Dr. Peter McGuire, Dr. Eliza Gordon-Lipkin and Ms. Shannon Kruk

Behind the Mask
April 12, 2021

Barr: Good afternoon. Today is April 12, 2021. My name is Gabrielle Barr, and I'm the archivist at the Office of NIH History and Stetten Museum. Today I have the pleasure of speaking with Dr. Peter McGuire, who is an investigator with the Center for Precision Health Research, Dr. Eliza Gordon-Lipkin, who is a staff clinician with the Metabolism, Infection and Immunity Section and Ms. Shannon Kruk, who is a research nurse with the Metabolism, Infection, and Immunity Section. Dr. McGuire, Dr. Gordon-Lipkin, and Ms. Kruk all work for the National Human Genome Research Institute. Today they are going to speak about viral exposure in children with mitochondrial disease, which is part of a larger study that they have been conducting for the past few years, what their symptoms look like and the proportion of the population that these diseases effect. Will you provide clarification of what mitochondrial diseases are, what their symptoms look like, and the proportion of the population that these diseases affect? Is it something that someone is born with, or can it develop later in life? Is it diagnosed mostly in males or in females? I know that's a lot of questions.

McGuire: Yes. Before we address mitochondrial disease, I think it's important to point out what mitochondria actually are. Mitochondria are what are called organelles. They're basically very small factories that are present in nearly every cell of our body and they're really responsible for making energy. Therefore, if you have mutations or changes in genes, that are disruptive to genes, that are involved in mitochondrial function, they can lead to what is called mitochondrial disease. The clinical picture of mitochondrial disease is actually quite varied and involves multiple organ systems in the body. Usually, these organ systems require a lot of energy. It can affect things like the heart or the liver or the brain or even skeletal muscle, and these mitochondrial diseases actually almost fall out of the range of rare diseases even though they're kind of considered rare diseases.

Their prevalence, the minimum prevalence, is one in five thousand. They're actually almost falling out of that range of what's considered to be a rare disease. They are the most common types of diseases in a category called “inborn errors of metabolism”. These are metabolic disorders that are due to genetic defects in enzymes or cofactors that help your metabolism work well. In this particular case, it's about making energy. So, it is actually fairly common. It affects males and females equally and it affects all age groups.

We are particularly interested in children and those are the individuals that we look after in our study. From a clinical standpoint one of the most challenging features of mitochondrial disease is that patients can experience life-threatening deterioration during common infections, infections which for us wouldn't necessarily present a problem, but for these patients can be very problematic. If the patients actually survive these episodes of infection, they're oftentimes left with a progression of their disease and increased disability. To understand why patients with mitochondrial disease can deteriorate during infection, I began a study back in 2013 known as the NIH MINI study. MINI stands for Metabolism, Infection, and Immunity in Inborn Errors of Mitochondrial Metabolism. That's a mouthful, so we decided to just abbreviate it to the MINI study. This is a longitudinal natural history study, a study that occurs over many years where we

recruit children with mitochondrial disease from all across the country and we evaluate them at the NIH Clinical Center.

Barr: You say it's at the verge of being a rare disease. Is it just becoming more prevalent now due to different factors or is it just becoming easier to diagnose?

McGuire: That's a great question and the latter half is probably more responsible. We are becoming better at being able to diagnose these disorders and that's because of genomics; the ability to sequence the genome and look for these deleterious changes in genes that are involved in mitochondrial function; the other part as well is due to increased recognition amongst providers. Mitochondrial disease can be very difficult to diagnose. The average number of specialists that someone will see before receiving a diagnosis of mitochondrial disease, I think, is about eight. They will see eight different specialists before receiving a diagnosis. But as I said because of increased recognition and genomics, we've actually become better at recognizing these disorders.

Barr: That's interesting. Can you speak a little bit about the premise of your study that includes COVID?

McGuire: So, I'm not sure, Eliza, is that one of yours?

Gordon-Lipkin: No, that's one of yours Dr. McGuire.

McGuire: So, the premise for us is kind of shifting our studies and looking at COVID patients. It really has to do with infection and mitochondrial disease is something that we've been studying the entire time. And with the emergence of the COVID-19 pandemic, it was a natural progression of what we were doing already since infection can result in disease progression and decline in these patients and increased disability. It was a matter of adapting to a unique situation, which I think we'll speak about a little bit later.

Barr: Okay. That is my next question. Can you talk about how you adapted your study including your methodology and types of technologies for these COVID situations?

Gordon-Lipkin: Yes, and I can take it from here. So as Peter has discussed, our study has for a long time really focused on patients with mitochondrial disease and better understanding their metabolism when they become sick. We have over the last several years brought patients to the NIH Clinical Center to do these studies and have them participate. But during the COVID pandemic, it really wasn't safe for them to travel to come to the NIH. Our patients are from all over the world and all over the country. We really had to adapt to make sure that we can study the patients and continue to study them where they are. We did this in a few different ways. We use a lot of

different modalities as part of our natural history study. We, of course, like to obtain conversations through them with telehealth portals. We started to meet with our patients virtually over video conferencing rather than in-person. That gave us good face-to-face time with all of the research team and with the families that we enroll.

We also converted some of our outcome measures, which would be done on pen and paper or through other modalities at the NIH Clinical Center. We converted them to online portals, so our patients are able to do them from their computers in their own home or in the hospital, if that's where they happen to be if they're very ill. Finally biological specimens are a big part of our research at the NIH; so, blood samples and other types of specimens had to shift from where the patient is back to the NIH Clinical Center so that we can perform all of our studies on them. We were able to use a technology with collaboration with some of our colleagues at National Institute of Allergy and Infectious Diseases to actually be able to give home sampling kits to these families. We'd ship to their home where patients can do a simple finger stick, get us a little blood sample, and ship it back to us overnight. We can bring that directly to the NIH Clinical Center, so the patients don't actually have to be at the physical Clinical Center to be able to participate in this study. This has really been huge for facilitating our study during COVID.

Barr: How did your patients do well with performing, drawing their own blood or did they have some difficulty with that? How did you walk them through that? Sometimes people get kind of overwhelmed when they have to perform their own medical functions.

Gordon-Lipkin: I think that varies for all of our different families just like it would vary for any person. Many of our patients with mitochondrial disease and families are a lot more used to being involved in a medical setting. Some of them were very comfortable performing their own finger sticks and some had a little more anxiety. Shannon, I think you could probably speak to some of that a little bit too.

Kruk: Yes, a lot of it is assessing where the families are. A lot of these kids are, and the families are, familiar with blood glucose finger sticks such as what we utilize for diabetics. A lot of them at least were familiar with it. Every time that we were communicating with them before families even decided to enroll, we were sending them videos of the finger stick sampling process. We were sending them copies of the actual protocol so that they could know before they even decided to participate what that would look like.

Barr: Do you think that you may continue with some of these processes after COVID, because it seems like you know in some ways it may be easier for people who are very far away from NIH?

Gordon-Lipkin: I think this has absolutely facilitated our ability to enroll some patients that we might not have been otherwise able to enroll. As you know patients with mitochondrial disease are very ill and sometimes, they weren't stable enough to travel to the Clinical Center and this has really provided us an opportunity to enroll some of those families that otherwise wouldn't be able

to come here. I think we will continue to bring patients to the Clinical Center. But I think this will help us facilitate being able to integrate both approaches.

Kruk: It really allowed us to address some of the challenges we have because we are studying infection and we are studying mitochondrial disease. You know one of our biggest challenges, like Eliza said, is that our patients can't travel when they are ill, nor would we necessarily want them to. By transitioning as much as we could to a remote platform, it really allows the families the flexibility to participate when they can, whether they're ill or whether they are well. It really provided an opportunity for other families who were previously unable to participate to participate now.

Barr: That's really great. How many individuals do you hope to enroll in this part of your study? How have you all gone about recruiting patients particularly those with mitochondrial disease that were either around COVID or had COVID?

Gordon-Lipkin: Yes. We want to include about 150 families to this portion of the study remotely, and we've gone about recruiting. We partner with a lot of mitochondrial disease advocacy groups in the United States and throughout the world that really reach out to families for all sorts of reasons for support. We've partnered with some of those groups to disseminate information about our study and sort of spread the word that we're hoping to recruit families that way.

Barr: Have you reached your goal at this point, or are you still working to get that number?

Gordon-Lipkin: We're still enrolling.

Barr: You've spoken a little bit about what has it been like for you all and coordinating this part of the study. That's kind of largely been done from afar. And what was the learning curve for you all to adapt to this very novel situation? You know you all were in person and now it's so much just remote. I'm sure that was a learning curve for you all.

Kruk: It was a learning curve. I think the biggest challenge is time. As soon as the pandemic hit we are a very good group in terms of really having decisive leadership and close collaboration. Once the pandemic hit, we really had to decide what are we going to do and how we do it quickly; in addition to writing the protocols and creating our online tools, getting the online tools, determining what our needs were, we were creating and adapting almost simultaneously with the developments in the pandemic. That was a little bit challenging.

The other thing is we had to completely change from being an on-site study to how do we allow for our families to participate remotely. In addition to that we really had to look at how do we create an environment where our families can feel safe and comfortable participating because for us to ask them to go to a doctor's office to have labs done would not be appropriate, especially in these

families. For them it's not unusual to have been isolating themselves during flu season. COVID really impacted them considerably. We really had to figure out what can we do to address their participation; how can they feel comfortable. Then on top of all of that the other challenge was assessing these families and the changes that they're going through during the pandemic. So how do we make this as easy as possible for them, how do we make it quick, how do we make it easily understandable? Fortunately, we've had a lot of families reach out and they do want to participate. The drive is out there. What we needed to create was how can they do it.

Barr: When did you guys start working and making that transition?

Kruk: Almost immediately.

Gordon-Lipkin: We specifically realized early that not all patients would be able to travel during COVID. Our specific population would be the first patients that really can't travel during any high-risk infection situation because it is so high-risk for these patients. I think we realized early that if anyone wasn't going to be able to come to the Clinical Center our mitochondrial disease patients wouldn't be able to do so. We almost immediately started to pivot as soon as there was talk of a larger COVID situation.

Barr: What was it like for you all to create web portals and things? I'm sure you had to kind of create them very quickly. Were there certain standard models that you went with or was there any discussion about that kind of thing?

Kruk: Well, we had a lot of discussion. It was difficult creating the portals but deciding what we were going to put in and what we needed was actually fairly easy with the level of collaboration that we have.

Gordon-Lipkin: It did require a lot of work. We didn't just pick an online portal and go with it. We had to meet with other teams at the NIH to make sure that it was safe to transmit health information through those portals. We worked with several different teams at the NIH to facilitate, to upload all of either paper or other protocols to an online platform, to update our website to create links and again to make sure that it was safe to transmit health information through those venues.

Barr: I had a question. How has COVID affected those with mitochondrial disease in comparison to how those with mitochondrial disease experience other infections? Has it been harder on them? Has it not been as much of an issue?

McGuire: Yes. That's a great question. I mean at this point it's a little too early to tell how COVID-19 infections have really impacted the community or their health. We are in the process of

documenting these cases via the NIH MINI study. So far what we've witnessed is that response to infection has ranged from individuals who have unfortunately passed away to individuals who actually have tolerated the infection rather well. You know I think one of the main questions that we try to address in our study is that not every infection causes these patients to deteriorate. It's not known which specific infection will do it or is it the patient's condition at the time? There are a lot of unanswered questions around this. I think an additional consideration too, which is something that we are discussing as a group, [is] what's known as this COVID-19 long-hauler syndrome.

You probably have heard about this where we study children—basic symptomatology due to COVID-19 can persist for a very long time after having had the infection—and how this actually may complicate their mitochondrial disease. As I mentioned, we currently have plans to study these children via our NIH MINI study.

Barr: Have you all been surprised by any of your observations or findings so far or is it too soon to tell?

McGuire: Yes. I think at this point we found some things that are not surprising with regards to how our patients perceive the pandemic and how they're able to manage their risk mitigation behaviors. What they will do [is] to try and keep away from individuals or exposure essentially so that was not surprising because they do it every single year. Every single year when flu season rolls around, they are prepared; they know that they have to limit their interactions with other people and really try and reduce their risk for getting infections. But as far as, you know, things that have surprised us--we're still kind of going through the data but so far we have seen, as I said, what kind of behaviors that we would have expected from this community already because they're so in tune with the seasons of the year and what infection can potentially do to patients with mitochondrial disease. Their behaviors essentially follow similar patterns from previous years of flu.

Barr: That's really interesting. You've spoken about some challenges that you all have encountered to date have you all experienced other challenges that you haven't mentioned yet?

McGuire: Again, I guess I'll start because I'm sure we all have—I mean working from home. The NIH obviously has a policy as far as occupation for the building. You know a percentage of the building can only be filled at this point. It's only 75, I believe. Therefore, running a program that involves patients, collecting samples from patients, but on the other end, on the back end, is the laboratory. To be able to provide people in the laboratory opportunities to work—that has involved a lot of my staying away from NIH. We can adhere to those recommended guidelines for safety. That has presented challenges where everything has shifted as we're doing right now to kind of a video conferencing type of model.

Barr: Just the three of you on this study. Are there other people involved?

McGuire: The group is about eight people. The people that you're talking with at the moment are the clinical people. In other words, the people that interface with the patients are responsible for coordinating the study, collecting the samples. But then on the laboratory side, there are a number of individuals who work on a number of projects that are related to infection and mitochondrial disease. So that involves working with the samples that we collect from patients as well as using various other models like animal models and things like that to try and simulate what happens in mitochondrial disease patients.

Gordon-Lipkin: I think to add to what Peter said, another aspect that has been challenging during the COVID pandemic is when we communicate with our [patient's] families. These families are also under a lot of stress and they're balancing their own lives and their own other children. Part of one of the studies that we looked at during the pandemic is we surveyed this population to see what challenges they're going through. Almost half of these families are under some sort of financial stressor during the pandemic and some of them have had limited access to their health care resources like physical therapies or nursing therapies that are sort of critical for their healthcare needs. I think other challenges are coordinating with some of our families, not just for the purpose of their research, but we're understanding that the mitochondrial disease community is really undergoing a complex situation of different needs that are not just infection based. It really has to do with the socioeconomic situation of COVID and how it's impacting families and especially families with complex neurodevelopmental disabilities.

McGuire: I also think the surveys that Eliza was mentioning goes back to your previous question of something surprising. I think maybe one thing that was surprising is we found out that a good number of our parents or caregivers of children with mitochondrial disease are essential workers. So that of course increases the risk of the child with mitochondrial disease being potentially exposed to COVID.

Barr: Does it run in families, mitochondrial disease or not so much?

McGuire: Yes. It is a genetic disease right, so yes it can run in families.

Barr: Yes, more than one child can have it.

Gordon-Lipkin: What's interesting is when we looked at those risk mitigation behaviors that we talked about earlier and how families protect themselves against infection during the pandemic, whether families had one person in the household with mitochondrial disease or several people in the household with mitochondrial disease. Either way, they had heightened risk mitigation behaviors.

Barr: That's very hard. How long do you anticipate that this particular part of the study will last? Can you envision subsequent studies based on this part of your research?

McGuire: We have a study going on right now which involves looking at exposure to viruses, COVID-19, and other viruses during this pandemic and that's the 150 families that we had spoken about earlier. This is where we survey not only the child with mitochondrial disease, but all members of the family because as I mentioned before a good proportion of them are essential workers. We want to see basically what the exposure of families has been to various viruses during this pandemic. This will continue to go on as long as the pandemic goes on basically. But also, out of this there are other studies that are either in development currently or for the future. One of which is vaccination. We have found that, and Eliza can speak to this because this is her study that she's running, a lot of our caregivers have what's called vaccine hesitancy. That means that they have concerns about the COVID-19 vaccination for themselves as well as for their child with mitochondrial disease. One of the things of future studies that we'd like to do is to see for the people with mitochondrial disease who have been vaccinated, how protective is that vaccination, how long does it last? There's a lot of questions surrounding whether that vaccination will be protective for patients with mitochondrial disease. That's one thing we want to study. The other thing I mentioned as well is this long hauler syndrome—in other words, complications from having COVID, which can also then complicate the mitochondrial disease as well. I mean this is really for us just the beginning. There are a lot of things that a lot of studies that will actually follow from this pandemic and from the current work that we're doing right now.

Barr: Have these children with mitochondrial disease been more likely to get the MIS-C [multisystem inflammatory syndrome] condition at this point?

McGuire: We have not heard of any patients with mitochondrial disease that have the MIS-C, which is the multisystemic inflammatory syndrome that children can get. Fortunately, we have not heard of any cases like that. However, even before the pandemic, we certainly have been referred patients with mitochondrial disease who may be more prone to having this kind of uncontrolled inflammation. Therefore, my point is that it's a concern for patients with mitochondrial disease if they happen to get COVID. You know that they may have some very heightened inflammatory response. Fortunately, we have not seen any patients like that yet.

Barr: Were these parents, these caregivers have vaccine hesitancy? Is it just surrounding this particular vaccine with COVID, or did they have vaccine hesitancy prior to the pandemic? Therefore, they and their children were not vaccinated ever.

Gordon-Lipkin: That's a really good question. We actually had studied this prior to the pandemic. We were interested in vaccine attitudes in the mitochondrial disease community. So, a substantial portion of families do have anxiety and hesitation about vaccinating their children with mitochondrial disease because they know that any sort of infectious trigger could make them deteriorate. Many patients, many families with mitochondrial disease have been able to have vaccines safely, but there is anxiety in the community about the safety and efficacy of vaccines

forced specifically for patients with mitochondrial disease. During the pandemic we looked at comparing what their attitudes are towards the COVID vaccine versus, for instance, the annual flu shot. And there is more hesitancy surrounding the COVID vaccine than your annual flu shot and other vaccines, for instance the tetanus shot, that is routine for all children. And many families require boosters throughout the years. There is more hesitancy surrounding the COVID vaccine in mitochondrial disease and in the general population than there is surrounding the flu shot and other vaccines.

Barr: In other vaccines certain mitochondrial disease advocacy groups like having those with the disease get their vaccine in a different type of setting. Then may be everyday Americans you know that are more controlled or have they been working on things like that.

McGuire: Yes. It's not a general recommendation at this point from any of the family groups or advocacy groups. However, some practitioners in the community where they have concern about a patient with mitochondrial disease is that they may have an adverse reaction to a vaccination. They will actually follow them much more closely and sometimes even hospitalize them and observe them while vaccinations are given. Now in general, there aren't many studies about vaccination and mitochondrial disease. We do obviously advocate for it because getting the disease is much worse than actually, you know, having the vaccination, but the only study that's been published is a somewhat large study that was conducted in California that looked at not only mitochondrial disease, but a lot of related disorders. They found that after vaccination there was no increased risk of having these kinds of episodes of deterioration like we mentioned. There is something truly different about having a vaccine versus having an infection. They are not the same thing, but yet as Eliza had said, some parents have this fear that a vaccination will trigger their child to have this deterioration.

Barr: Interesting. Can each of you speak about how your individual educational and professional backgrounds prepared you to address COVID with the study?

McGuire: Sure. I'll let Shannon start first.

Kruk: Yes, oh my goodness. My background is pediatric rare diseases and pediatric HIV all within clinical research. I'm actually really comfortable in working with fields where the data isn't completely there and it's rapidly evolving. Working with COVID was just a natural extension of that. I'm working with an infectious agent. We're not really sure what it means. We're not sure how it's communicated. We're not sure how it's spread, how it's going to affect people so for that it was a fairly easy extension. Of course, as a nurse you know I'm used to constant assessment and looking at a lot of fine details and then having anticipatory problem-solving. As soon as this pandemic hit, we all kind of collaboratively looked at each other and said, "Okay so what can we do and how fast can we do it?"

McGuire: By the way we're very appreciative of Shannon in that role because she is very good at what she does.

Kruk: Thank you.

Gordon-Lipkin: Guess it's my turn. I have a background in neurodevelopmental disabilities. I've worked with patients similar to the mitochondrial disease community prior to coming to the NIH. Prior to joining the team in 2018, I actually worked on a couple different studies or projects, which I should say prepared me for this. I worked with patients with acute flaccid myelitis, which you may or may not be familiar with. This was an epidemic of children who had a polio-like syndrome that was thought to be associated with an enterovirus. It's likely a viral-associated form of paralysis in children. The work that I did with those groups really prepared me to respond to a public health crisis and concern for children with disabilities. Also, I had worked in the past with an online study of children with autism. I had some experience in online methodology for research in patient-centered outcome measures for children with disabilities.

McGuire: I guess that leaves me. I'm actually a pediatric geneticist. I am trained initially in pediatrics and then clinical genetics and then something called clinical biochemical genetics. That's a mouthful, but what that means is metabolism. In other words, how your body converts its food to energy. Therefore, as a biochemical geneticist I would take care of patients with different types of what are called inborn errors of metabolism or kids who have enzyme or cofactor deficiencies, which cause them to have problems with basically extracting the energy from their food. Mitochondrial disease as we mentioned is a disorder of not being able to make energy. I have a long history of experience with taking care of these patients and managing them medically. Before even coming to NIH, I was actually up in New York working at a hospital up there with these patients for many years before coming to NIH.

My background also in graduate school is in microbiology and immunology, so essentially infection, right, and how the body responds to infection. Throughout my career I've always been kind of focused on ways of trying to improve the care of these children with mitochondrial disease. What I've done essentially is I've tried to combine all of my background together in one program and that's basically the microbiology, the immunology, the genetics, the metabolism; [they] basically come together in a research program where we help, where we can understand essentially the relationship between mitochondrial disease and infection.

Barr: Okay, lots of different perspectives. Are you all involved in any other COVID activities at NIH?

McGuire: Not at NIH but actually I am a member of the scientific medical advisory board of the United Mitochondrial Disease Foundation. That's one of the parent or patient advocacy groups for mitochondrial disease. My advisor role is really focused on the COVID-19 pandemic and vaccinations in patients with mitochondrial disease.

Barr: We're going to transition from you all as scientists and clinicians to you all as people living through this pandemic like everybody else in the world right now. What personal opportunities and challenges have arisen for each of you during the pandemic?

McGuire: Who would like to start with that one?

Gordon-Lipkin: So, we all have children, and I think we've all been balancing families and childcare and education during COVID. I think being part of a team where my collaborators have also understood those challenges has been really important. My daughter is now two and a half, but when we started the pandemic, she was one and a half and we didn't have any childcare for her. I spent all of the first six months sort of juggling a toddler and chasing a toddler around while also getting all these protocols up and running. So, while as a mother it was a real truly wonderful opportunity to spend so much time with my daughter, during that time it was definitely a challenge. We spent many meetings working on this protocol where I'd be pushing her in a stroller and have my headphones on and chatting with Peter and Shannon and working on our protocols after she went to bed. We'd all schedule all of our team meetings during her nap time. I think it was absolutely a challenge to balance that, but I've helped feel very fortunate to have a team that has been so understanding and collaborative during that time and I'm really proud of how we've worked together despite that.

Kruk: I would echo everything that Eliza has said, the same sentiments. I mean for me personally; I have four children at home, and they were all at home. You know the schools also shut down so that in and of itself presented some challenges. However, the ability to be able to create all of this and work from home and still be contributing to the community and to COVID-19 has been quite a privilege, the ability to do both of those things.

Barr: It's a lot for being a mother of four children at home and all the things you had to do for NIH at that time. That's quite an accomplishment.

Kruk: Well, thankfully they're a little bit older than Eliza's. I didn't have to deal with running around with the toddler. I have a really good support system here. It all worked out. Yeah.

McGuire: So, my experience is pretty much very similar. I have a tween and a teenager and my teenager, my oldest, just started high school. He graduated middle school and started high school during the pandemic, which has been kind of rough as you can imagine because freshman year of high school is a very big deal, a big transition, a lot of changes in life which you look forward to. Some of those you know obviously have not happened at least in the same traditional way that he would have expected so that certainly has been a challenge. I would say the internet has been a challenge because you know we're competing. We have four competing individuals in the household at one time all video chatting at the same time, so fighting for bandwidth has been really a challenge.

But I think you know, as Eliza and Shannon had mentioned, it's really been a great opportunity because I think working at NIH one of the things that it allows you to do versus other places is to be able to make this kind of quick transition where we took our studies and kind of moved them from in-person to online modalities and remote sampling and things like that. I've worked, obviously, in the extramural community, and I can't think of any other place where you could do that. You don't have the support system to be able to do that. It's a unique environment, really, that allows investigators to be flexible and accomplish these research goals. This was something that was, I would say, the mitochondrial community expected from us because of what we do and what we study. They look to us almost immediately, meaning like the family groups, the patient groups, the providers to say, "Okay, you know what you are doing during this. This is your area. You know how you are going to address this pandemic." So out of all these challenges most of which I mentioned are personal challenges. The NIH has allowed us to be able to make that transition, which I think we're really thankful for and live up to you know the expectations of the mitochondrial disease community.

Barr: That's really great. This is a thought-provoking question. What lessons do you hope that NIH has imparted to the medical and scientific field as well as to everyday American citizens?

McGuire: Okay, I guess I'll start. I think that the COVID-19 pandemic has reminded the scientific and medical communities, I think, about how adaptable science can be, especially during times of national emergency, and how different areas of the government, industry, and public-private sectors can come together to really address a problem that's facing our country and the world. That aspect obviously also extends to the public as well in understanding how government and public health play a role.

I think also what's been really important for the public is basically they've kind of had first-hand, upfront witness to how science is conducted right and how the data may be analyzed and then turned into public health policy. I think it's important for the public to realize that public health recommendations are obviously developed from scientific inquiry, and that's not a static endeavor in other words. The goal post actually keeps moving. I mean that's progress in science. As new data emerges, those data are incorporated into public health policy. Then recommendations are refined or even changed. I think that was somewhat of a learning curve, I think for the public, because it was obviously a national emergency which affected all of us in every aspect of our life.

Barr: Does anyone else have anything they want to add?

Kruk: I think Peter summed it up quite nicely.

Barr: Okay, well is there anything else that you would want to add that you didn't get to say either about your study that's going on right now or just your thoughts about COVID or life in general?

McGuire: I think this has been obviously a difficult situation for many people. There are many sacrifices that have had to be made by people in multiple walks of life, but we will get through this. I mean I do have a firm belief in science, in the power of science, the power of science to provide guidance. I think in the end it will be a learning experience for everyone and I think we will come out the better for it.

Barr: Thank you very much and I hope that your study continues to go well and that you and your families continue to stay safe.

McGuire: Thank you very much.