

**Tick-Borne Disease Working Group
12:35 PM TO 1:27 PM**

>> Richard Wolitski: Well, good afternoon. I'm Richard Wolitski, and I'm the Director of the Office of HIV/AIDS and Infectious Disease Policy here in the Office of the Assistant Secretary for Health at HHS. And it's a pleasure to welcome you to the pre-portion of our first meeting of the Federal Advisory Group for Tick-Borne Diseases, the working group. We are not officially in session yet because our public members have not yet been sworn in.

And so, what we're going to do first is hear from our acting Assistant Secretary for Health, Dr. Don Wright, who will say a few words of welcome. And then, we'll swear in the new members and then we'll be able to officially start our first meeting. Dr. Don Wright is the acting Assistant Secretary of Health in HHS. He's been in this role since shortly after the new administration came into town. He assumed that role since February 2017, in OASH, the Office of Assistant Secretary for Health. Oversees 12 core public health offices, including the Office of the Surgeon General, and 11 advisory committees.

He's also the Deputy Assistant Secretary for Health and the Director of the Office of Disease Progression and Health Promotion, a position he's had since 2012. As part of that role, he's responsible for overseeing Healthy People 2020 and the navigating work on Healthy People 2030. He has a long career in federal service, and I'm not going to go through all of his accomplishments and the many, many, things he's done. But I will say that Dr. Wright has been a great supervisor and leader of OASH and it's a pleasure to welcome him to the stage.
Dr. Wright.

[applause]

>> Don Wright: Thank you, Rich for that very kind introduction. Let me begin by just issuing a warm welcome to each of you to the U.S. Department of Health and Human Services headquarter building here in Washington, D.C. And in addition to that, I want to thank all of you for being here for what is unquestionably a historic event. The inaugural meeting of the Federal Tick-Borne Disease Working Group. I think most of you know that Congress established the working group as a part of the 21st Centuries Cure's Act. And I know that many of you in the room were instrumental in making this a reality.

Like you, HHS is keenly aware of the seriousness of tick-borne diseases, their spread, and the risk that they pose to the health of many Americans. I think it goes without saying that we are very eager for you to start your work and ultimately, we look forward to receiving your recommendations for how we can improve our current efforts to prevent new infections and to improve the health of everyone with tick-borne diseases.

In order to succeed, you will need to work together as one team. The legislation creating this working group was very clear that the group was to represent a diverse range of perspectives. And to include physicians and other medical providers with experience in diagnosing and treating tick-borne diseases. Was to include scientists or researchers with expertise in the field. It was to include patient and family members, patient advocates, and federal experts, who work

in related areas. I'm pleased that each of you sitting around the table brings a unique set of experiences and perspectives to this effort.

I think we're all aware that you have challenges ahead of you. We know that you will not agree on everything, but you've been chosen because we believe you will serve with open minds, evaluate information fairly, and do the work that Congress charged you to do. Your mission will be to review all the efforts within HHS related to tick-borne diseases, to examine research priorities, to help ensure interagency coordination, and to minimize overlap. We expect that you will issue your first report to the HHS Secretary and to the Congress by December 2018.

We will support you in your efforts and in helping you to earn the trust of the public by making the activities of the working group both transparent and open to the general public. On behalf of Acting Secretary Hargan and myself, I thank you for your commitment to this effort, not only on this advisory committee, but in the work that you do in your community each and every day. We're confident that you will provide the leadership we need to move forward to help improve the lives of those who have been affected by tick-borne diseases.

The work that you are here to do on behalf of the committee is built on a foundation of possibility and hope. And it's an honor and a privilege for me to swear in the first members of the Tick-Borne Disease Working Group. I know that some of you on the committee have already been sworn in for other duties within the federal family. But a number of you haven't and so I want to invite six of you to the stage for the swearing in process along with Doctor Wolitski and Jim Berger. And those would include Wendy Adams, John Aucott, Richard Horowitz, Lise Nigrovic, Patricia Smith, and Karen Vanderhoof-Forschner.

So, if you all will come in and stand over here to my left. Okay, very good. Rich will be holding the Bible. If we could ask you to put your left hand on one of the bibles, if you feel comfortable, and raise your right hand and repeat after me.

"I, enter your name, do solemnly swear --

>> Multiple Speakers: I do solemnly swear --

>> Don Wright: "-- that I will support and defend the Constitution of the United States --

>> Multiple Speakers: -- that I will support and defend the Constitution of the United States --

>> Don Wright: "-- against all enemies, foreign and domestic.

>> Multiple Speakers: -- against all enemies, foreign and domestic.

>> Don Wright: "That I will bear true faith and allegiance to the same.

>> Multiple Speakers: That I will bear true faith and allegiance to the same.

>> Don Wright: "That I take this obligation freely.

>> Multiple Speakers: That I take this obligation freely.

>> Don Wright: "Without any mental reservation or purpose of evasion.

>>Multiple Speakers: Without any mental reservation or purpose of evasion.

>> Don Wright: "And that I will well and faithfully discharge the duties --

>> Multiple Speakers: And that I will well and faithfully discharge the duties --

>> Don Wright: -- "of the office of which I'm about to enter.

>> Multiple Speakers: -- "of the office of which I'm about to enter.

>> Don Wright: "So, help me God."

>> Multiple Speakers: So, help me God.

>> Don Wright: Thank you, and welcome to the committee.

[applause]

I would also like to invite all the members up. So, we can have an inaugural photo of the entire working group. Is there any order you want these people in?

>> Richard Wolitski: The chair should be in the center.

>> Don Wright: All right, the chair should be in the center?

>> Richard Wolitski: Yes, the chair should be in the center. How's that?

>> Don Wright: Thank you for you service.

>> Richard Wolitski: So, now it is my pleasure to turn the meeting over to our chair, Dr. John Aucott and our vice chair, Dr. Kristen Honey.

>> John Aucott: Welcome to all the members, the public audience, and the web audience. It's a great day to be here and to begin the process. We're here to begin a process to make life better for Americans whose lives have been affected by tick-borne disease and to prevent others from having to go through what many have suffered.

Our job is very specific, it's to identify the gaps in what we know. What are the important questions that need to be answered in order to help our patients and their physicians and care givers. One of the keys to accomplishing our goals will be to start with the patients first.

I was taught in medical school, as a young doctor, to listen to the patients. And as I've matured as a physician, I've coupled this listening to my patients with a willingness to admit to my patients that I don't always know the answer to every one of their questions. That's what we're about here today. Our job is to fulfill the charge from Congress and to identify some of the difficult and painful issues and questions that are unresolved or controversial in tick-borne diseases.

Those difficult, "I don't know the answer to your question" questions. We're not expected to solve the problems. But we're charged with coming up with the ways that these issues may be resolved or answered. In other words, a process. It's up to Congress and the Secretary to make policy, programmatic, and funding decisions, it's up to us to identify the gaps in the pathway forward. So, how will we answer or identify these unanswered questions. What is the work?

I'll tell you there's an amazing group of people up here. I've never seen such a -- if the charge was to put together a diverse group of people representing all views, this is an amazing group of people here. And I'm just incredibly enthusiastic about working together. It's sort of like the analogy of the parable of, you know, the blind man and the elephants. I think everyone at this table has seen part of the elephant, but as a collective group we really should be able to put together the whole picture. And so, our charge is to put down our specific views of the elephant and combine together to see the whole picture.

And the key to our success will be constructive and collegial. We all have the knowledge that it takes. And we're all willing to put aside past differences and to put aside past prejudices to accomplish that. Each one of our perspectives will be important and will be shared in an open manner. I believe we can really make a difference. That this is perhaps a historic moment of progress. And I'm really asking for the working group's courage in addressing this. I think it does take some courage. This is a difficult topic. But I think that with courage and a belief that we can do something, we really can.

We'll have to be honest with dealing with uncertainty. Because there is a lot of uncertainty. But I'm a firm believer that knowledge can surmount uncertainty. I'm old enough to have lived through the HIV epidemic in the early days where we knew nothing. And yet we accomplished great things through collaboration, and hard work, and good science, and listening to our patients. So, my hope is that the working group similarly, will have a commitment to this process that will be rooted in knowing and respecting each other.

A little bit about my professional experience. I think it illustrates that it's possible to do this. As many of you know, I've taken care of patients with Lyme disease for 20 years. And done so in continuity. So, I've lived the illness experience with my patients over decades. And I still to this day follow patients I diagnosed in the late 1990s. My career has also taken a turn to become involved in research and to understand that the way to solve our patient's problems is through research.

And I think those two can coexist. And that's what this group is all about. People that are researchers, healthcare professionals, patients, patient's advocates. We've got the tools here, and I believe in the process of listening and discovery, and science, that is really at the root of I think

solving this most vexing of issues.

I do want to acknowledge my role as the chair of the working group. There are some practical aspects. There's going to be the tyranny of time, we're going to have to work through things efficiently. We're going to have to identify and focus on things we can get through and do so in a focused way. And there will be times that we'll have to table some things or put things to the side and return to them later.

Finally, in my role as a chair, I want to personally commit to encouraging the building of bridges. That's one of my themes, is that we can build bridges between all of us here at this table and with the audience. And that is all about bridges that will illustrate to everyone that this is about not making differences, but bridging perspectives and bringing all of our expertise together. And I think it's going to be an exciting time. And I just thank you all for being part of the working group.

I'm going to turn things over now to the vice chair, Kristen Honey. And she has some additional comments.

>> Kristen Honey: Let's give a round of applause to our chair, John Aucott.

[applause]

Thank you, John. And thank you to Dr. Wright and HHS, and everyone here, for your continued leadership and signaling how tick-borne illness is a health priority for our nation. It is my pleasure to share this stage, this table, with distinguished leaders and innovators on the front lines of tick-borne illness from Lyme disease and others. Which are an epidemic today a national security issue. And as John said, building bridges for next gen solutions. Bringing all of our disciplinary expertise to solve this complex issue.

And I also want to thank those who are watching on the live stream. Maybe those who are too sick to travel or to financially destitute because of what these diseases can do to people. You are also with us here today and your voices online, you know, through technology will help co-create solutions with us.

Together this committee, in my role as vice chair, I want to make sure that we give new voice to people who have felt forgotten. Whether we call the forgotten Americans, Lyme disease people falling between the cracks. I'm not just the vice chair, not just a PhD scientist from Stanford University, I also fell in the cracks and was misdiagnosed with late stage Lyme disease for a decade and found my way out.

So, there is hope. Full remission, functional cures, is absolutely possible. But it can be traumatizing to be told you're not sick, you're faking it, and that there is no cure for you. So, with that in mind, that patient perspective, that humanity is what this group is hoping to do -- hoping to bring. I am here -- we've had questions, I am here not in the patient seat, but in my official federal capacity with the Office of Management Budget, which is part of the Executive Office of the President. And the mission of OMB, is to assist the President in meeting his policy

budget, management, and regulatory objectives. And to fulfill all federal agency statutory responsibilities. Including helping HHS to fulfill its statutory responsibilities and duties with this tick-borne disease working group.

The office I'm in, with OMB, is the office of the Federal Chief Information Officer. Where we do federal IT and data across all of government. So, I will be approaching this from a tack of let's follow the data. Let's follow the evidence, where ever it takes us. Open minds, open data, open science, open innovation.

So, now the challenge that we're facing is large. We'll hear from stakeholders in a bit. And the theme I want to have people take away is that combating this challenge will require a coordinated effort. We need a very diverse stake of stakeholders to tackle this public health crisis. And this is just a beginning; this is a start.

We must intersect data, and technology, and public health, to address the Lyme disease epidemic and other tick-borne disease challenges and promote innovative solutions, next generation solutions. Ones with emerging technology that are just on the horizon but soon ready to scale. I believe we can do this through better tick-borne illness next gen solutions, with a three part combo. Inspired partially by the U.S. Surgeon General, who gave a great talk about combating the opioid epidemic last week.

And that three prong approach involved better data. We can't stop an epidemic that we do not understand. This tick-borne disease working group is committed to improving our understanding of this crisis by supporting timely public health data and reporting. We are committed to being evidence-based, data-driven. The second prong is better research. We need more tools to help us fight this. So, we need to synthesize and evaluate cutting edge research opportunities and gaps. And hopefully that will be the outcome of the report we will publish in the next year.

And I would argue most importantly, better collaboration. As different subject matter experts and perspectives, we each have a unique niche in and a unique expertise. It does not matter whether you are an MD, PhD in a fancy white coat, or a patient, or the loved ones of a patient with lived experience, or fighting for your child's life. Your perspectives are equally valuable.

And everyone's input is valued here. So, the Surgeon General's message was "better health through better partnerships." In combating this challenge will require coordinated effort and our working group here is committed to creating and maintaining strong relationships across all these different groups. And forging new partnerships with non-traditional partners as well as the more normal federal government academic and non-profit groups. We can think outside the box and engage tech partners.

So, we're embracing the moto of a new U.S. Surgeon General, Dr. Jerome Adams: "better health through better partnerships." And by identifying diverse partners together we will move the needle on this disease. This means communication and cultural change platform. So, again going back to open data, open science, open minds, and the free exchange of ideas.

No one woman, no one man, no one organization, can defeat Lyme disease or any of these tick-

borne illnesses alone. We must embrace better health through better partnerships. Which, to me, means no more working in silos. We need to develop cutting edge solutions and better mechanisms for data sharing and bring in non-traditional partners to the tables, including the patient voices. And when the patients are too sick, they're loved ones who can be their voice. And this is why events like today are important. So, thank you for being here at the very beginning as we kick off next gen solutions beginning now.

[applause]

>> John Aucott: I will now ask the members of the working group to introduce themselves and to let everyone know about you.

>> Patricia Smith: My name is Patricia Smith. And I'm currently the President of the Lyme Disease Association. I'm also a member of the Columbia University Lyme and Tick-borne Diseases Research Center. And I sit on the congressionally directed Medical Research Programmatic Panel for Tick-borne Diseases.

But most importantly, I feel, is I'm a mother. A mother of two children who developed Lyme very early in the disease when very little was known. And so, that has given me a drive and given me a purpose in my life. Which to be honest with you, I did not intend. That wasn't what I was going to do with my life. But I am here, and I intend to do everything that I possibly can to work with everyone here to try to get a resolution.

Because I've been involved for 34 years, and I have not seen a resolution. But I've seen a lot of sickness, a lot of death, a lot of suffering, and quite frankly I'm tired of it. And I think everyone here, I assume, feels the same way. Thank you.

>> Dennis Dickson: Good afternoon. I'm Dennis Dickson, I'm from the National Institutes of Health, National Institute of Allergy and Infectious Diseases. I've been at NIAID for just over 25 years. I'm trained as a microbiologist. I've had experience in the academic setting for over 10 years, in the industrial setting on sabbatical on the state laboratory, reference laboratory work.

And Lyme disease and tick-borne diseases are within my branch in the extra mural programs at NIH. And we are also in communication with the intermural programs at NIH, who conduct research programs as well. And I'll be proud to represent the NIH and to the very best of my ability share with you the activities we have underway and basic translational and clinical research in these areas.

>> Lise Nigrovic: My name is Lise Nigrovic. I'm a pediatrician and an emergency physician. I work at Boston Children's Hospital. And my current research is on the acute diagnosis of Lyme disease in children. And to that end, I founded a research network of six emergency departments where we enroll children undergoing evaluation to help evaluate new approaches to the diagnosis.

>> Allen Richards: I'm Allen Richards. I work for the Naval Medical Research Center. I've been working with them for over 25 years on rickettsia diseases. I'm the Department of

Defense's research coordinator for rickettsia diseases. I look forward to working on this panel to figure out what we can do better to manage tick-borne diseases.

>> Wendy Adams: I'm Wendy Adams from Bay Area Lyme Foundation. I'm the Research Grant Director there. As a personal survivor of Lyme disease, who was misdiagnosed for many years, I have lived this with many of you. I've talked to many of you on the phone. We want to make sure that this is a patient-centered, patient-focused group. And we are here working on solutions to get us past the impasse where we seem to be right now. So, I want to say I'm really happy to be here with this group and to assure you that we are working on your behalf.

>> Scott Cooper: I'm Commander Scott Cooper with the U.S. Public Health Service, where I'm a physician assistant officer. I've been a physician assistant for over 20 years. For the last 10, I've been stationed -- I'm sorry, for the last 15 I've been stationed at the Centers for Medicare and Medicaid Services. Where for the last 10 years I've been Senior Technical Advisor and the lead officer responsible for hospital patient health and safety regulations.

Where our policy is, protecting patient's safety, looking out for the patient, but also balancing that. Allowing providers, hospitals, other medical providers, the flexibility to develop best practices that are evidence based and further take care of patients and stay on the cutting edge of medicine.

>> Estella Jones: Hi, my name is Estella Jones. I am a veterinary officer in the U.S. Public Health Service. But I'm also stationed at the FDA; Food and Drug Administration. And I serve there as a senior regulatory veterinarian, as well as the Director of Medical Countermeasure Regulatory Science. I've worked in government for 26 years with animal modeling. I've served 10 years at NIH, 14 years at the FDA.

I've also been on faculty at Baylor College of Medicine where we developed many animal models for various diseases. And I had the honor of working with the late Dr. James DeBakey. I'm very pleased to be able to serve on this group and offer my area of expertise, particularly vector control. And I also still practice, so, I see all those pets that come in with Lyme in your families.

>> Karen Vanderhoof-Forschner: I'm Karen Vanderhoof-Forschner. I crossed paths with Lyme disease decades ago in '85 when I contracted it while I was pregnant. It was transmitted to my son, and he developed symptoms and developed a positive western blot for the disease. Eventually, we started the Lyme Disease Foundation with the request of a number of medical practitioners that wanted someplace where they could get together and debate the science and figure answers and solutions.

Unfortunately, he died in '91 and on his death, after a somewhat longer term treatment, they found *Borrelia burgdorferi* in his optic nerve. So, they know that the treatments being offered in the length of time were just not accurate. During his life, he was attacked a number of times because they thought transplacental transmission didn't occur. But I was lucky to have some doctors who sent me the published literature. And what I discovered was there's a lot of information out there already in publication that can help us get to the truth.

And I see it as one of my missions to get a lot of that information to the right people on the committee. To help them find answers for all the people that are suffering so other people don't have to go through what we had in our family.

And just to let you know, I have a daughter. She was born in '93. She turns 24 tomorrow and she's supposed to be in this room and she's, I think, lost.

[laughter]

Once a Mom, always, a Mom. So, I hope we can do a great job here. And I love the committee, this is great. Thank you. Your turn.

>> Ben Beard: Thanks. My name is Ben Beard. I'm Deputy Director of CDC's division of Vector Borne Diseases. I've been at CDC 27 years. The first half of that career I was in what is now CDC's Center for Global Health in Parasitic Diseases. The last half, I've been in Fort Collins in CDC's division of Vector Borne Diseases. We have responsibility at CDC for surveillance, disease outbreak, and really prevention and control for all of the vector born diseases that are not parasitic. So, this includes Lyme disease, the rickettsia illnesses, plague, tularemia, West Nile Virus, Zika. And for the last year and a half or more I served as Deputy Incident Manager for CDC's Zika response.

>> Richard Horowitz: My name is Dr. Richard Horowitz. I'm a board certified internist. I moved up to the Hudson Valley, New York about 30 years ago. And I didn't realize at the time I'd moved into one of the largest Lyme endemic areas of the United States. I've seen over 12,000 chronically aligned patients now. And I've been looking for solutions for these sick and suffering patients and have found that it's multiple infections, environmental toxins, inflammation with autoimmune manifestations, that's causing these people to be sick.

And I look forward to sharing this knowledge and working with the group to find further solutions. It's a great honor to serve the American public. And finally, for all those people who've been suffering coming to me looking for answers that we finally have a great working group. We can work together and do the work that's needed.

>> Vanila Singh: Hi, good afternoon everyone. My name is Dr. Vanila Singh. I'm the Chief Medical Officer here in the Office of the Assistant Secretary of Health at HHS. My background is, I have been here for six months and I come straight from the clinical trenches. I'm a physician at Stanford University for the past 13 years, where I have worked in anesthesiology and pain medicine. Serving in the chronic pain arena, I have come across many folks who have been diagnosed and misdiagnosed with Lyme disease in the area of prevention and treatment is something that I care deeply about.

I believe very much in a patient-centered approach to medicine. And I also hope that we have folks who bring -- which I've already seen their compassion and care, what I do believe in is that there is an individualized approach that is important. I believe in this era of precision health, we can hopefully identify the various different factors that are playing a role in this. And what I've

also learned is great humility in all these years in all the complicated cases that we've seen. It's really an honor to work with my peers here. And also, to be part of this wonderful group. Thank you.

>> Jim Berger: Good afternoon. My name is Jim Berger. I serve as the alternate designated federal official to this tick-borne disease working group. My background is that retired military. Worked in medical readiness preparedness and response. Now, my new role is to serve in supporting this committee in finding the data to alleviate all the concerns of those patients that are suffering.

>> Richard Wolitski: So, I'm Richard Wolitski. And I'm the designated federal officer for the committee. And I'll be here working with Jim. We are not members, we are really part of the support team. We play a role in helping to coordinate the process, to helping provide input, and guidance, and to ensure that the work is done in a way that it is complying with all of the laws related to federal advisory committees that the activities are open and transparent. And that information is available to individuals in the public. And that the public has opportunities to participate in this work as well.

So, it's really -- I was nervous, to be honest with you, when I was first asked to consider taking on this working group in my office. I've worked for let's see, since 1985 on HIV related issues. And then, later bio-hepatitis, STDs as well. And I really haven't done any work whatsoever on tick-borne disease before this. And so, I was nervous that people were going to say, "You don't know anything. What are you doing this for?"

But I've come to really appreciate some of the advantages that being naïve and knowing that I don't know the answers to things really brings with it. I see our role in this process as supporting the group, and also facilitating the process so that we ensure that it's fair, it's balanced. That everyone can have a voice, and that all perspectives are heard, listened to, and treated with respect. And I also have to keep us on our timeline, to get us to our product, report to Congress and the Secretary by December of this year.

So, I'm going to be a little bit of a task master behind the scenes as well. But it's been great meeting so many of you. I see a number of familiar faces in the audience already. And I just really, you know, want to support you, and help you do the work that you do and the work that needs to be done. Thank you.

>> John Aucott: Let's have a big hand for the group.

[applause]

>> Richard Wolitski: Yeah, and I'm going to do like a little combo, sort of updates and some highlights of the charter. We're not going to go into a lot of detail today about the change in the 21 Century's Cures Act or the charter. Today, is really focused more on hearing from the organizations that represent patients and hearing from the public themselves. So, we're going to

start out more in listening mode rather than a talking to each other, or a you sort of mode.

I want to just talk a little bit about membership and sort of how we got here and where we are today. So, we had an amazing response to the call for nominations that was put out in the Federal Register. We had a public call. And we received 64 nominations for the seven public seats. It was a highly qualified group of people. So, we had really, basically, almost one for every one seat almost 10 people applied.

The decisions about selection, the recommendations, were made by the group of federal representatives from the four agencies that have a permanent seat on the committee. They were the only people other than us in the office, who can identify this part of the process. And so, we've brought them in to help inform the decision making process. They used a set of criteria to score each of the nominations based on the information that was available in what was submitted.

And they made recommendations that considered the balance of the group. That patients were included, providers were included, researchers were included. And from that, they made recommendations, they went forward, through HHS up to the Secretary. And it was the Secretary who made the final decision on the positions.

There are a lot of really great talented people who were nominated who couldn't have a seat in this working group at the present. But we're going to be talking tomorrow about some of the other opportunities for people to be considered. And we've discussed that those will be a starting point for looking at other potential individuals to participate actively in the work of the group.

We have had one member resign. Dr. Gary Wormser has withdrawn his membership from the committee for personal reasons. We have gone back to the list of nominees, looked at the individuals in the physician category and have selected an alternative based on the categories and the procedures that we used to select the first group of people. That name has been submitted and it's currently undergoing review. And as soon as the process is done, we'll announce that individual and then he or she will join the committee and become part of the process.

All of the members are here up until the submission and shortly thereafter of the first report to Congress. Individuals may be able to have their terms extended and there will also be opportunities for new people to come in and serve as well. And some folks may be exhausted by the time we get to that point, because there's going to be a lot of work to be done.

So, I was going to talk a little bit then about what the group is here to do. It's been interesting going out and talking to people and hearing the different things that people hope the group will do. And, unfortunately, the charge for the group is pretty narrow. This group has been brought together primarily to advise HHS, to write advice to Congress on tick-borne diseases and what needs to be done to improve our current federal response. The primary product that will come out of this is through a report to Congress.

So, the 21st Century's Cures Act has charged the Tick-borne Disease Working Group with providing expertise and reviewing all efforts within HHS, related to tick-borne diseases. Helping

to ensure interagency coordination and minimizing overlap, and examining research priorities. There's language in the Cures Act as well that suggests that the scope could include other federal agencies. That's something for the group to discuss and decide as we go forward. This group is covered, like all federal advisory committees, by a couple of laws that govern how this work has to be done.

The Federal Advisory Committee Act and the Government and Sunshine Act. Both of these together put requirements in place that require notice about all meetings of the group. The meetings have to be open to the public when the full group is meeting and there are decisions and discussions going on about substance of the work that would feed into the report. There will always be an opportunity for public comment at each of the public meetings. And they're charged with making recommendations that are objective and accessible to the public. And you will have access to the information from these meetings.

For full meetings, this is being webcast live. The video of that will be saved online at YouTube. And people will be able to view segments of the meeting as they wish. There will be a full transcript of the meeting available as well. And for any subcommittee meetings that take place, there will be a list of who attended, what was discussed, and that information, any presentations and things that are made at those meetings, are also made available to the public. Those groups cannot make any decisions on their own. Anything that's going to be a decision, a recommendation, any kind of action, goes to the full working group for discussion.

So, I was going to talk a little bit more about the scope. Because one of the big challenges for this group is quite frankly, the task is huge. When you think about Lyme and all the other tick-borne diseases, there are a lot of different issues that still need to be addressed and in where we can improve our response.

So, with regard to, you know, what Congress has asked the group to do. When you look at the specifics this report, at a minimum, has to address the research across a full range of issues. So, look at advances resulting from the research. Look at federal activities writ large related to tick-borne diseases. And so, here in the act, it says federal efforts and before it said HHS efforts. So, we've got to kind of have that discussion to sort of figure out how the group wants to move forward. The groups can identify gaps in the research and the programmatic responses as well.

And to do that work, tomorrow there will discussion opened up about the process for that. And how the full working group and any committees that the group may decide are beneficial to establish, how that work will happen, and what the processes and mechanisms will be for selecting members. There's somebody wrote me an e-mail the other day saying, "I heard you're going to select the members tomorrow at the meeting." And if anybody is worried about that or wondering, I think, I have to look to the two of you. But as I understand the answer is no.

People will not be picked tomorrow. There where will be a process where there's time for nominations and for consideration to be given to people who would like to serve. So, I will say, just kind of in closing, you know, from our perspective, our job is really to make sure that this a transparent and fair process. And to me the process itself is really important.

I mean, we're committed to making sure that everybody at this table is treated equally. There's not going to be a difference between people who are in a seat that's a public seat versus a federal seat. There are not going to be separate meetings with the feds. Separate from everybody else. This is one group, one committee. And we're coming together to identify the problems and to define the solutions together. So, I think with that, I'm going to go ahead and stop there for today.

>> Patricia Smith: Yes, I would just like one clarification to be made. And that is that those of us that are sitting here, it's my understanding, we're sitting here as representatives of the particular categories that were included in the legislation. We are not sitting here as representatives of any group or university or anything that we come from.

>> John Aucott: That's correct. You know, we're not here representing where we come from. We're here to serve. Yep.

>> Patricia Smith: And I just have one other quick question, if I may? What relationship do we have with the other federal working group on tick-borne diseases that's federal members only?

>> Richard Wolitski: So, that issue has not been explored for clarifying. So, I think there's a discussion to be had about what relationship would this group like to have. And then, we could work with that group and see what relationship they would like to have. And so, I think that there are opportunities certainly for at a minimum, hearing from them. And having discussions about the work that they're doing. And there maybe other opportunities that folks want to explore. But at this point in time, there are no plans, or nothing in the works.

And I will say one thing that I want to do point out, it is a slight difference. It's true that nobody is here to represent their organization. But for the federal agency positions, those individuals are here as a representative of their agency. Now, that does not mean that they're here to defend every policy, every action, that's ever been put in place by their agency. They're not here to be the agency. But they're sitting in an agency seat.

And so, in some cases those members may have other duties that prevent them from being present. And so, there are alternates that will have been following them along in the process and they will sit in their seat and serve in that role when that member is not available to do that work. So, they will kind of make sure that we have the continuity that we need in the process. So, I think with that I'm going to say thank you to everybody. It was a pleasure meeting folks this morning. And I will say we had not a meeting this morning, but we were required to provide training and orientation to all new members of federal advisory committees. We did that this morning.

And the training covered ethics. It covered communications, and it covered one more thing that I'm blanking on right now. Oh, the federal advisory committee act regulations, as well. So, that everybody starts out with the same understanding about the rules, the laws, and nobody does anything by mistake that gets them into trouble. So, that was what we did this morning. And a good discussion, a productive session, and I think we're starting off with a lot of energy.

I will say that compared to other groups I've worked with, I'm impressed by how motivated everybody is. And how people are already kind of doing homework that they haven't even been assigned yet to help inform the process and to make sure that it gets off to a good start. So, I am really looking forward to working with everyone and with the community, in the room and online as well. So, thank you.

>> John Aucott: So, Kris and I are going to talk a little bit now about what we hope to accomplish today. It's our first day. Starting with the first steps, and I'll let Kristen start us off.

>> Kristen Honey: Sure, thank you, John. So, one of the goals that we'd like to do with this working group is kind of hit reset for some of these diseases. And not focus on the past of the old Lyme wars and what you might hear about, but look to the future. And when I think about that I think of creating a safe space where everyone can voice their opinions. No matter, you know, how bad the past has been to this is where we are now. And let's move forward. So, a safe space but do so in a way that is constructive, and we can learn from.

And then, I think of it as like the people who are coming to the table, rolling up their sleeves, volunteering to be part of sub-committees, and help our working group to produce this report to Congress, we're kind of forming a new generation of Lyme disease and tick-borne illness solutions. So, thinking of we're creating a tick-borne tribe. So, thank you all for being here and being part of this tick-borne tribe. Together, I firmly believe we can and we will contain and cure these diseases.

I wanted to just touch on one point before passing it back to John. Something that Rich alluded to. That he was little nervous when he started in this office with expertise of HIV and AIDS. What does he know about Lyme and all that. And I'm sure many patients and loved ones of patients feel intimidated with doctors and Ph.D. scientists, and experts, in these diseases. And please don't be. Please know that your expertise is equally valid. You're lived experience, your patient experience, is what is going to help us navigate this and find new solutions.

Now, my background is training in evolutionary biology and ecology. And one of my favorite words, it's kind of a niche word from genetics, is exaptation. I'll spell it, because it's not expectation or anything like that. It's exaptation, E-X-A-P-T-A-T-I-O-N. Exaptation. And it's a term originally from genetics, where you have natural selection and a trait evolves and it becomes part of a population. And it obviously has some fitness advantage, or it never would have evolved in the first place.

And then, that trait finds a different purpose that is even more valuable for the population. And has a bigger, bigger, impact, greater survival. Different from the original reason why this trait evolved. And that word of exaptation has actually been co-opted by business and innovation literature. It's been exapted from genetic biology to talk about transformative genius and innovation and tipping points happen. And often genius and big tipping points are not new ideas. They're old ideas that get repurposed and recycled to a new discipline in a new way.

So, you take an idea that someone in this room has out there. Or someone watching the live webcast has out there. And they use every day in their business, or technology, or medical

practice. But we're not thinking about it through tick-borne illness. So, you exapt that idea and apply it. So, what that means is that everyone, you know, your perspective is equally valued, and we have to think differently. We have to go outside the box. And there is an old saying, that if you get stuck on a problem, expand your thinking.

So, with this working group, I'm hoping that we expand our thinking. And really, we expand the solution space to include patients, put them front and center. And we have examples of success in this area. Ben Beard, and people at CDC, and other agencies in federal government, were part of an Ebola response and a Zika response. And U.S. Aid through those efforts decided let's innovate. How do you contain some infectious disease that we don't know a lot about? And one of the big problems with Ebola was that the suits, the medical protective suits, were uncomfortable. Doctors couldn't do their work, it's hot. So, they didn't want to wear them. If you don't wear them, right, you won't be protected.

So, U.S. Aid launched this innovation challenge. And guess who won that challenge? And they came up with a better protective suit; it was a team of students with a wedding dress maker. So, where is innovation going to come from for tick-borne illness and Lyme disease? We don't know yet. But we know it's out there and this group here, your tick-borne tribe is about creating that safe space where you can share your ideas. We can freely exchange them, and we will have open enough minds to go where the data and evidence take us. And thank you for being a part.

>> John Aucott: So, our specific agenda today will start after the break. It's going to start with listening. And two principals I want to put out there about listening. One is, we don't always know who the person is. There's many people in this room and many of us have never walked in the other person's shoes. And the first place is to understand that we don't know each other. So, part of listening is going to be hearing each other and people that have wildly different experiences than each of us.

The second principal is one that the question that every doctor hates. That he get's asked after talking to a patient, and going over things, and coming up with a plan, and maybe expressing some uncertainty. The patient looks at you and they say, "Well, what would you do if this was your mother? Or your father? Or your son or your daughter?" So, I want us to take a little bit of that approach too.

As you know when people are talking, pretend it's your mother or father, or son, or daughter. Because that really makes it personal. And I think this is a time to listen and to let it be personal and to hear the voices of our patients and the audience. And that's the kind of attitude I'd like us to go into this with. And again, we'll really reap the benefits of listening first. So, with that we have a break. We're ahead of schedule, thank you very much. And we reconvene at 2:30. So, thank you very much.

[end of transcript]