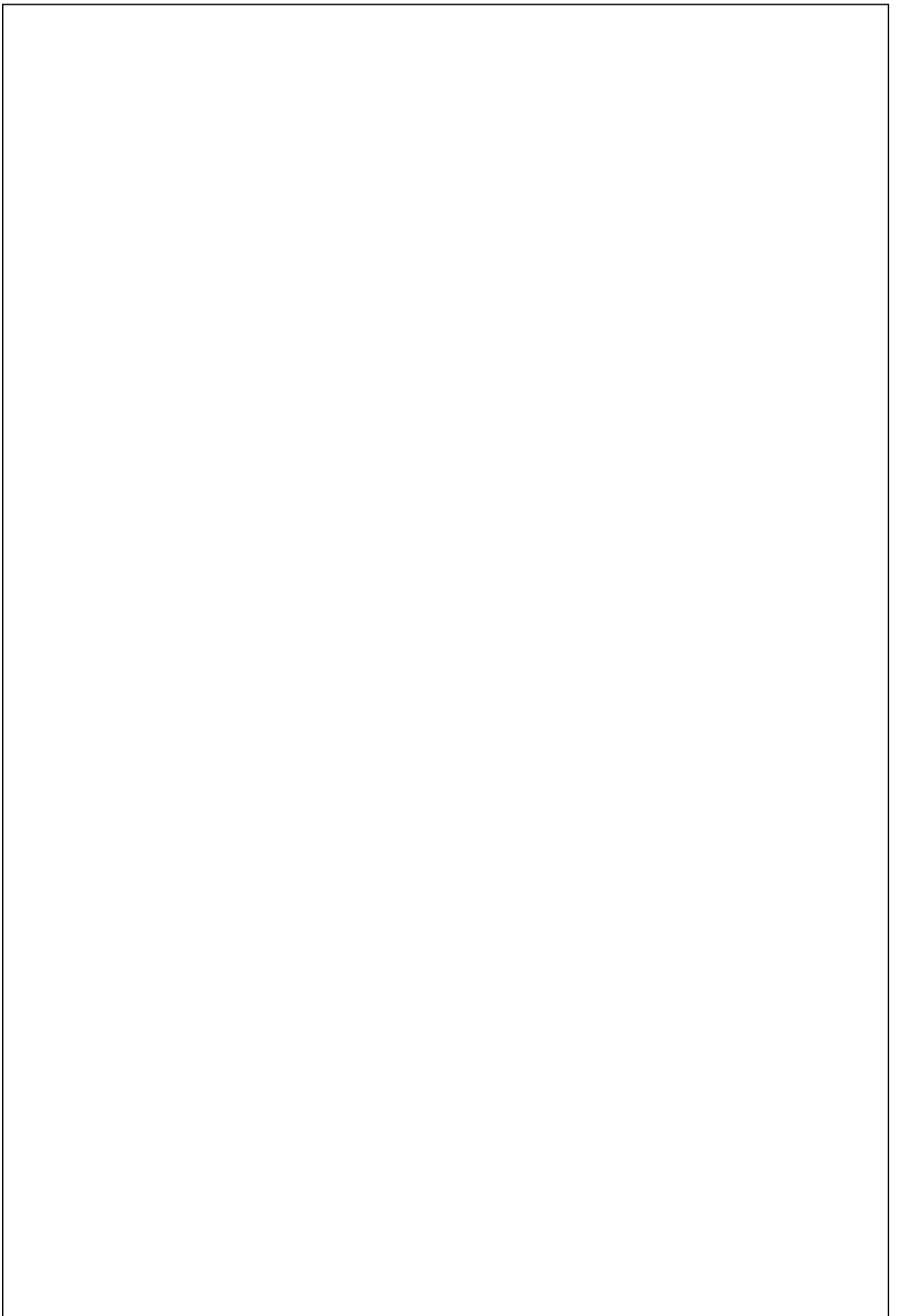
1 for preschoolers. And working in collaboration
2 with the White House Let's Move project on a
3 new website and several PSAs for the early
4 elementary school age, around their key
5 components for Let's Move. Thanks.

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 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

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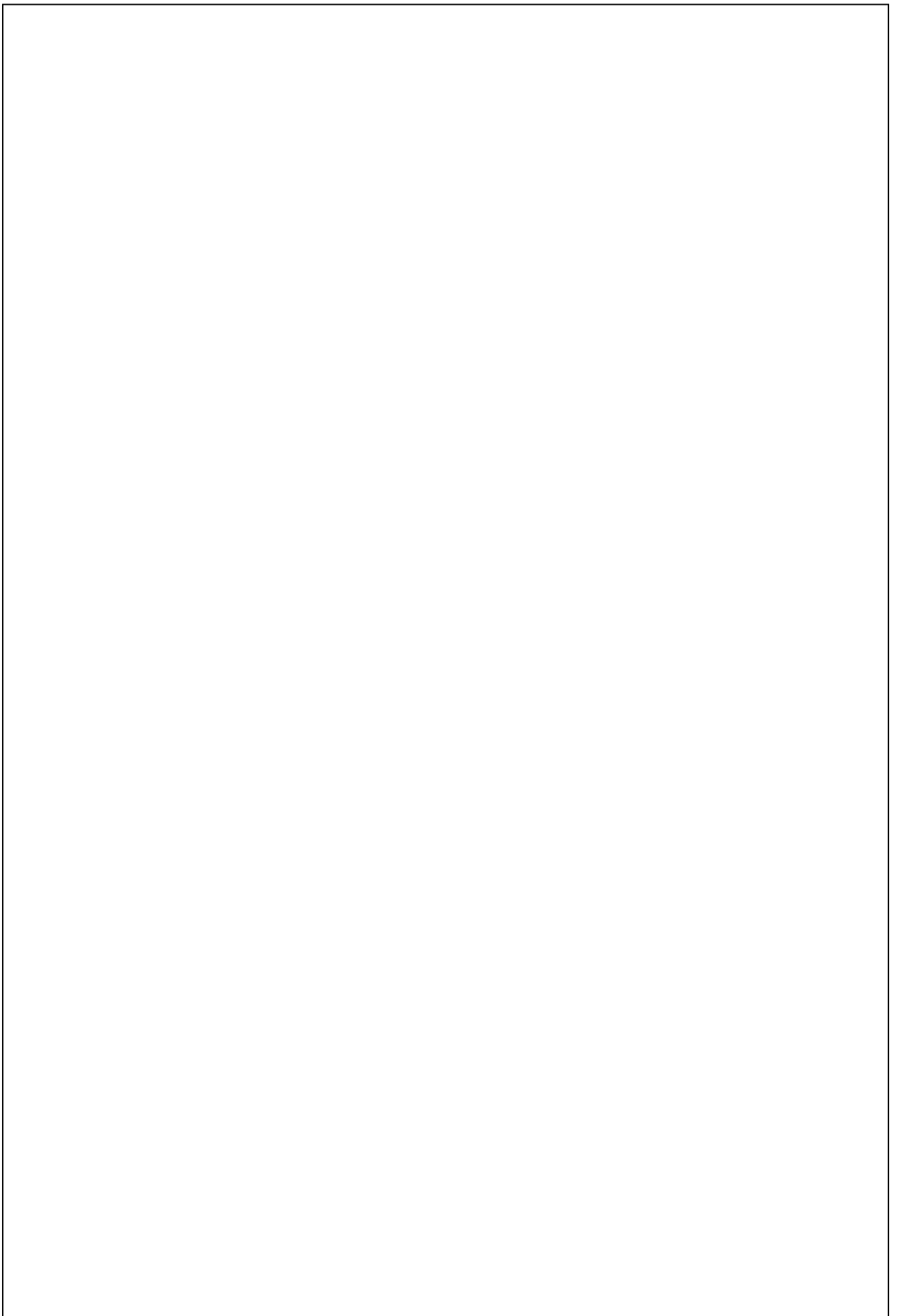
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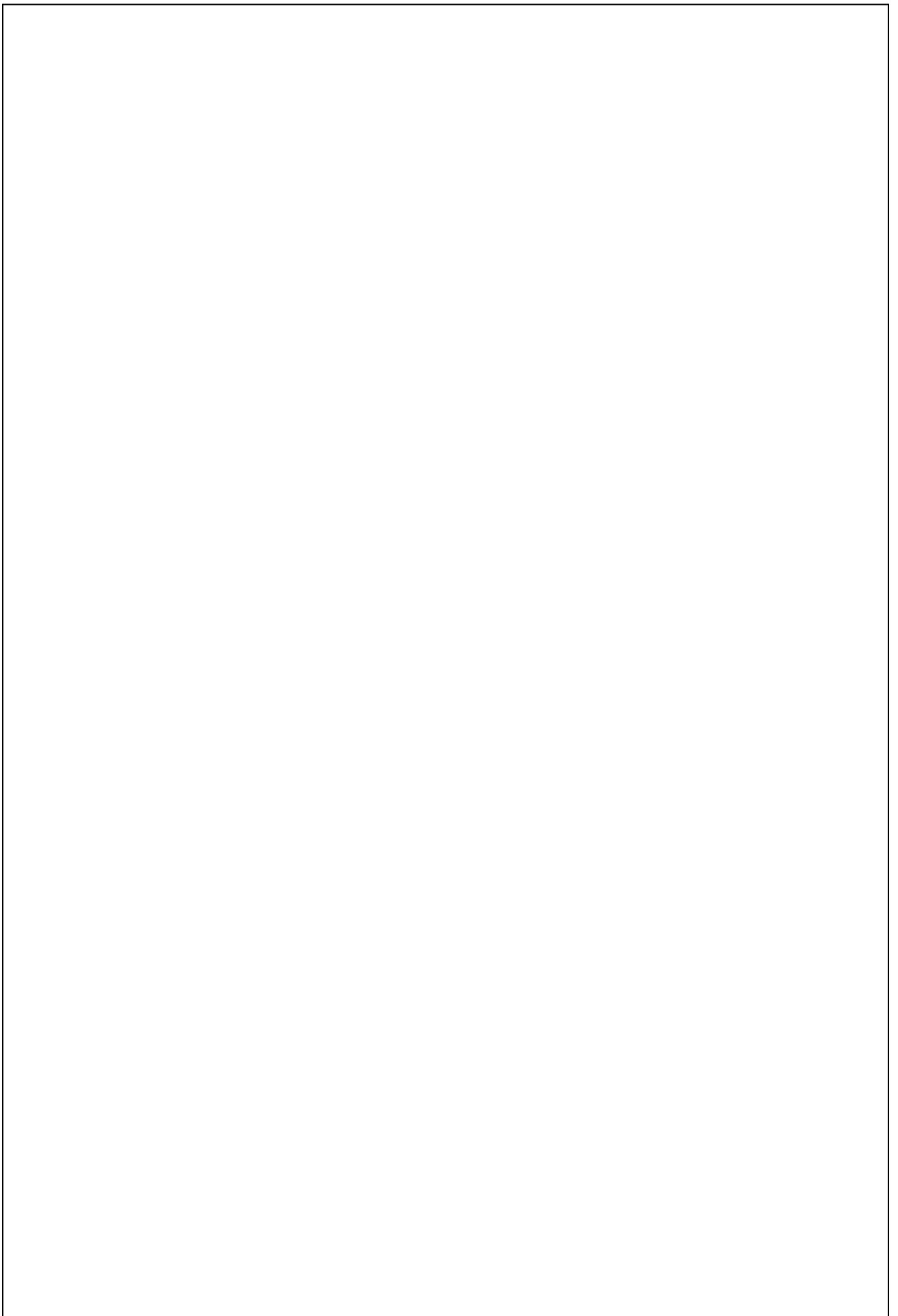
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1 we were able to work so that we changed the
2 law, placed the--in the prenatal screens the
3 HIV panel and, yes, we identified more with
4 HIV.

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

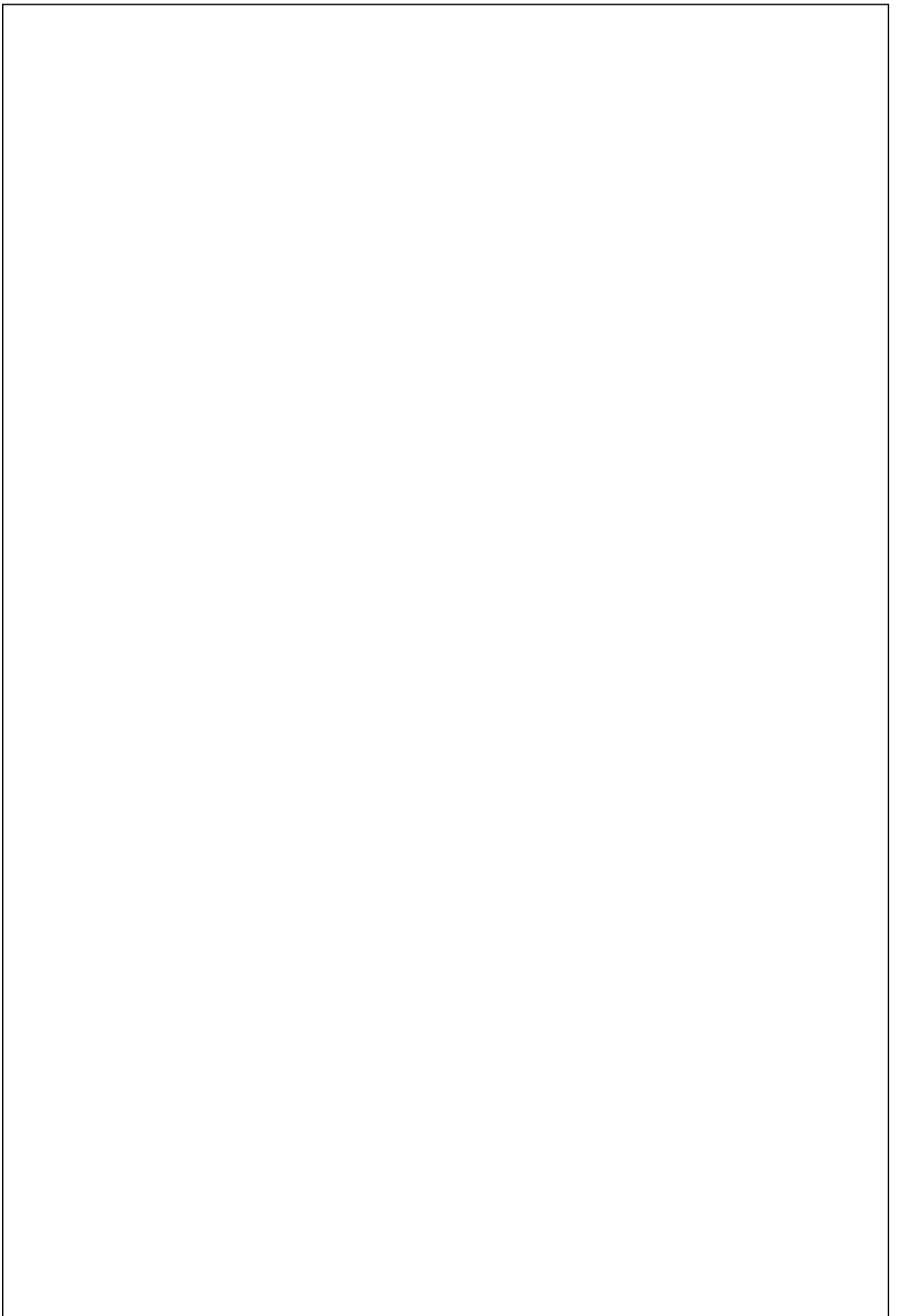
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1 tanning booths as a number carcinogen, similar
2 to tobacco.

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

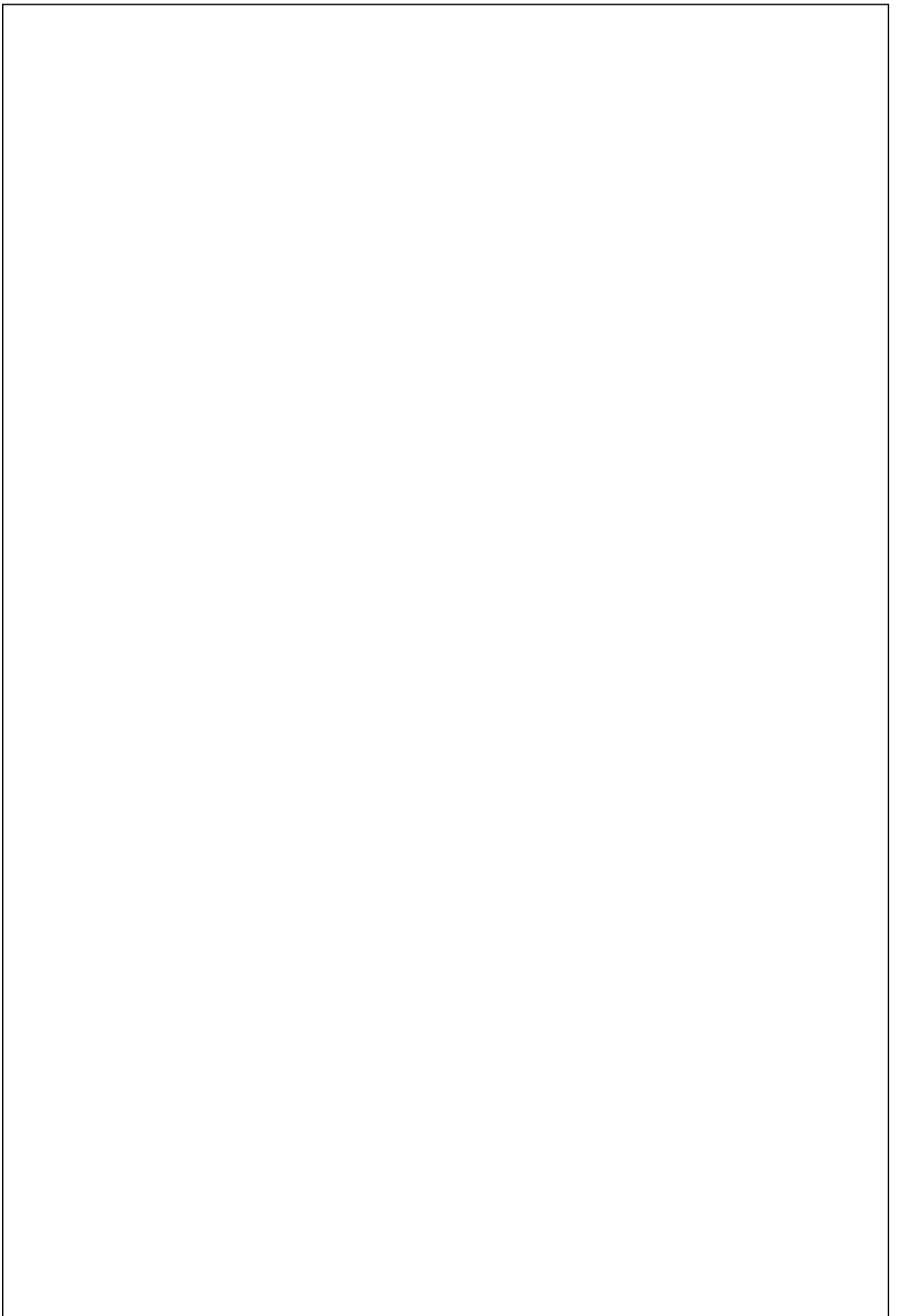
3 We do have clinicaltrials.gov.
4 It's been around for a long time. It is
5 updated but the parameters and the sections
6 that could be available for increased
7 participation, we're actually suggesting that
8 they somehow be merged in some way. So we'll
9 see how that goes but they still have a long
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.

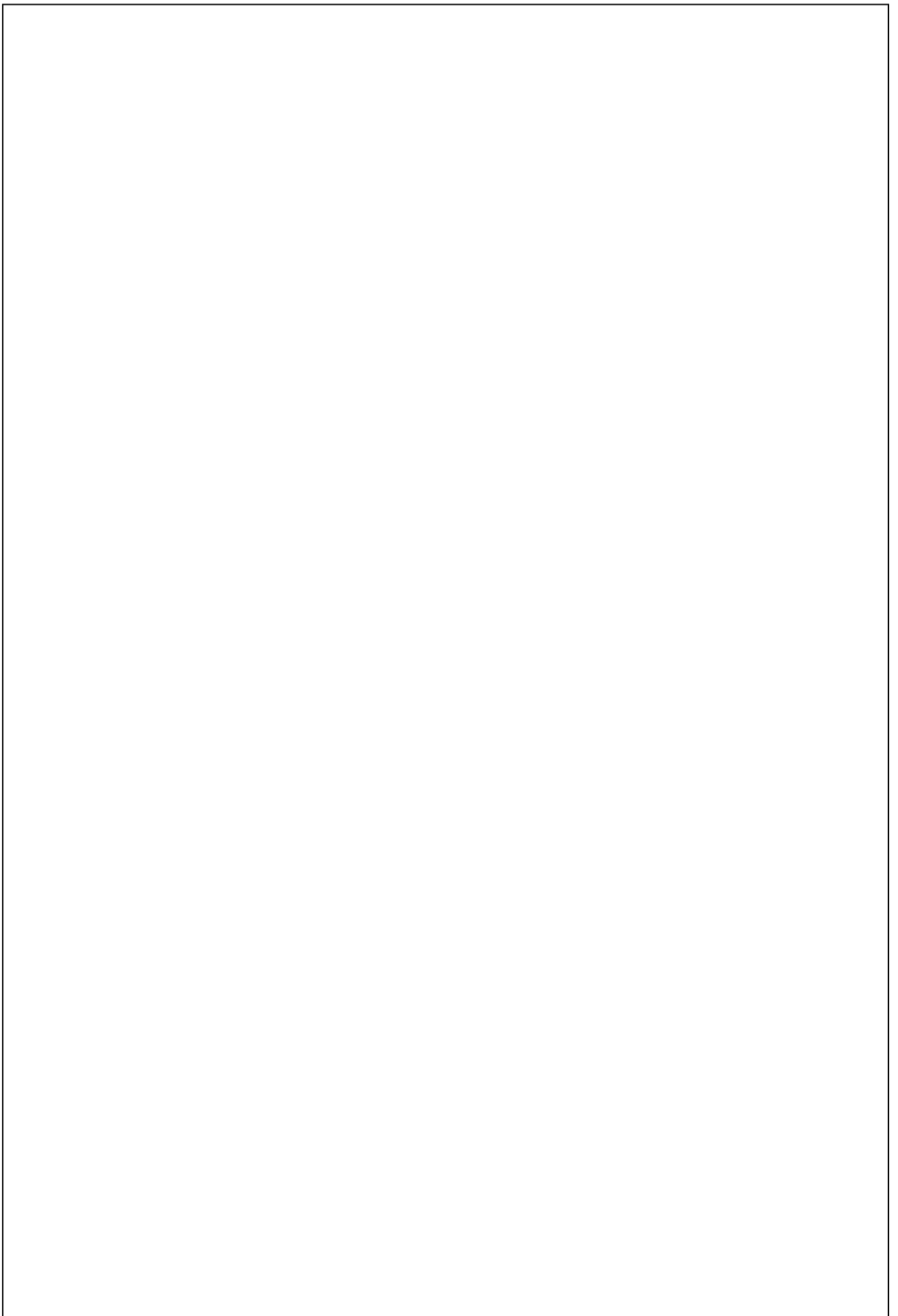
16 In the development and design of
17 research and, in our case, at international
18 research, as it relates to developing outcoming
19 measures in rheumatological care. And we have
20 been invited, based on over two-and-a-half
21 years now, of patients, people, community
22 members, and healthcare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

1 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 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

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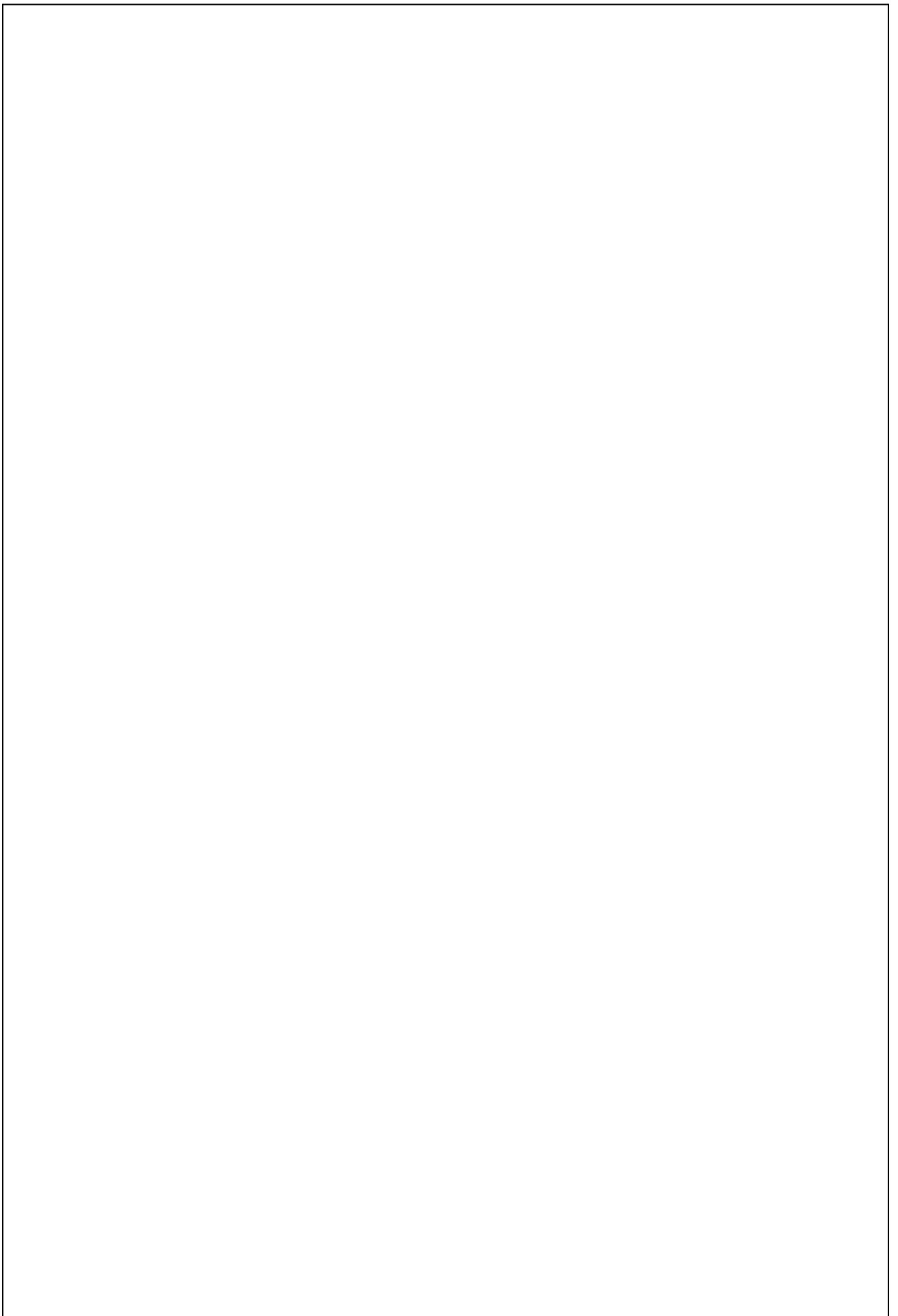
1 And then jumping ahead 22 years
2 from that point, by year 2042, minorities in
3 the U.S. will have become the majority. So not
4 only does that mean healthcare delivery
5 practices need to change in order to
6 accommodate the changing patient population,
7 but also, I feel that our biomedical research
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



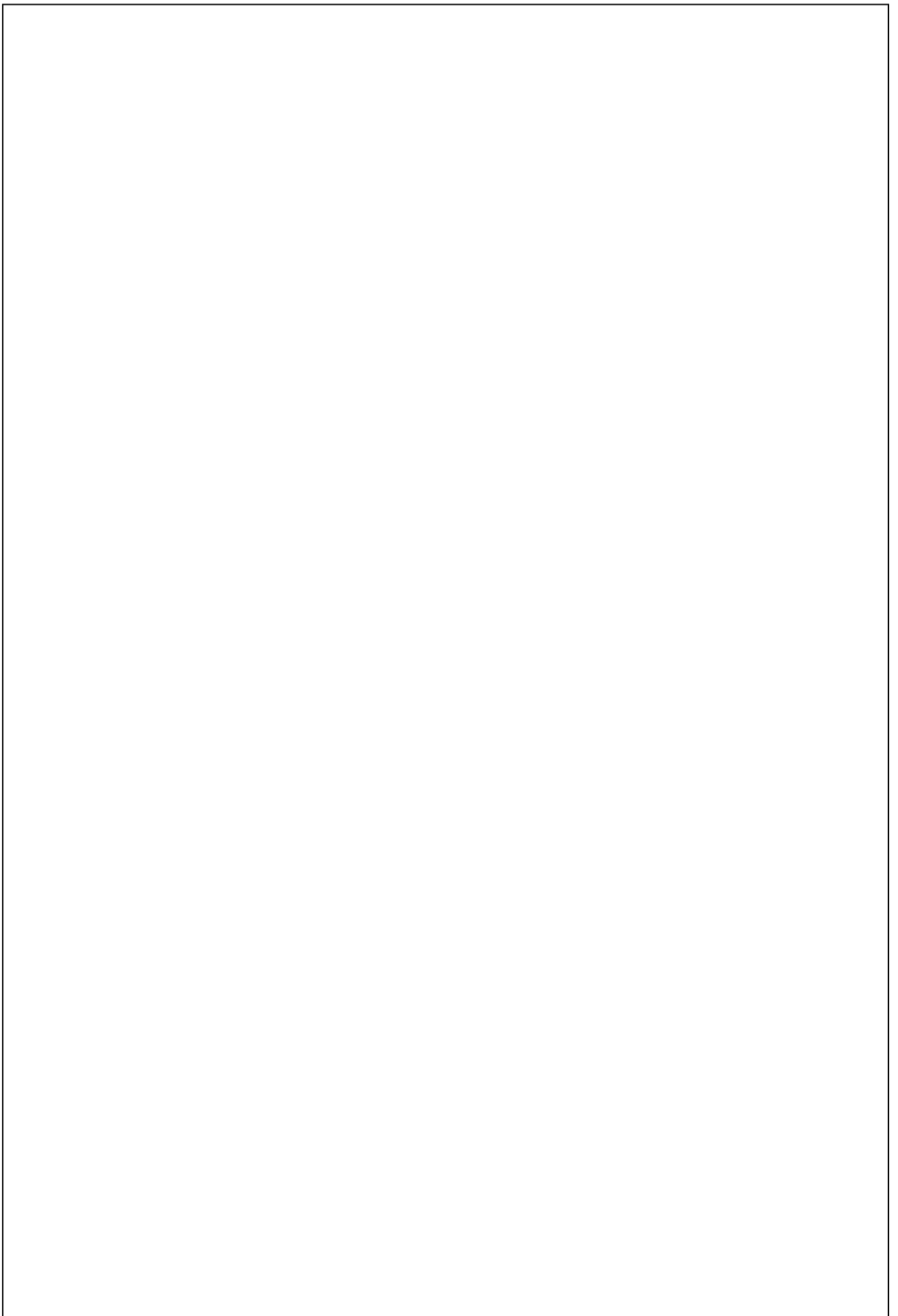
1 our structure fit our ever-evolving function.
2 And they've created some (unintelligible)
3 lately by making such recommendations and
4 change is not always easily absorbed. So I'll
5 mention a little bit about that in a moment. I
6 have a council of councils, which actually
7 reports to Jim Anderson, 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



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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.

1 share with you a happy tale of three dentists.

2 Think about that for a minute.

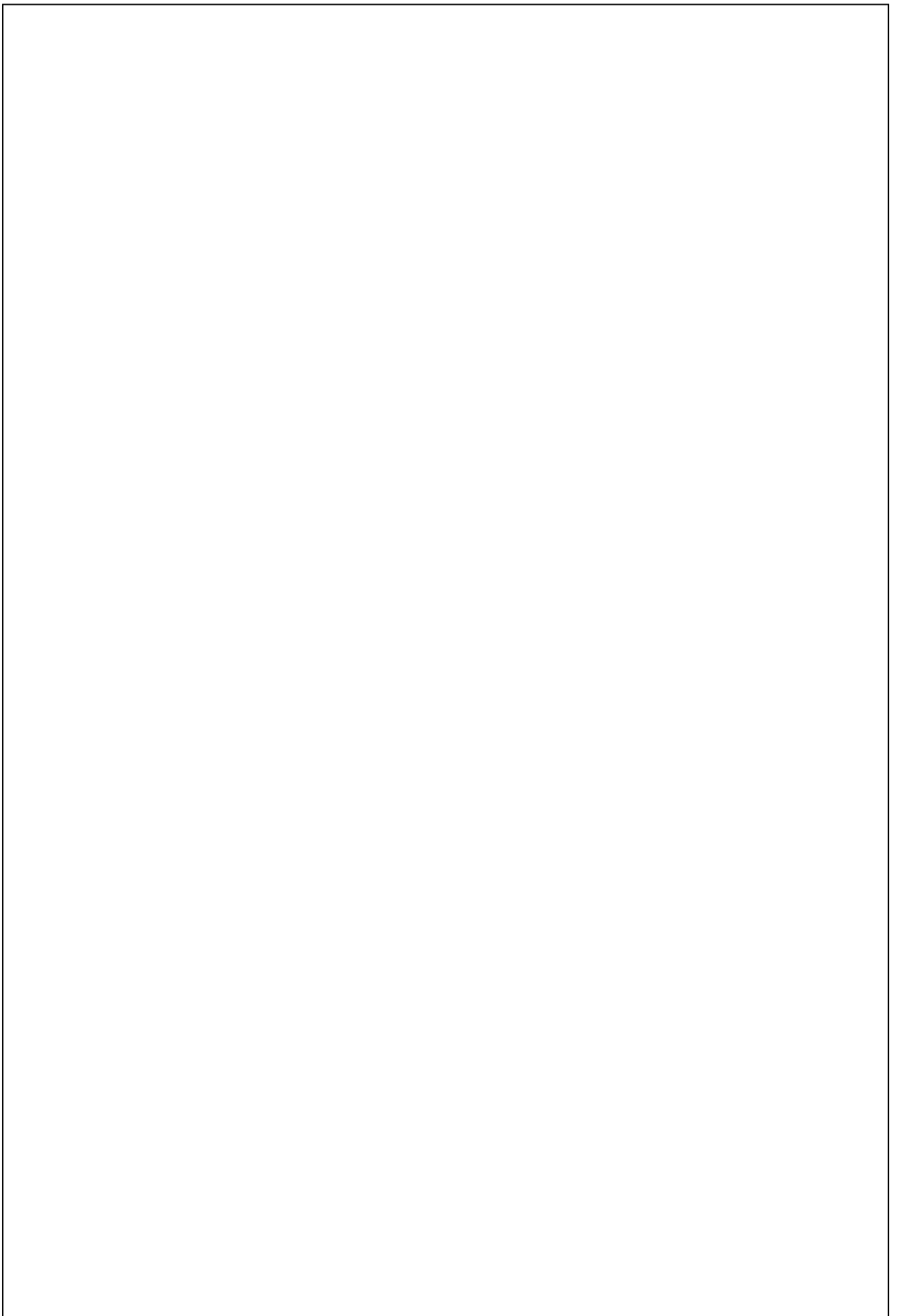
3 So earlier this week, I announced
4 the appointment of a new institute director,
5 Dr. Martha J. Somerman, who is a DDS as well as
6 a PhD, who will join us as the Director of the
7 National Institute of Dental and Craniofacial
8 research at the end of August. She has been
9 Dean of the University 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



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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

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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.

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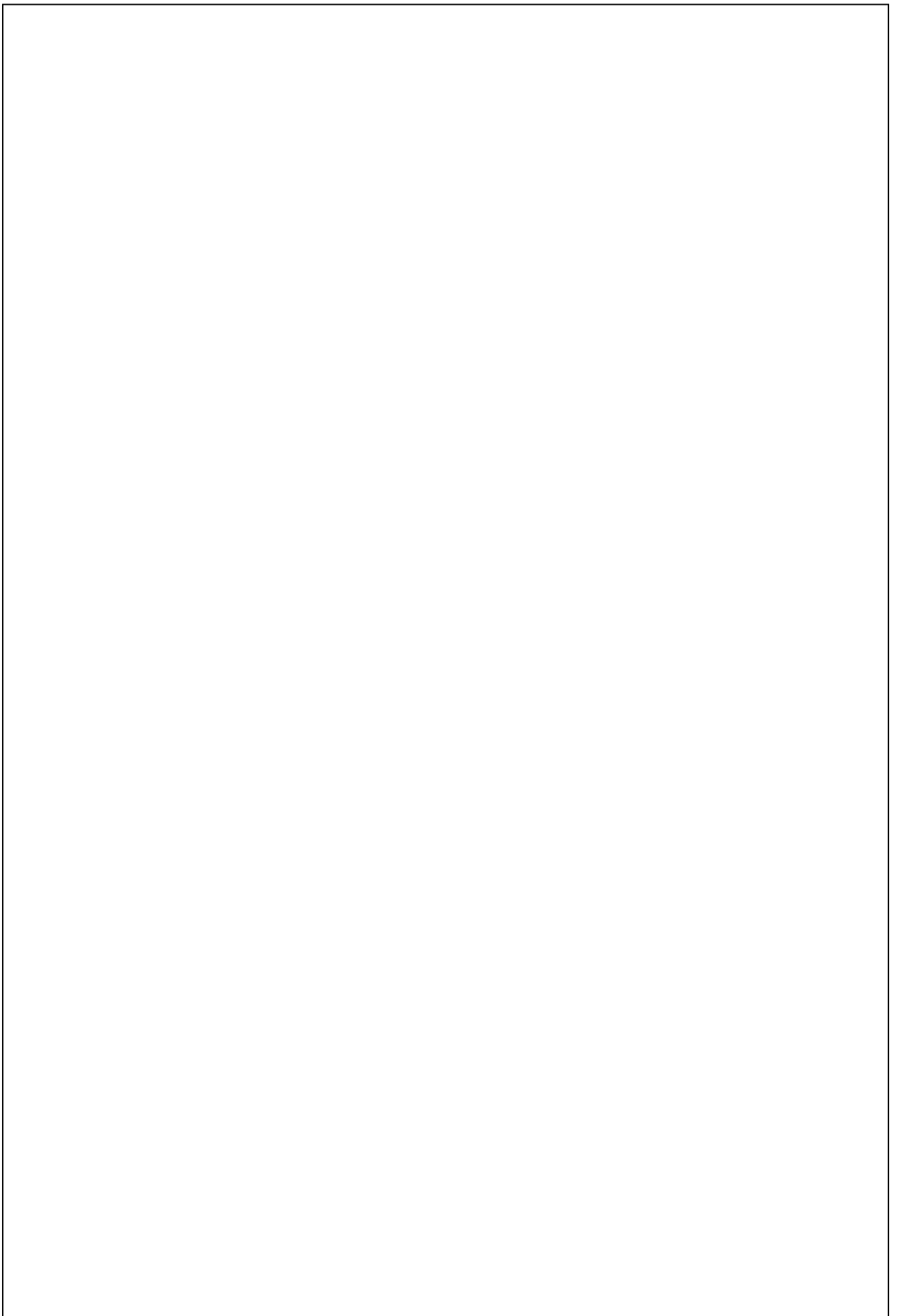
1 Seems like it would be a good
2 thing to do this in an open-access environment.
3 Well, that's what we're all about. So the
4 scientific management review board received a
5 lot of public input and ultimately, last
6 December, concluded that we should, for the
7 first time in quite a while, create 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 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.

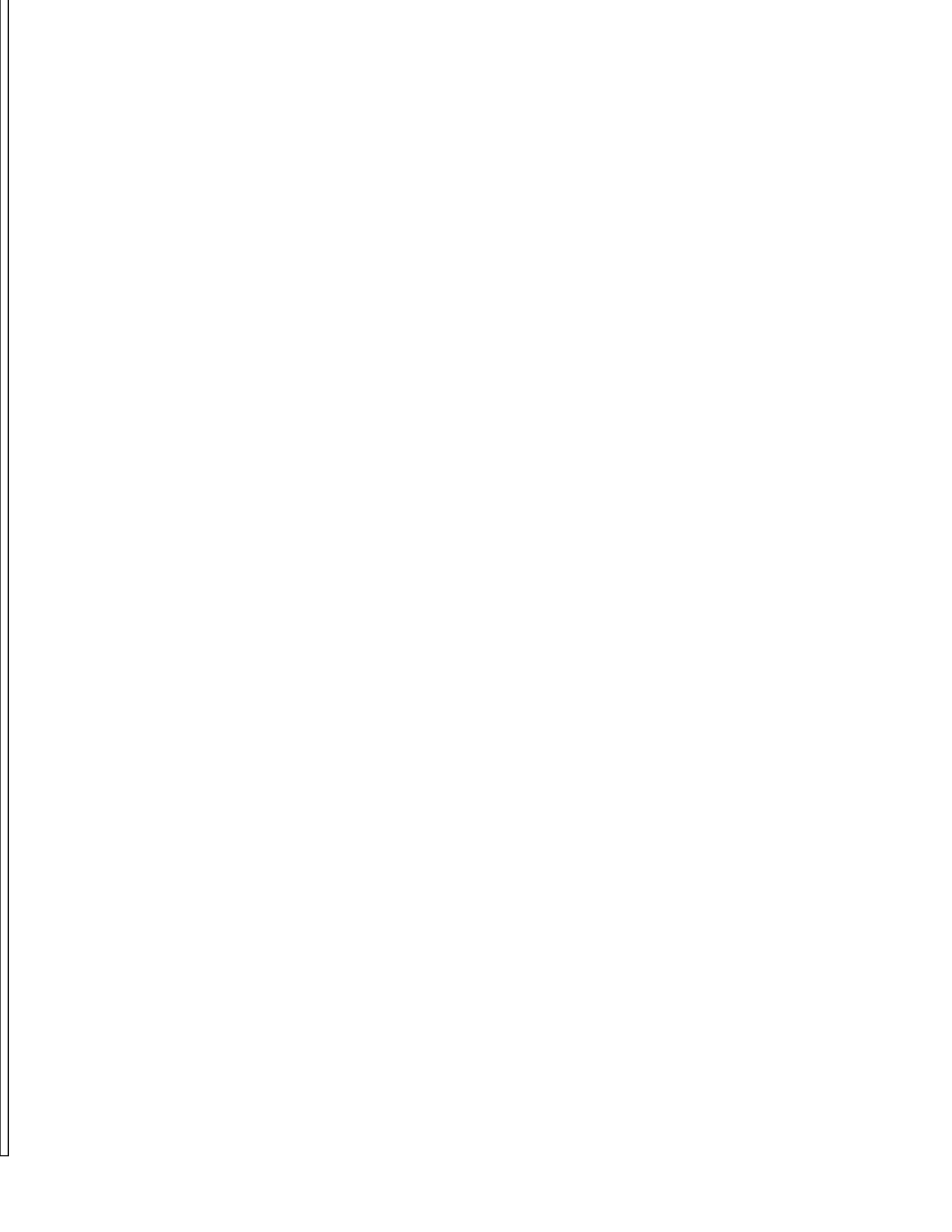
5 When I talk to companies about
6 that idea, they're like, oh, yeah, I wish you
7 would do that. But by the way, please talk to
8 the FDA because if you're going to do this and
9 if it's going to succeed, FDA has to agree that
10 this is useful information that they can
11 include in their evaluation 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.

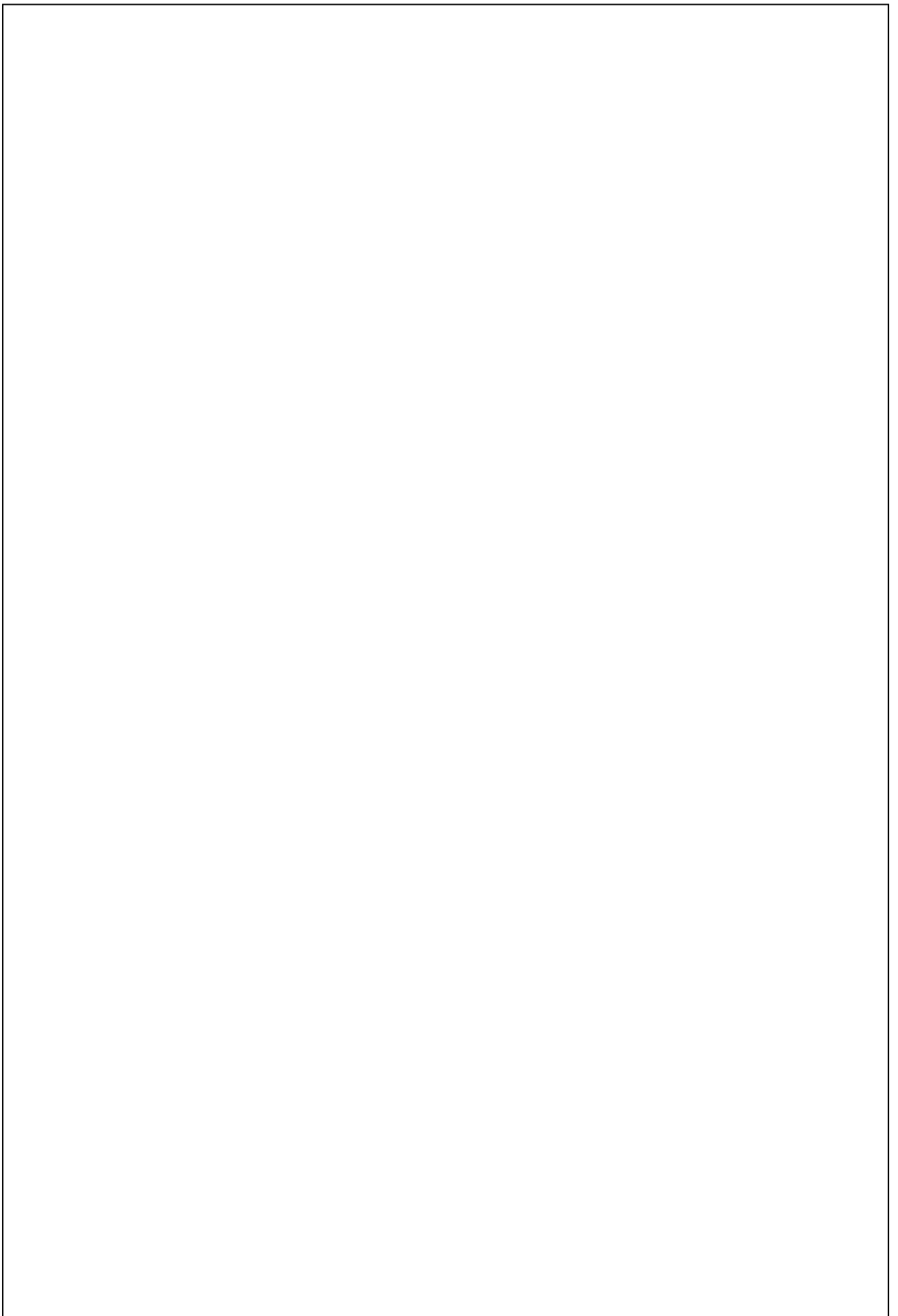
17 We have this joint leadership
18 council that Peggy Hamburg and I have set up
19 with six working groups--one of them on
20 tobacco, another one on toxicology, and four
21 others on other topics--to try to be sure that
22 we're making the most in 2011 of how these

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





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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

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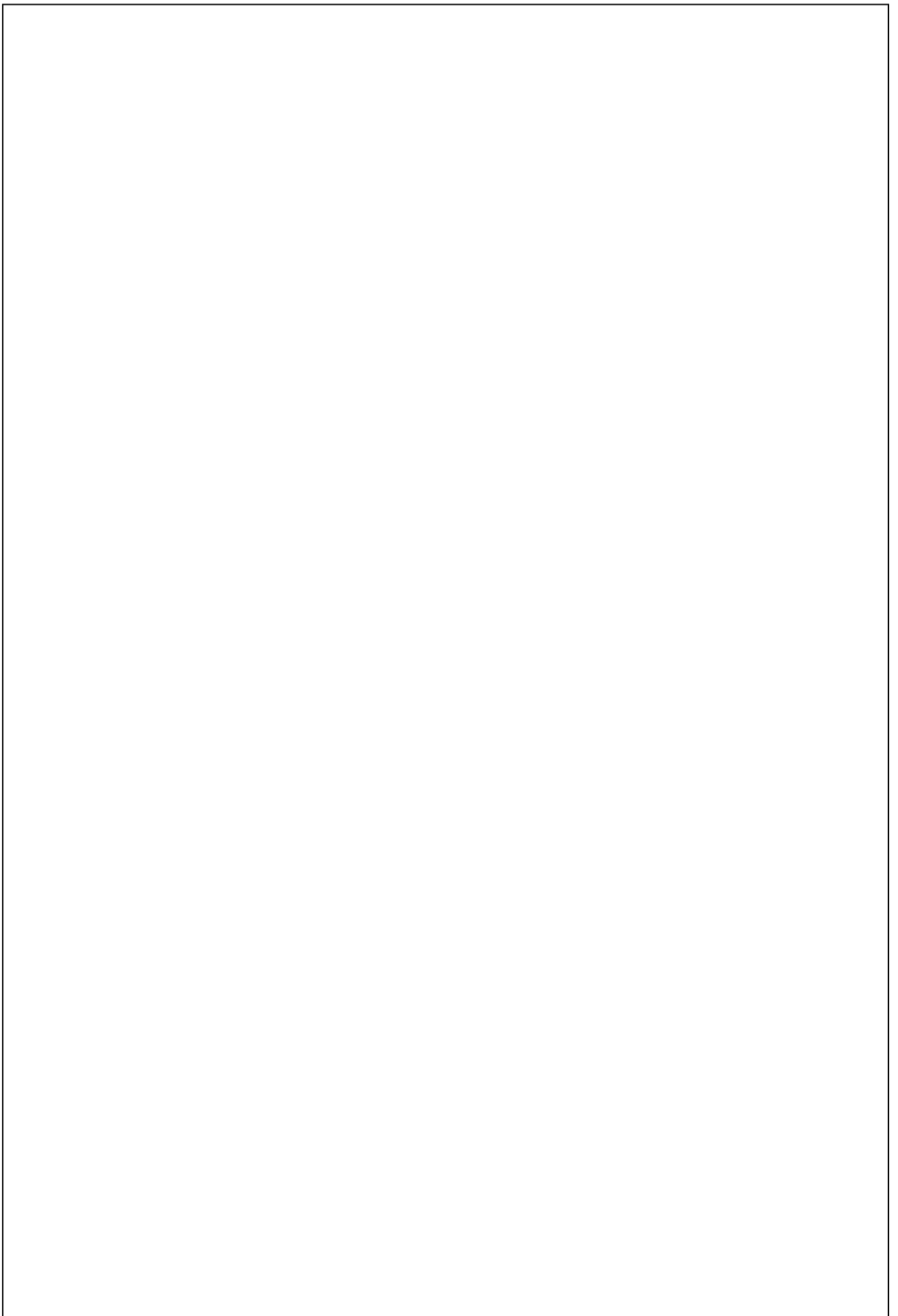
1 would have to be turned away, kids with cancer,
2 for instance, that got their attention, also,
3 that this is not a bunch of people in the lab
4 playing around, this is really significant for
5 human health.

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 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.

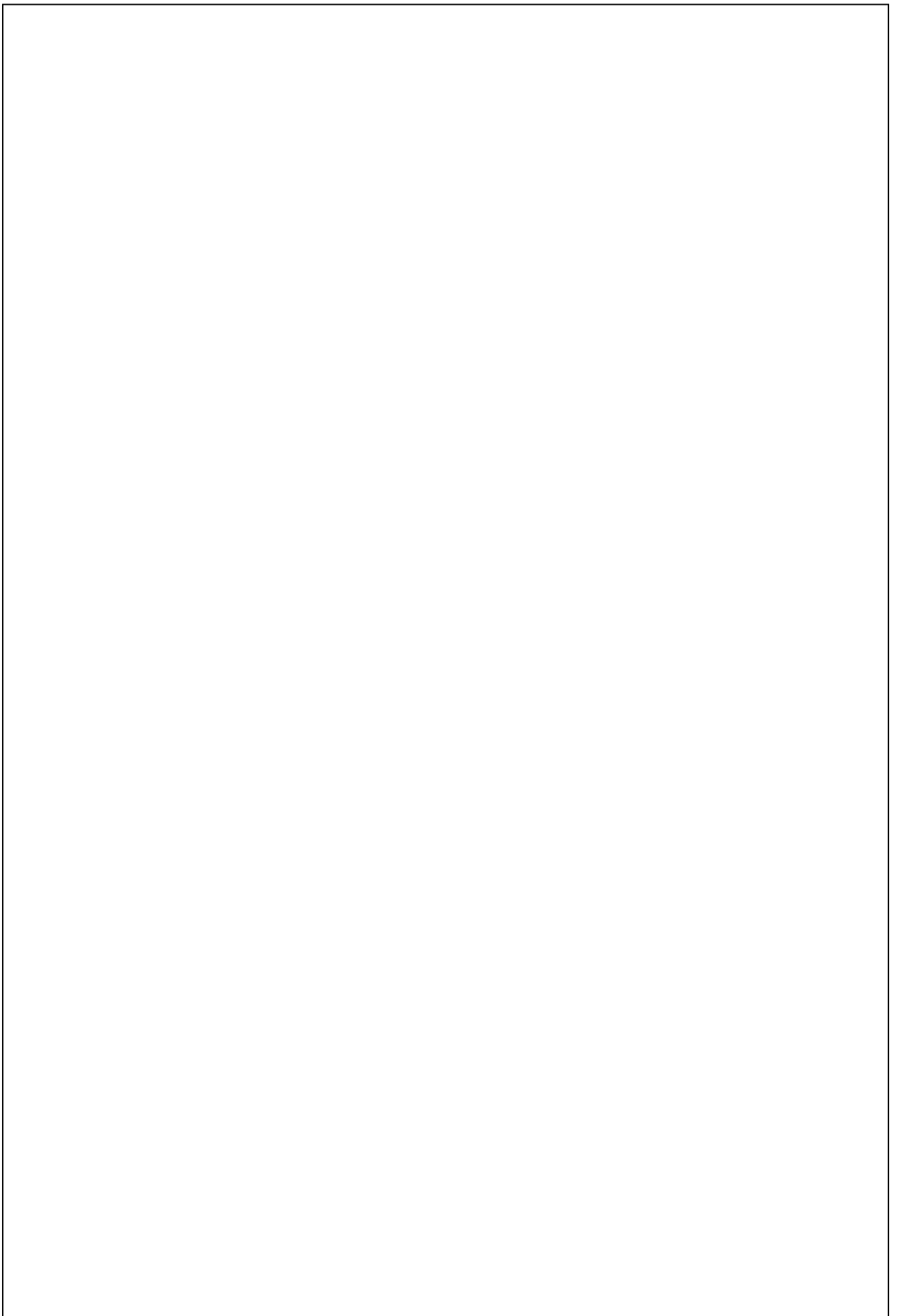
10 MALE ONE: So I guess we'll do a
11 couple minutes of discussion and then we'll
12 move onto our (unintelligible) presentations,
13 as well. So Donna?

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 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 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?

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

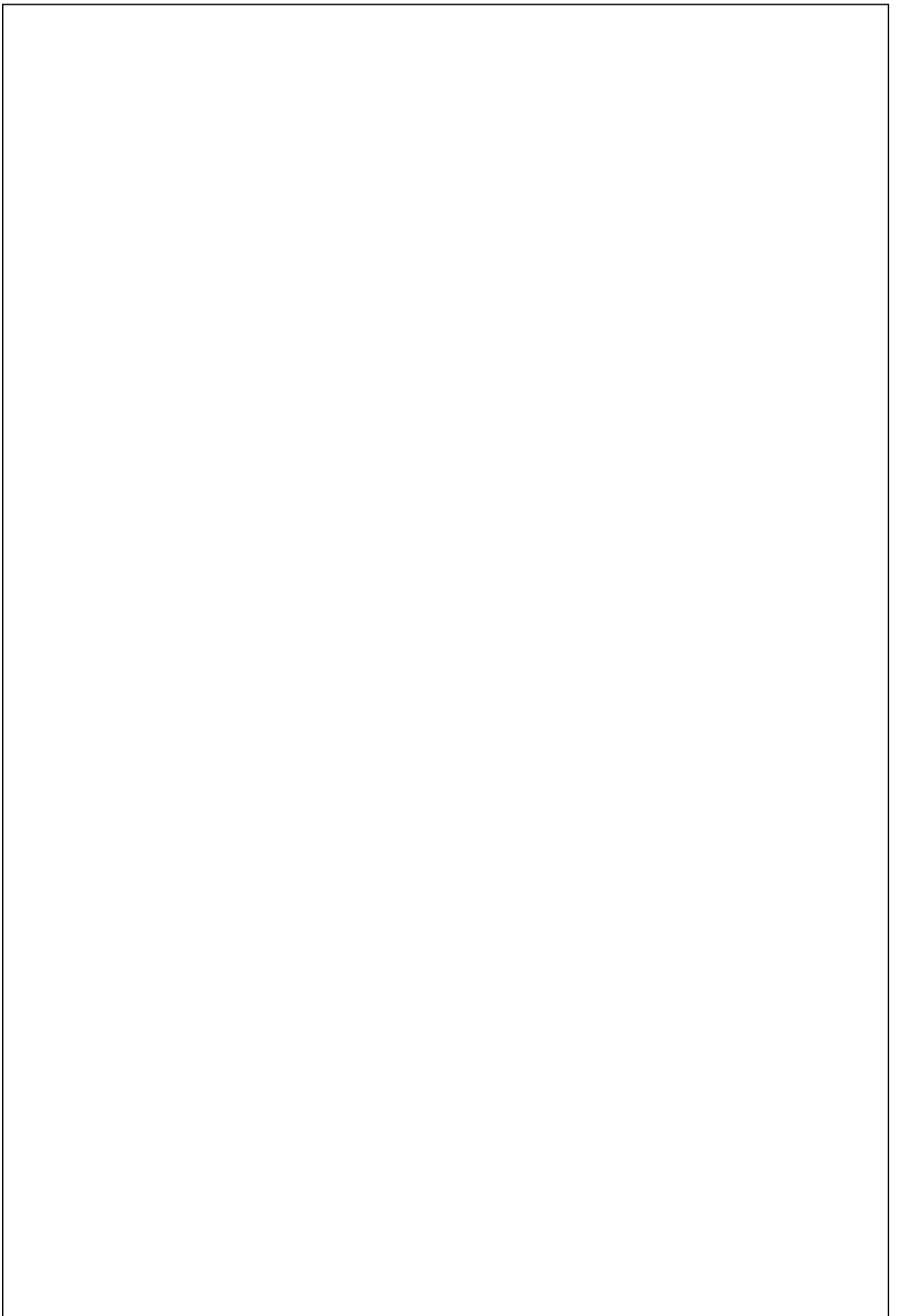
4 And as you said, Dr. Collins, in
5 the beginning, is that there's various, various
6 workgroups out there that are very, very
7 specific. We're not that. We are literally--
8 we represent a lot of different constituents
9 and when we walk in here, we don't walk in here
10 with hats of agendas, we walk 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



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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.

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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
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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 p.f22 <.256 Td6e5stry
12 education, such as media and technology. And
13 that might be useful and that NIH could expand
14 on. We think that it's important to encourage
15 to reach beyond what they're doing now and

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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

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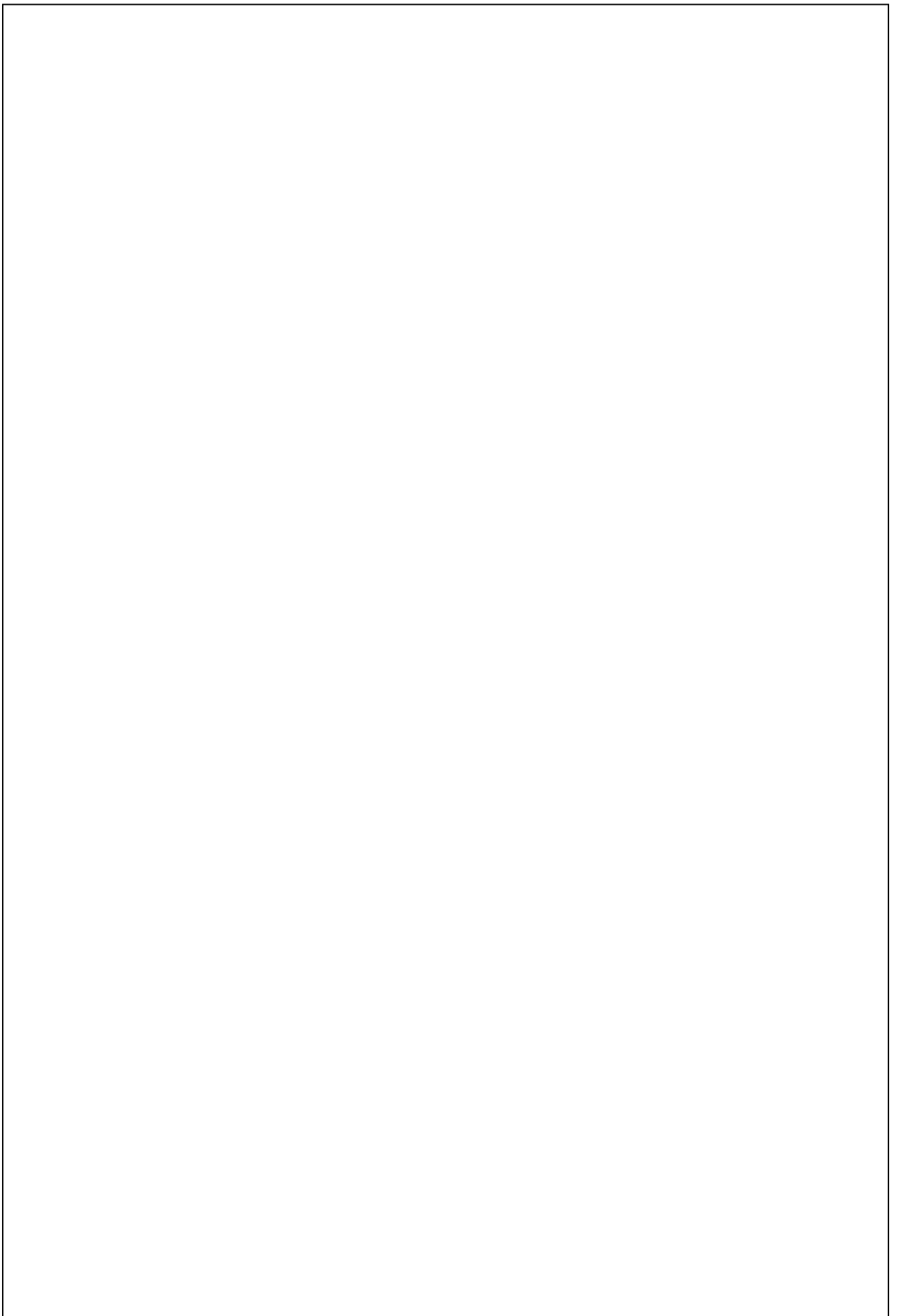
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1 the development of education outreach programs
2 but we're not sure how much the target
3 audience, the students themselves, are engaged.
4 They may be in pilot programs, but are they
5 involved in the development? And so that's
6 something to think 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-

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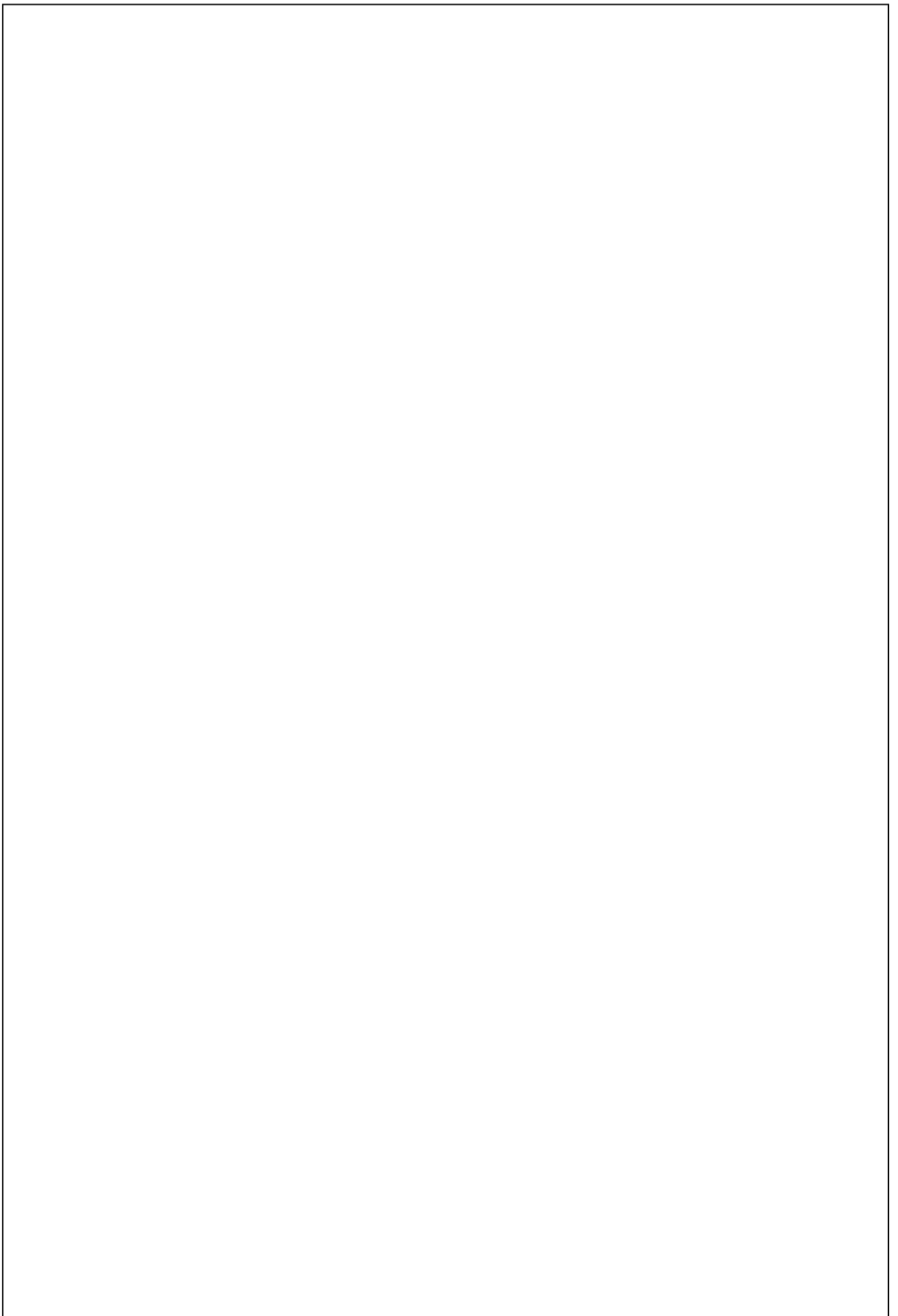
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1 the messages from the public about what their
2 concerns are, that perhaps that we haven't
3 fully addressed.

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.

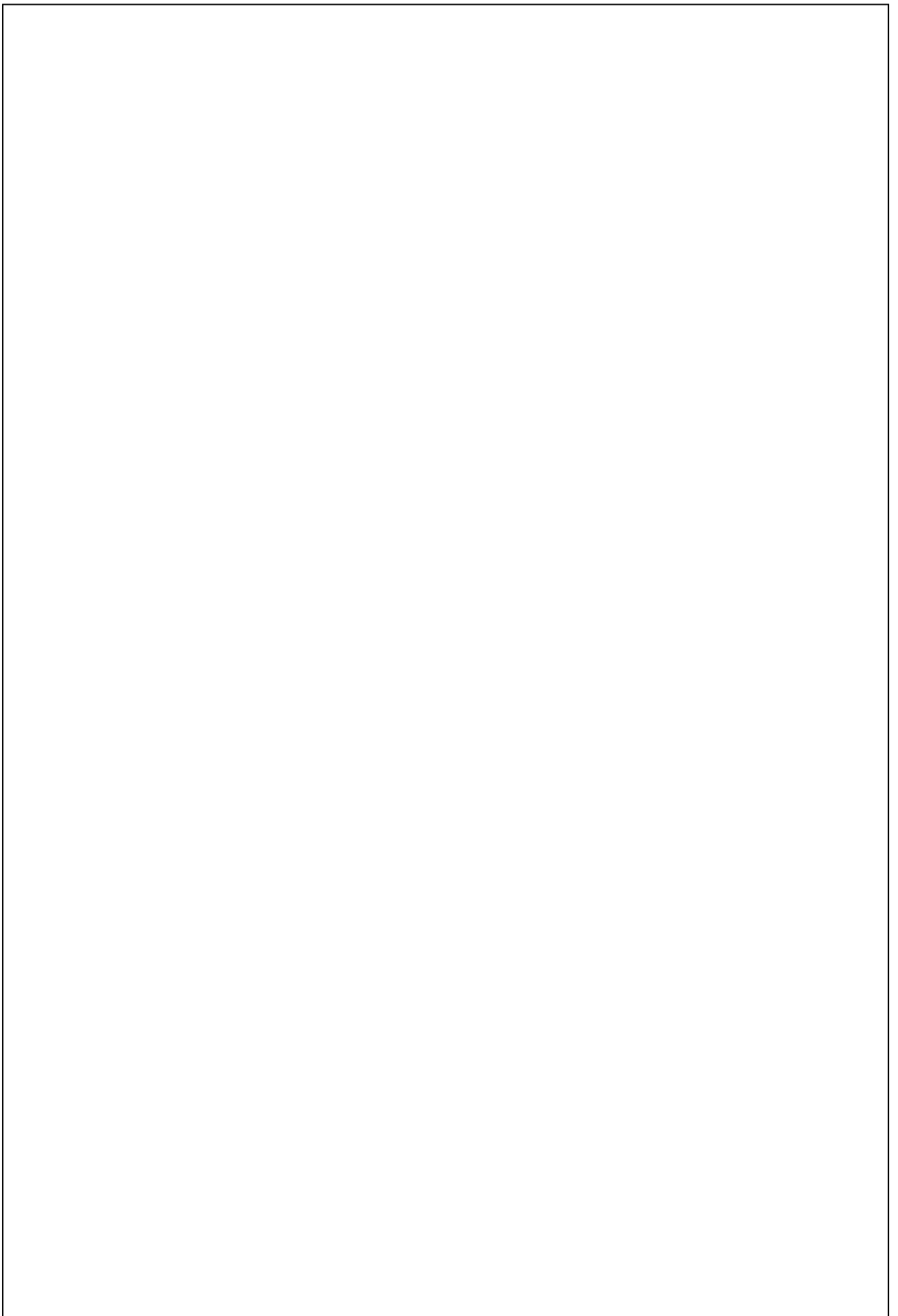
18 In fact, I would worry that you
19 may have taken on board, in terms of your own
20 responsibilities for being COPR members, some
21 sense that you should be out there talking to
22 your own rotary club and making the case for

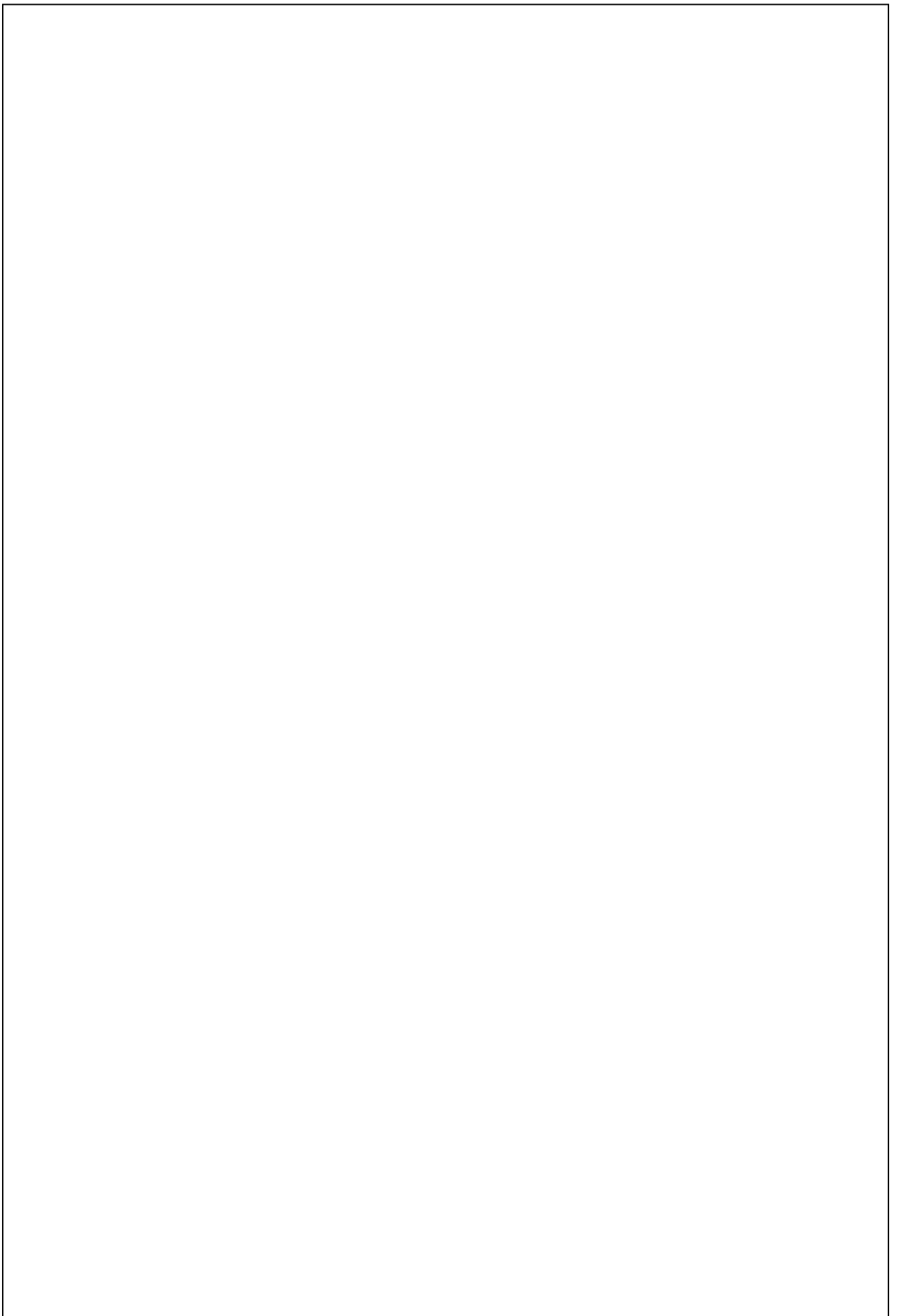


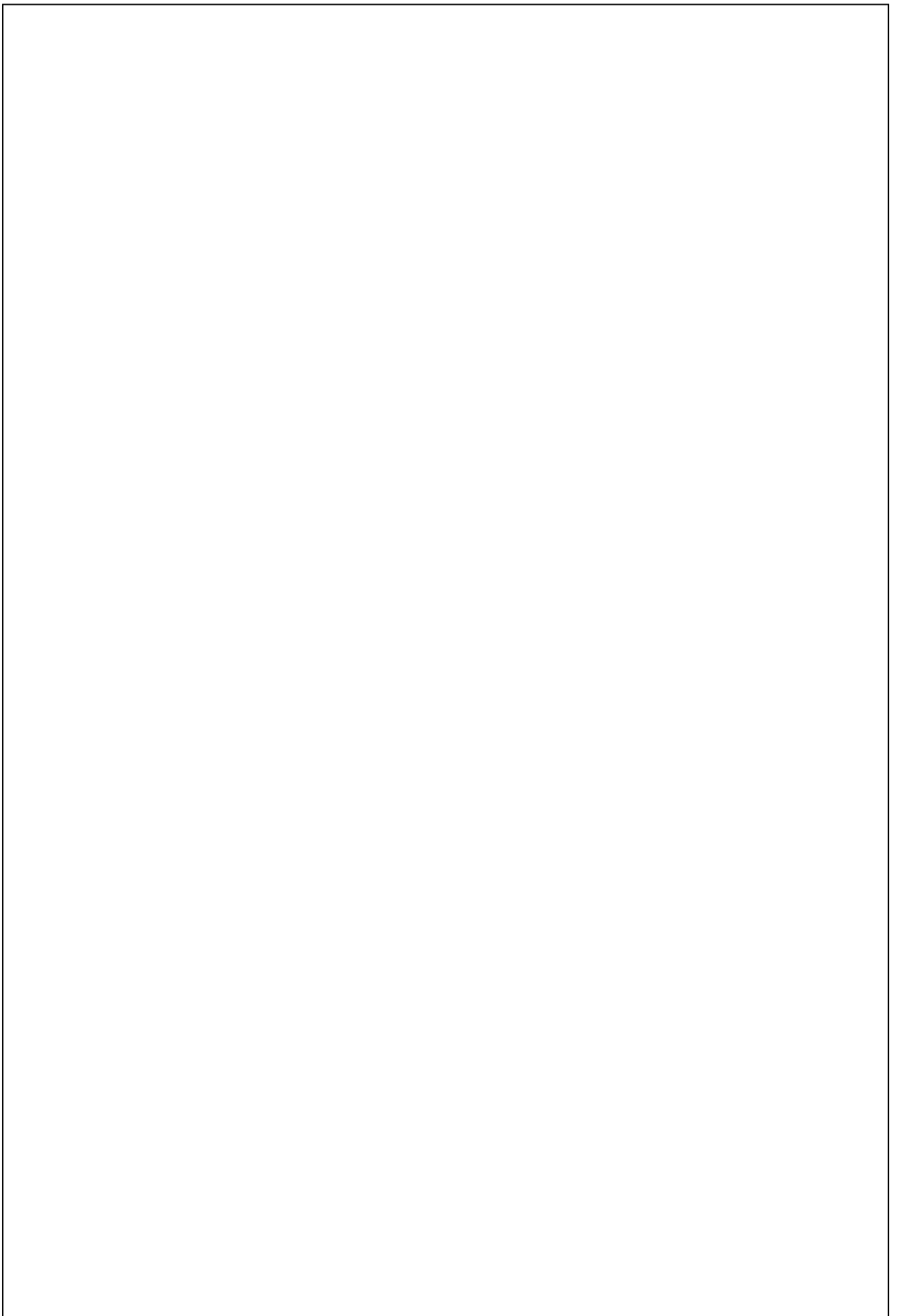
1 made a lot of money targeting specific clients
2 based on their preference. And we can look at
3 the constituencies that are out there and say
4 how do I convince my colleagues, as a health
5 center director, that you have something to
6 offer us and that you can make us better.

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 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.

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GARDINER LAPHAM: Well, we need to
be all piggybacking on one another. When I
first came on COPR, realized that there are
other people that I had known on COPR. And

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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 an, I do

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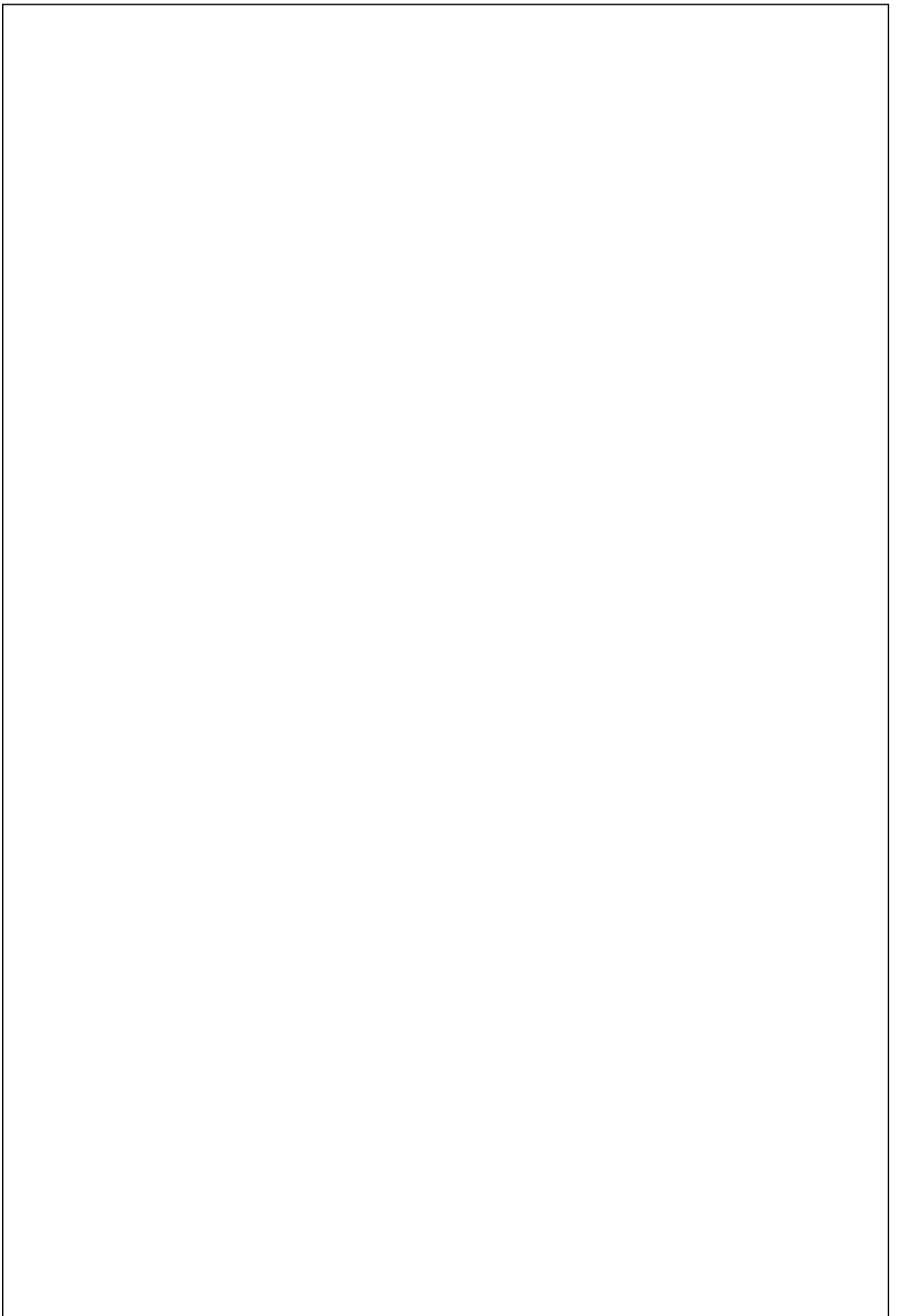
1 taking a scale back and say, you know what,
2 let's just focus on not one, you know,
3 institute or division but let's focus on a
4 cross-trans NIH theme that cuts across
5 different aspects.

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 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 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?

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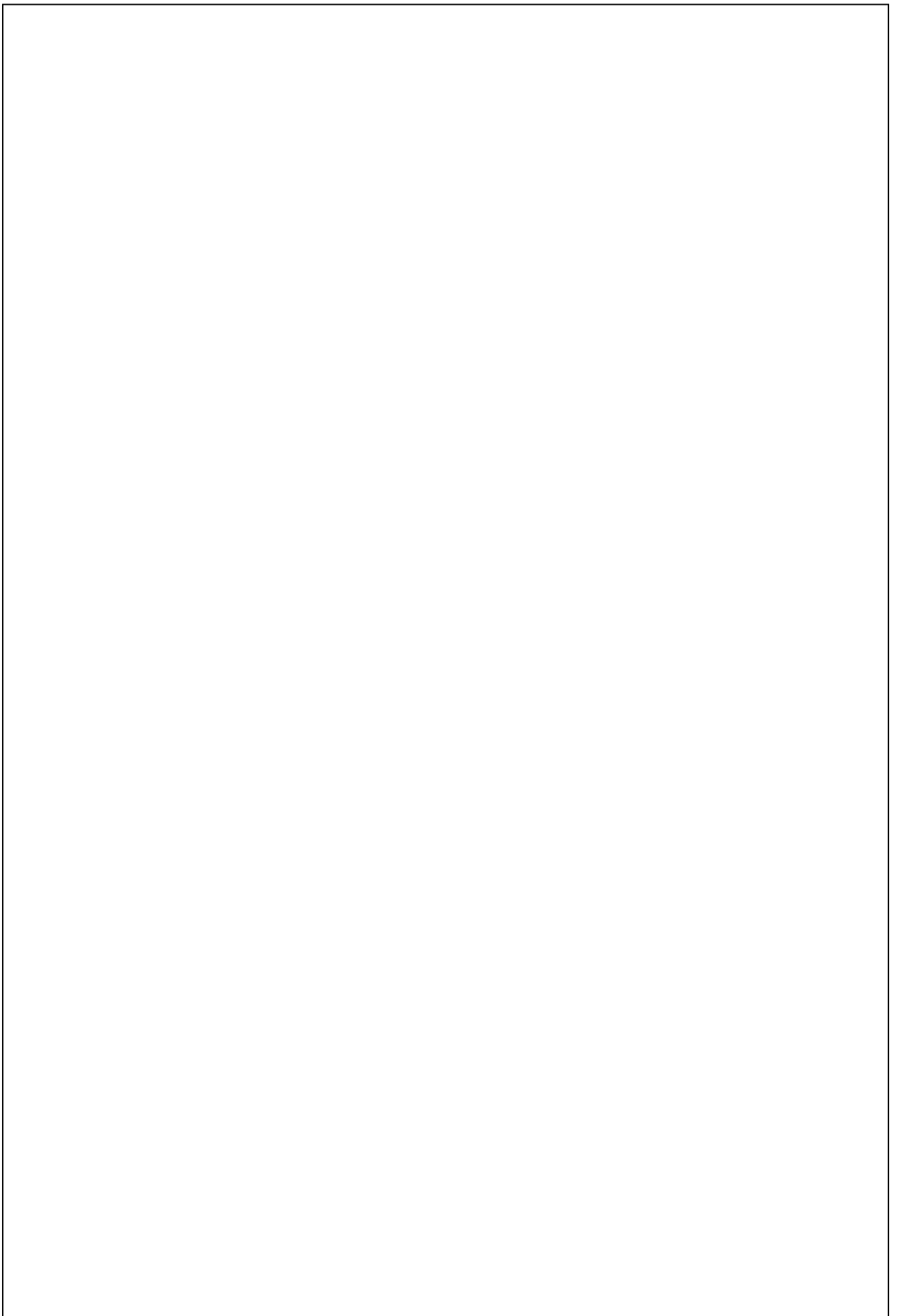
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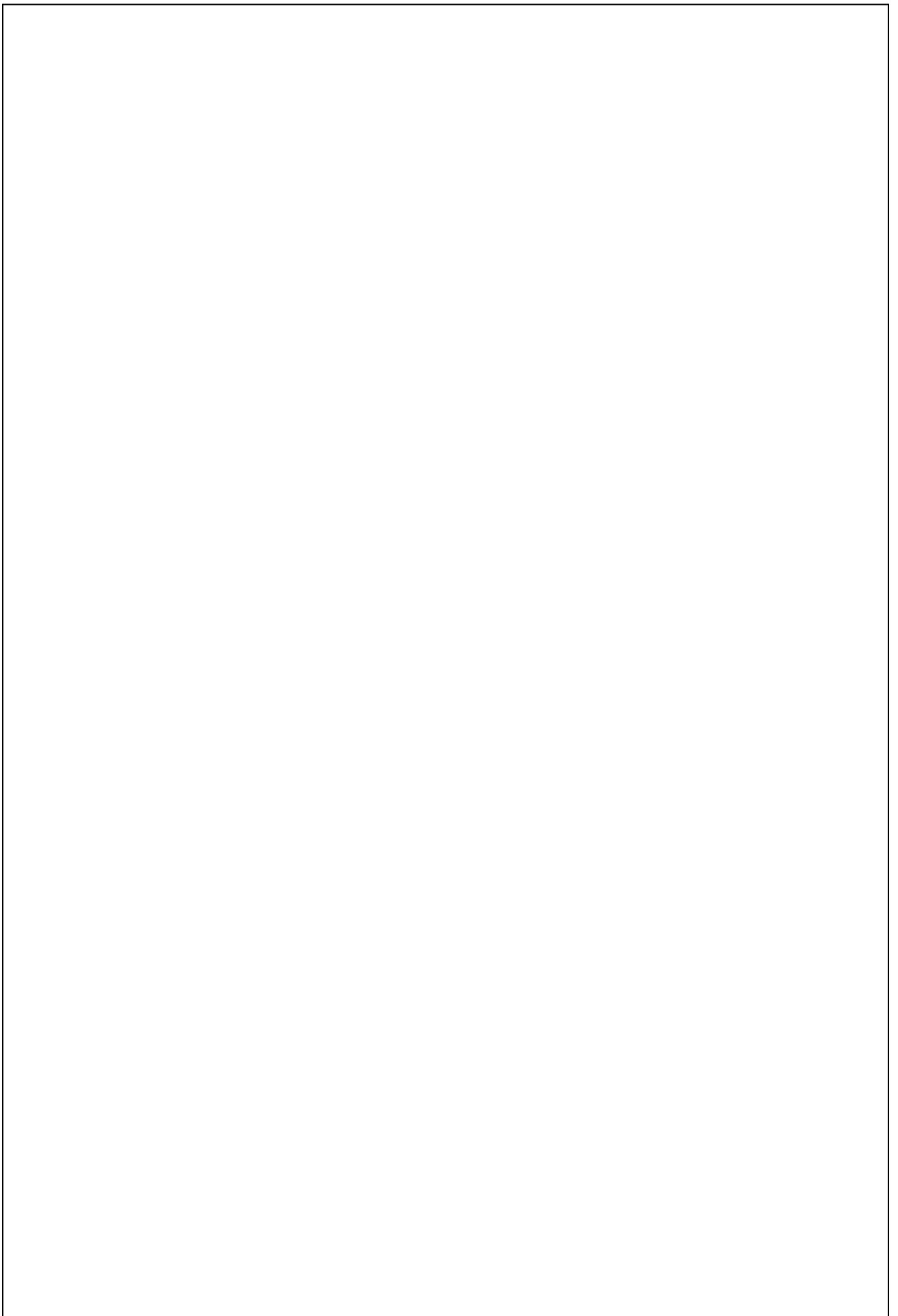
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1 infrastructure, the support mechanism in the
2 wider community, reviewing state laws about
3 various food chains, about calories, about
4 what's in--making partners, as the First Lady
5 has done with Walmarts. Which is providing
6 fresh fruits, vegetables, 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.

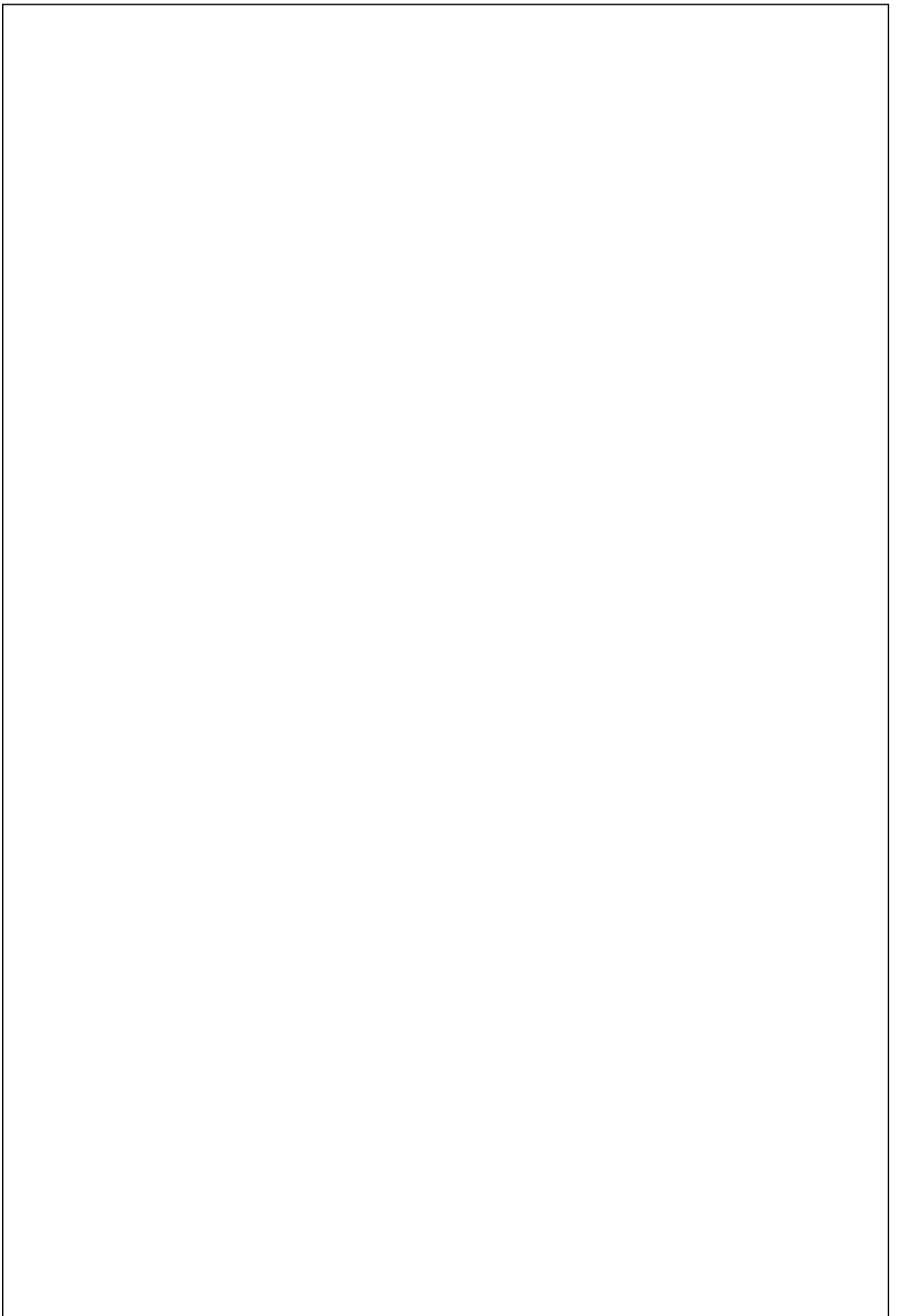
12 There are still some outstanding
13 questions for us to deal with on ethics of
14 determining someone might be subjected to
15 having diabetes and what kind of consequences
16 our insurance companies, not just healthcare,
17 our life insurers, etcetera, put those
18 individuals immediately at high 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

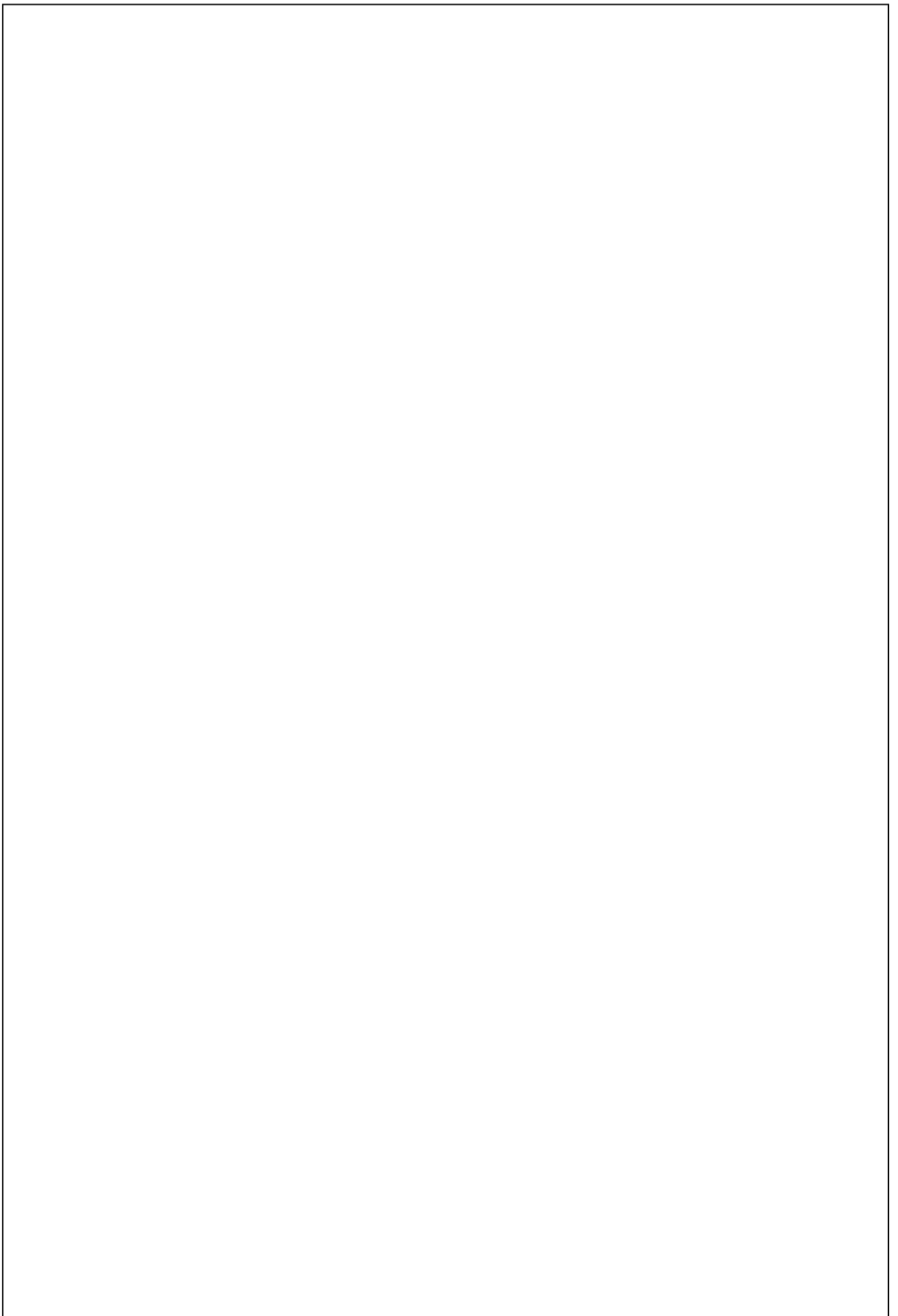


1 different and another community, it means
2 something different.

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





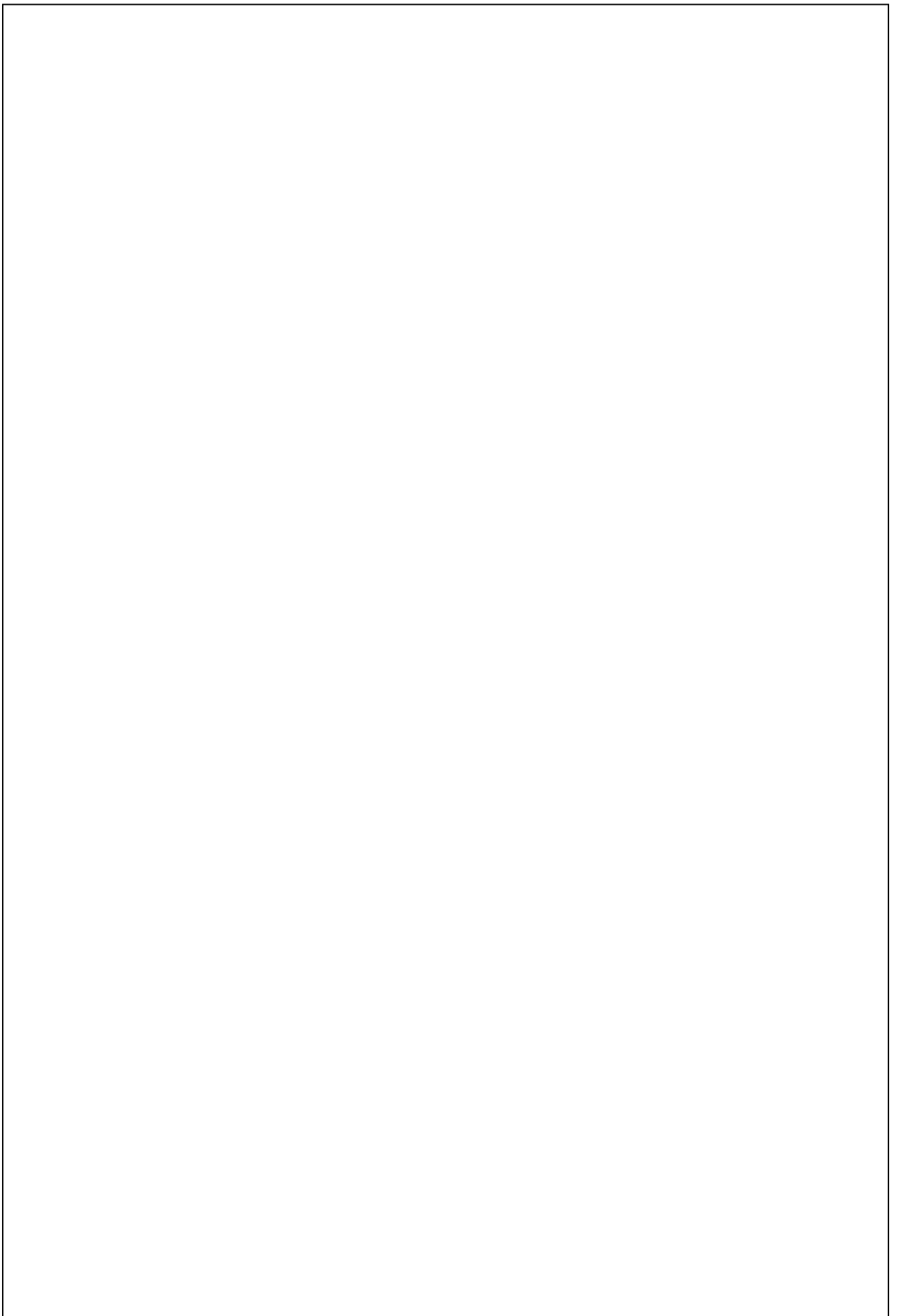
1 advisory group. I guess COPR's input, though,
2 I think, would be particularly helpful in
3 understanding what's the public's response to
4 this sort of increasing drum beat of why this
5 is important. Are we--are we getting that
6 message out there in a way that is actually
7 constructive or are people 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.

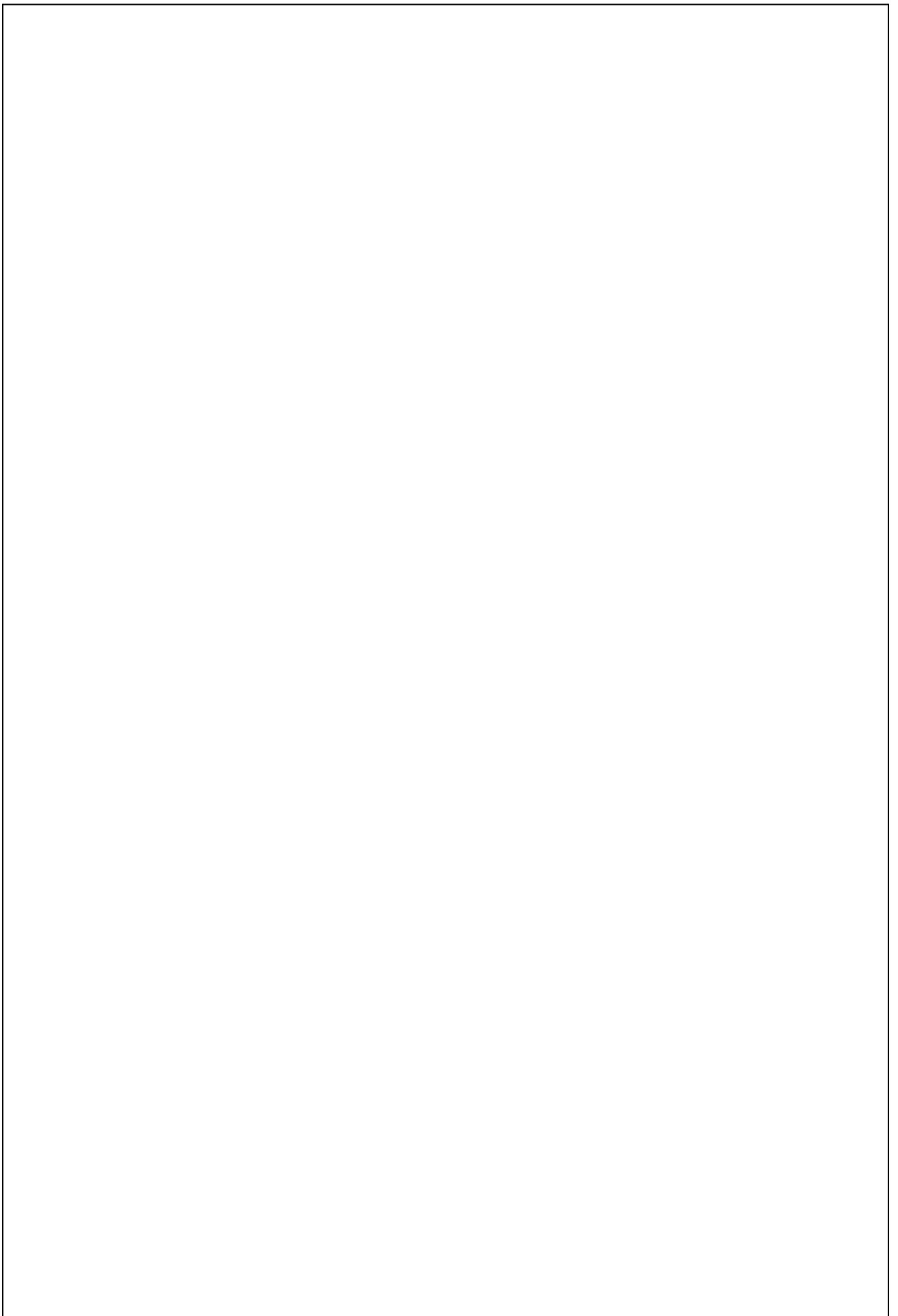
14 And it's this woman, I can't think
15 of her name, but I think her last name is
16 Freedom--Freedman, and she basically has
17 studied why people make choices. Because she's
18 studied it from an international context and
19 she's studied about how people access health.
20 And I think there's a lot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

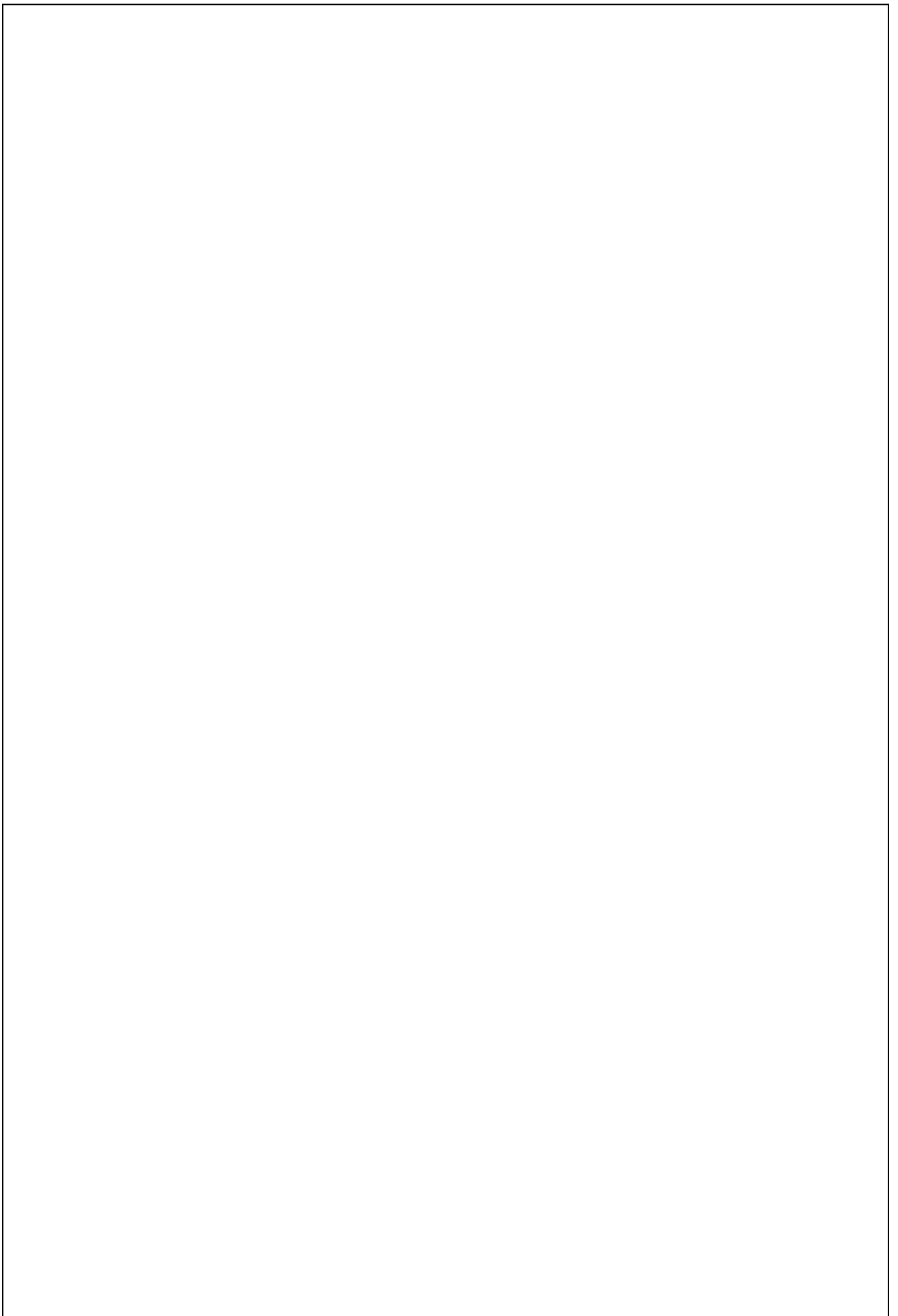


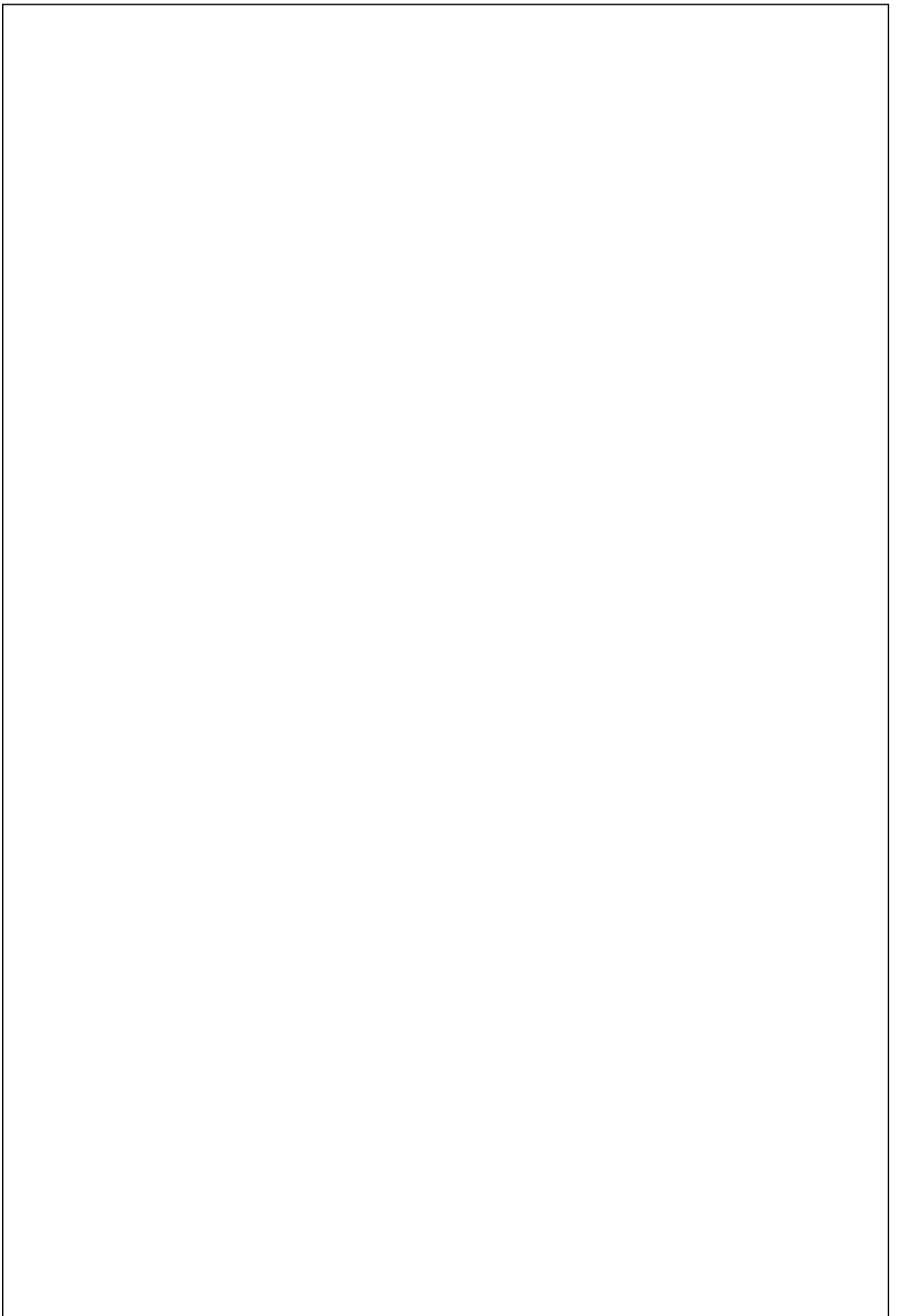
1 the Kaisers and the Marshfields. I'm sorry,
2 Greg has left. The Geisinger, all of these
3 very forward-looking HMOs that have a pretty
4 good system in place.

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 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.

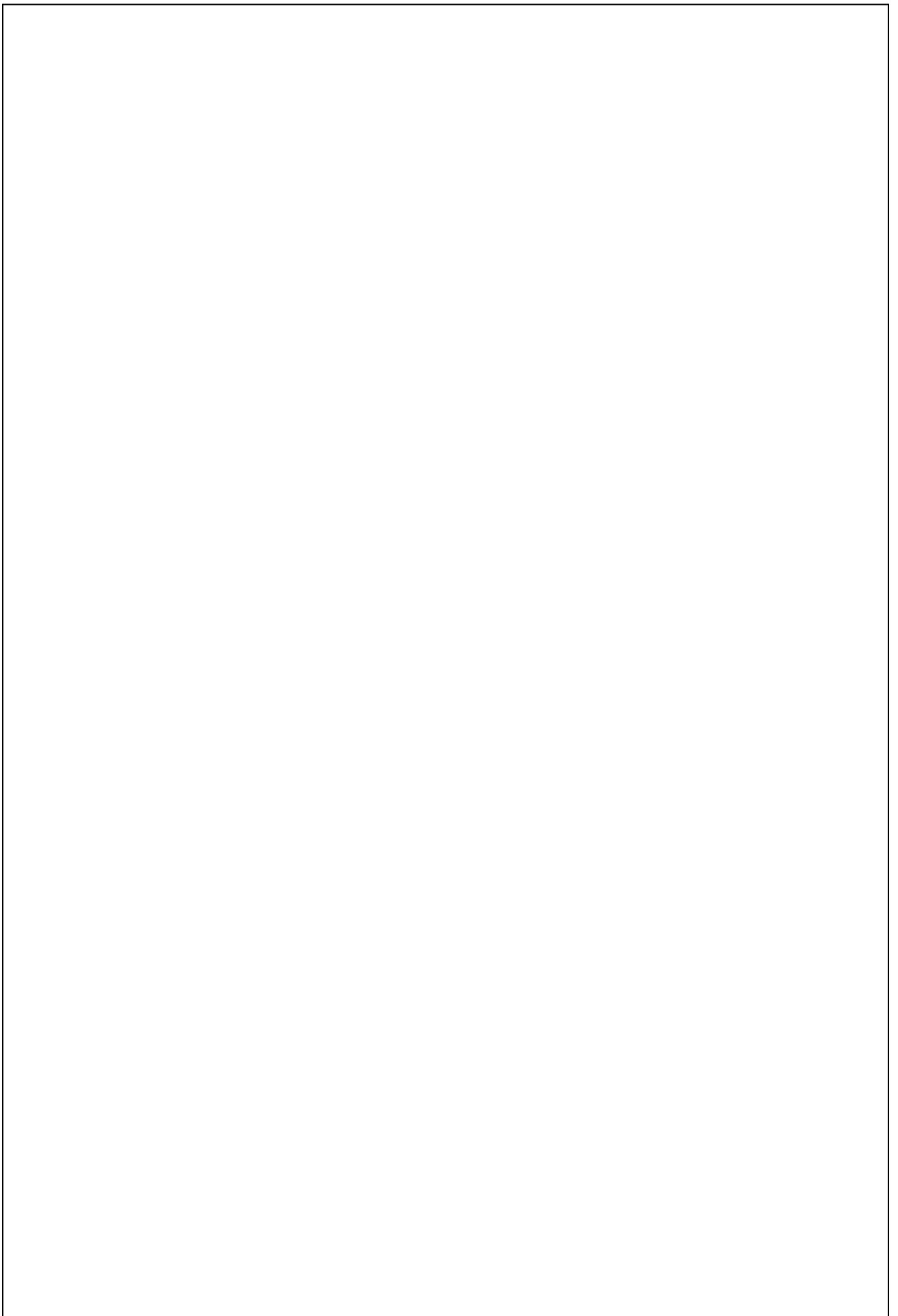
6 So we've really spent a lot of
7 time just trying to show the positive side of
8 what the goal is, which is playing soccer or
9 reading or whatever--how it helps your brain.
10 And I think that's made a lot of difference.
11 But it's--we want to test that. We'll try to
12 take our content to, and look 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 MICAHA 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 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 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]

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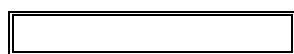
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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH (NIH)
DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES (COPR)

November 4, 2011

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1

WELCOME

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MR. PAVAO: Welcome, everyone.

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

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today.

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We have a very, very good presentation for you

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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

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

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

10

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

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any observations that you've noticed when it comes to

12

biomedical and behavioral research lately in your

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communities that you think that NIH needs to hear about.

14

So with that said I want to turn to Lynn.

15

INTRODUCTIONS

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

17

am the Director of Research at the American Academy of

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

19

observation I would make are a couple of very recent

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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 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 25th 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

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 175th 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

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

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

1 into NIH, which allowed us to do so very, very many
2 things. And what I think the data and analysis will

3

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

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

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

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 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

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

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 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

1

HIV therapies--now this is the most remarkable

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 then if there's additional discussion we can do it at

2

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 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

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

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 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 Department of Education, National Science Foundation and

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 ~~Wakab~~

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 inform9TT1 1 Tf -0.001 Tc 13.02 0 0 13.02 112.5 536.61477.696 3 4482

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

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

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. 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 11 12

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

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.)