Transcription for: Legislative webinar

Emma Mertens: Alright. Well, good evening, and welcome to another session in the immune deficiency foundations living well with PI series. Tonight, we will hear from a panel of experts on the impact of recent federal policy changes on the PI community. My name is Emma and I'm the Program Manager for Education at the Immune Deficiency Foundation. On behalf of IDF, we thank you for tuning in to this virtual event.
Throughout this series, we will explore lifestyle management topics through a PI lens informing and empowering our community to live life to the fullest. We hope that through your participation in these programs, we may move forward in our vision of a healthier day, every day for every person living with immune deficiency. A brief disclaimer. Please remember that information presented during this meeting is not intended to be a substitute for medical advice, diagnosis, or treatment. We are here today as a trusted source and friend to provide you with information.
Always seek the advice of your physician or other qualified health provider with questions concerning a medical condition. Never disregard professional medical advice or delay seeking it based on information presented during an educational event. This webinar is made possible by our wonderful sponsors. It is due to their partnership and contributions that we can provide programs like this for the PI community. Please join me in thanking today's sponsors.
And now I am so pleased to introduce our panel for this evening. Lynn Albizo is IDF's Chief Public Policy Officer. Angie Kotarski is IDF's Community Resource Navigator. Jodi Taub is a psychotherapist and owner of Jodi Taub Therapy. Jody specializes in chronic illness and rare disease and is a patient herself.
And to kick us off, we have IDF's CEO and President, Jorey Berry who will share some remarks from the Immune Deficiency Foundation. Welcome, Jorey.

Jorey Berry: Thank you, Emma. Well, welcome, everyone. I just wanted to provide some opening remarks to help frame our conversation tonight before I'm going to turn it over to Lynn to get into some of the specifics. It's important to me that our community and our supporters know that we're engaging in several issues as a result of actions at the federal level. Between our government affairs consultant, our policy team and a multitude of coalitions and stakeholder groups.
We are developing and executing strategy. We are present and participating in what matters most to our mission. You might not see it all because strategy can be different, it can look different depending on the situation or the issue. But it goes without saying that these changes are reshaping the health care landscape and they are having an impact. And please know that is not a partisan statement.
It is an objective and factual statement. That being said, I don't have to tell anyone here

that these are polarizing times, so let me take a moment to provide a few comments in that regard. We are a diverse organization. We represent a diverse community and we engage on a variety of issues that cross both sides of the political aisle because primary immune deficiency and issues impacting those with compromised immune systems are neither red nor blue. We often say that PI can affect anyone regardless of age, gender or ethnicity, So let me add also, regardless of political affiliation.

I think the beauty of our organization is our ability to have complex, non partisan conversations because our issues affect everyone, not just one party or one demographic. Isn't it interesting how we tend to focus so much on what divides us? So this is a season of uncertainty. A lot is happening fast. It does season of feeling intense responsibility, but please know that the immune deficiency foundation, we were here in the past, we are here now, and we will be here in the future.

We will be a stabilizing foundation that stays clear, calm, rational, and focused. We're going to strive to build relationships while amplifying our issues. I've always felt that until you have a relationship with someone, it's very hard to have influence with them. And I acknowledge that it can be hard to build a relationship with someone who you really struggle to identify with or find that common value. But during our advocacy efforts, we're gonna stick to the issues and not make it about a person or a party.

And please don't view this as please don't view this as naive on my part because I did I worked in government affairs for almost half of my thirty plus year career. I understand the gravity of certain issues, but I refuse to lose my optimism, and believe that we can make a difference. I think you can face stark reality and stark facts and still believe that good can come. So we will pick a few issues that we will own. That we will use our political capital and our capacity on that.

But for the immune deficiency foundation, an important voice would be missing. And then we'll identify priorities that we'll work on as part of Coalition, we'll lend our voice to many and we'll share the work. And finally, and this is the hardest part of all, but the times we are in require it, we'll have to understand that there are issues that we might have to release to others to carry. Before I close, just a reminder to all of us, the immune deficiency foundation is a five zero one c three tax exempt organization. We are non partisan.

As I mentioned, we have a diverse community to represent in important issues on which to advocate and educate, and we will be strong and united on our messaging. And that's one of the areas in just a moment that Lynn's gonna talk about. Also, please note that the information is ever evolving even daily. We have some critical and important issues to address during advocacy day, which is really just in a couple of weeks. And based on information we receive from that effort, from engaging with legislators, will be updating our statement on federal actions likely in May.

So with that, I'm going to turn it over to Lynn Albizo, who, as you heard, is our Chief Public Policy Officer.

Lynn Albizo: Hello. Welcome. So I'm gonna give you some background on everything on the actions that we're doing and the priorities that we set and and how we got here in twenty twenty five. So we can go to the next slide. So twenty twenty five, as you all know, has been a very hectic and had a hectic and fluid start.
There's a new administration. There's a new Congress. And there's been an incredible amount of change in activity over a short period of time. With that, there's a significant amount of uncertainty. Next.
So what are the dominant themes that we are hearing. There were if we go back to January, there were a number of fast and furious executive orders that came out and there's continuing to be more executive orders. Including the [] Commission withdrawal from the World Health Organization and NIH Indirect cuts. There's been many aggressive acts from starting out at the beginning of the year with communication freezes, removal of perceived DEI initiatives, precision of federal funds and federal layoffs, And several of these issues are tied up in litigation, so they may be overturned. We have to wait and see what happens. Also, there's the nontraditional agency appointees. So we know Robert F. Kenny Junior is the secretary of health and human services in addition to a number of leaders under hit under the secretary that are not your traditional, you know, what we're used to. They're not they don't have experience in that area in the government area. But, you know, that can work both ways, so we'll talk more about that as we move along.
There's been the doge effort that's to try to reduce the size and influence federal agencies. And that's the effort that is being led by Elon Musk. It's there's been a lot of controversy around that. There's been a major reduction in HHS workforce. There's been consolidation of departments, and all of this has been a subject of intense pushback and litigation.
There's also in the background of all this, non health related actions regarding tariffs, immigration, foreign policy, all these different things, which as Jorey said earlier, you know, people may fall on one side or another. They could be controversial. But when we go to DC and when we advocate, when I advocate, I don't focus on those other issues. We want to focus on the healthcare issues that affect our constituency. Our the Immune Deficiency Foundation.
So, we can go to the next slide. So, first, I wanted to talk about the hundred nineteenth Congress. As you may know, there's a narrow Republic and majorities in both the House and the Senate. So the Republicans right now have the House, the Senate, and the presidency. So there's opportunities in in general of the new congress be to be able to introduce ourselves to new members.
Whether Republican or Democrat, there will be new members, you know, that we're just

recently elected because it's it's Republican in the House, the Senate, and the administration. The administration has significant influence over the Republicans and also just this the nature of this administration as such. There's, but in the past, we've had some agenda items last year, which we will continue to try to move forward. There's been modest progress to date on on goals and objectives. It's very difficult when it's a very slim majority. So regardless of who's in power, when you have a a very close number of people on both sides, it's hard to get things moving in the through Congress. So the the first half of the year up in or in the first part of the year, up until now, there's been a lot of focus in the Senate on confirmation of cabinet members and other nominees. So all the cabinet nominees have advanced We did do significant amount of advocacy regarding HHS with our specific concern about prioritizing vaccines. And be having concerns about the appointees in that area. We were we did have sort of a little win in the sense that the original appointee for the CDC director was Dr.

David Weldon who is known to be anti Vax. There was a lot of concern about that and we shared a lot of concerns in general about making sure that vaccines or something that are supported in the administration. And that, combined with the outbreaks and measles in areas of the country, led congress to and the administration to pull Dr. Weldon, and to appoint Susan Minarez, who holds a PhD in microbiology and immunology. And she's the new nominee.

She hasn't been confirmed but it appears that she will be. So that's helpful for us that there's somebody who's who has that experience in the CDC. We'll see as to how much power she has, but it is it is a someone who respects science and and has a background in science. So the the leg in terms of the Trump legislative agenda, the the Republicans have focused on tax cuts and immigration, sure if you're watching the news, you can hear a lot about those issues as well as tariffs. But from the democrats point of view, they're highlighting in opposition, the issue of Medicaid cuts and and the negative impacts that tariffs will have on the economy or may may have on the economy.

So next, So with that, again, like I said, we really want to focus on health care issues. And the administration put out a memorandum talking about the new HHS structure, and it's already taken a number of actions to begin that that process. So I I I'm not gonna get go through every bullet here, but suffice to say, we had twenty eight HHS divisions. They're going to be consolidated to fifteen, and ten regional offices are going to be consolidated down to five. The new administration for a number of the sort of chronic disease areas is going to be called the administration for healthy America, AHA, and that consolidates these agencies that I listed here.

And that includes HRSA, which is one of the agencies that we've done a lot of work with related to newborn screening and other issues for newborns and and and the like. So then they've restructured and you can see up here what what the proposals are in terms of restructuring. There was a memorandum that actually got leaked in the press just yesterday that had some more details But again, that is, you know, something that was leaked in the press so we don't know exactly. What we do know is that, you know, things are being consolidated and things are being reorganized. So what we do is we take we we carefully watch everything that's happening and we work with other patient groups to figure out, you know, what what is, you know, what we can do with that.

The there are also the advisory committee on heritable disorders in newborns and children that that was shut down. So that is the advisory committee basically for newborn screening that determines what conditions are on the RUSP. That's the recommended universal, recommended universal panel for those conditions that are on the list that are recommended by the state's screen for newborn screening conditions. Skid is on that list. It took us eight years to get skid screened in all fifty states.

So the first step of the process in the past has been to go through this committee and and get it on the RUSP. There's legislation that we've worked on in many states that basically from the RUSP will if a condition is is on that list, then it will I'm sorry, then the state will have to screen for that. But now that there's not that, we don't know what's gonna happen. But in general, what we know, our concern is really that the functions that these agencies have been doing need to continue. So administrations in many different every time there's a new administration, they have the power and the right to reorganize and often they do.

So our concern is if they're if they're taking away positions, if they're moving functions, where is the function that we rely on and and so that's the kind of questions we're gonna be asking. It's not so much what you call an agency. It's are they going to provide are they going to be doing the things that we want them that we need them to do to to protect our community? And, you know, will they have the capacity to do it? And, you know, as it all you can see we had there's a lot of decreases in workforce, and so we're concerned if there's if there's functions by the FDA, by the CDC that we rely upon, and there are, how is that going to be done?

So, with CDC, there's a lot of information about infectious disease, there's guidances that doctors use as to vaccines. All these things functions within the FDA and the CDC are things that we rely upon. So if they're going to take away staff who's gonna be doing some of these jobs. So we're gonna continue to advocate. We're gonna look at what kinds of structure and functions that they're doing, and we're gonna ask questions.

And we're gonna there's opportunities within the budget to do this kind of advocacy. We're also working closely with our immunocompromised collaborative partners to come up with priorities and ways to advocate on these issues next. So I I kind of started to talk about all this, but what what are all these cuts gonna do to how did these impact IDF's priorities? So there's these are some of the issues, declining government support for vaccines. So what have we done?

We issued a statement and a joint letter and submitted supporting vaccines. We've also provided questions at the hearing. We, you know, there's the measles outbreak was another impact that it happens because of, you know, less priorities for vaccines. And as I mentioned, Dr. Weldon's nomination was with John.

A decrease in NIH engagement, we had a we had a meeting planned in collaboration with NIAID that was that our collaboration on that was halted. And there was a workshop which we had been the ones who advocated to get this workshop done through language and the appropriations in twenty twenty four, that our team was uninvited to that. So not great for for NIH engagement. There's also potential stall in newborn screening advancement. As I mentioned earlier, I I kind of started to get in the weeds with that about the recommended universal newborn screening panel, the RUSP, and how that's going to be - that's impacted. And then there's a federal support for newborn screening as well. We're concerned about funding the states for those programs. There's also concern about reduced access to care and the fact that there's a big effort to target Medicaid and there's definitely gonna be legislative work and going back and forth about cutting Medicaid and that's something that we're gonna be advocating to maintain. And then in the background is our skilled nursing facility bill, which we have we have we're still working on, but It isn't as much of a priority because of all the new things that are happening this year, next. So what are we doing?

As I I said earlier, we're we're doing a lot of monitoring and listening and working with other coalitions to to find out and make sure we understand what the issues are. We're in doing that, we're prioritizing our advocate advocacy issues, so that we can prioritize what we can engage in. We can't do everything, as Dory said. So we can actively engage in issues that are important and directly impact our community and mission. And we also have to have the capacity expertise and reputation to have some influence over those issues.

For other issues, we can track them, we can join coalitions, and we can do things like sign on to letters, and and do you know, show our support without having to do a big lift because we can't do everything. We did release a public statement in February, which we're going to be working to update and will be, you know, because things are changing so much, we're adding to to what our priorities are. But we're kind of sticking with a lot of the framework that we had in that earlier statement. And I I encourage you to look at that online next. So, I'm going to just kind of quickly summarize the priority statement.

The first one is ensuring vaccines remain accessible and supported by federal and state health agencies to protect the immunocompromise. That includes both access to vaccines and government education and support of vaccines. We want to also support safeguarding public health data to monitor infectious disease and ensure experts in the fields are employed and able to conduct this monitoring. So we want to get ahead of infectious infectious spread before there's another pandemic that would impact our patients critically. We want to continue investments in research and innovation.

We've heard a lot from our medical partners, research partners, very concerning. There's both the NIH funding for the direct research that is done at NIH and many of our patients participate in clinical studies and get their have gotten their treatment there over the years. It's helped to develop new treatments and it's just been a lifesaver. There's also a lot of funding that comes through NIH that goes to our academic institutions. And that is also at risk of and being cut, so we're concerned about that.
And then we want to, of course, support full access to treatment. And right now, it's Medicaid that it's on a chopping block. So we'll be advocating to support Medicaid so that those in our community that rely on Medicaid and Medicaid that that also includes children's Medicaid, basically. Those are things that are very important for a lot of our community. And it's not always sort of the typical person that you the stereotypical person that people think of as being on Medicaid.
A lot of times infants that have very, very expensive treatment requirements or young people that can't work because they're so so sick or, you know, of any age may need to rely on Medicaid and it's important that in our community that people have access to that. So next, So I just I think I just pretty much wrapped up everything on what's happening. It's as as I said earlier, it's a moving target. Things are happening. Very fast and furious.
We're working with with our partners to to try to address these things. But if you want to engage and I hope you do, you can sign you should definitely sign up for action alerts. You should Vant, you can volunteer as a health access advocate. That way, you can be trained and and and help us advocate at the state level. There'll be a lot of people, a hundred and fifty people joining us for advocacy day, It's coming up in a week and a half, so you can't sign up now, but some of you will join us.
And we have state state advocacy workshops as well that are up there. So I think now I'm gonna pass it to Angie Kotarski and to do her part. Thank you.

Angie Kotarski: Thank you, Lynn. Hi, I am Angie Kotarski, and I am the community resource navigator with IDF. I'm also a board certified patient advocate. So I'm going to go over resources on how you can stay informed and up to date and really get explanations on what currently is in place as well as any changes that are happening. Next slide, please.
So I receive a lot of questions through the Ask IDF portal about insurance. And just some obvious ways to stay informed on insurance. If you have Medicare, you can go to medicare dot gov, and this will explain all the different parts of Medicare and any changes that could be happening. If you're looking for information on Medicaid, each state has its own Medicaid plan, you can go to medicaid dot gov and find your state to find more information on your state's plan. If you're seeking guidance on marketplace plans through the Affordable Care Act, including subsidized plans, those can be found at healthcare dot gov. Next slide, please. Having knowledge of any recent outbreaks or any other pertinent

information similar to that is really imperative for our community to stay prepared. You can find details for your state, city, or county by going to usa dot gov State Health. And you can find your state, click on that, and that will take you to options for your counties. You also can go to the National Association of Citi and County Health Officials, which is the nacho dot org, and find your county through that website as well.

Next slide, please. If you're looking for non governmental health policy agencies to access information about policy changes, health policy changes, as well as really detailed explanations on Medicare commercial insurance and how all of that works. There are two really great organizations that are also non partisan. That's the Kaiser Family Foundation and the Commonwealth Fund. They offer a lot of really in-depth detailed information.

Next slide, please. If you're needing assistance and navigating the disability process, your insurance benefits, or if you're having any trouble in accessing your care, In addition to IDF, there are a handful of other organizations that can help you with this. These three organizations here, accessia health, the patient advocate foundation and triage health, actually offer free legal assistance. Excessia Health has a legal program as well as other programs to help those PI community members. And the PatientAdvocate Foundation has a case management program that will help people in our community with all sorts of issues, including legal.

And Triage Health has actually run by, I believe, their teen different attorneys who are well versed in healthcare policy and situations. Next slide, please. If you're looking for financial assistance, if you have a commercial plan Mhmm. A commercial insurance plan meaning not Medicare, Medicaid, or TRICARE. But if if your plan is through marketplace or if your plan is through your employer, then we definitely recommend that you get signed up with the manufacturer copay assistance programs.

There are some nuances to that. So if you find yourself in a situation where you're still owing money, then please reach out to ask IDF and we can discuss that with you one on one. There are also some outside nonprofit organizations that offer financial assistance. Those are accessia health, the Assistance Fund, the Health Well Foundation, the patient advocate foundation, and the THINK Genetics Foundation. I don't believe that any of those have anything open at the moment.

But I do very strongly recommend that you get on their waitlist because very often people will get approved within a couple of months. The Pan Foundation has the Fund Finder And I recommend that you get signed up for that because you will receive text alerts whenever these organizations open up their funding. And they're they have, like, disease specific links that you can sign up with. So again, get on the waitlist for these organizations. And once you've done that, then ask your specialty pharmacy or your infusion suite if they have financial assistance.

This is not something that they can offer to you. You have to ask for it, but many of them have that as an option. So ask them specifically for financial assistance, not a payment plan. But if you're looking for financial assistance to eliminate your out of pocket, then be sure to ask for that. Next slide, please.

As Lynne mentioned, there are many ways to get involved with IDF. I know she discussed already signing up for action alerts, become a Health Access advocate, And tell your story. We have a phases of IDF program that you can tell your story and it's really important for us to know these different situations and how they impact our community so that when we do go to advocate we have specific stories that we can talk about. At an advocacy day, again, this year is already full, but please consider it for next year. You can volunteer in other ways too, like as a peer support coach.

We offer Pure Support one on one. So if you would like to sign up to be a coach and connect with others to help others through their journey, it's a great way to get involved. And also our walks for PI. They're a lot of fun and it's a great way to raise money to help our community. Next slide, please.

Other ways that you can get involved outside of IDF to help with policy legislative issues. The rare disease diversity coalition focuses on health access to those that need it. Patients rising as another health policy organization. And the national organization for rare disorders also called Nord. They have many ways that you can get involved.

You can also tell your story with them. You can also get involved in their in their advocacy volunteer. Next slide, please. If you have any questions, please reach out to Ask IDF. You can go through a portal on our website or you can email ask idfprimaryimmune dot org. Thank you so much, and Jodi.

Jodi Taub: Great. Thank you so much. So as I was introduced before, before I get into my presentation, I'm a chronic illness and rare disease and medical trauma expert, but I'm also a patient who lives at the primary immunodeficiency disease, and I think that's important to remember that I always lead with that hat. So I'm gonna talk about emotional strategies to manage this uncertain time. The emotional impact of uncertainty.

With medical policy changes, disruption to research participation, or funding costs, it can impact healthcare concerns for all of us. Uncertainty can lead to emotional dysregulation and setting off a fight or flight response. Health care policy changes can activate health anxiety and medical trauma responses for PI patients and caregivers. Many of us who were just coming out of, you know, five years since the beginning of the COVID-nineteen pandemic, we thought we're moving into a place that feels more stable and then all of a sudden there is and measles outbreak, and we don't know how it's going to impact our community. And so with changes not only in policy, but with changes in vaccine, hesitancy, and awareness, it can cause health anxiety and medical trauma responses that aren't too far away for all of us.

And online reactions from others can also trigger nervous system responses. When we're looking online, and we hear, you know, we see other people's reactions. So it's not just what we're saying ourselves, but we can also be triggered and activated by the responses of other people. And so if there's a post that someone sends, and a lot of people are responding with fear, we can have a response to that as well. It's important, so during these times, to stay grounded, despite the uncertainty, or healthcare policy research or funding changes.

Uncertainty can be challenging, but effective coping strategies can help build resilience and emotional balance. Planning and strategy building can reduce stress responses. Next slide, please. So what can we do about it? What are some strategies?

So strategies for healthy social media use. Social media use can impact mental health. But it also can be helpful for connection, especially for PI related groups. Many of us are on some of the Facebook groups that allow us to connect and find support with patients who are living all over the world. And this is a wonderful connective resource for our community. But there are times that we all use social media and it can impact us in negative ways. So what are some ways to deal with that? So setting boundaries, limit your screen time and silence over stimulating content. Refrain from social media arguments. Curate your feed. Delete toxic sites and choose supportive content. We all have control over our social media content and what we choose to engage in. And take a break. Try a social media detox and limit your content for a day or limit your use to specific times and set goals for yourselves. So maybe that is I'm going to limit my social media content to, you know, one hour per day or several days a week so that you're not constantly being bombarded by all of the messaging.

And engage mindfully. Ask yourself, is this content helping or harming me? Am I participating in a Facebook group and finding information from community members that's really helpful and informative? Or am I engaging in content that's causing me to feel stressed? Next slide, please.

Actionable steps for purpose and calm. There are ways in which we can actively try to manage our nervous systems and remain neutral and less reactive during this uncertain time. Check the facts. Ask your medical team how changes could impact you directly and look to the immune deficiency foundation to stay informed. The immune deficiency foundation is wonderful and that's part of why we're having this webinar tonight to keep our members and community informed about changes and what's happening.

And we really want to look to the experts and to our own medical team to find out how we might be impacted by a policy change or a virus or an impact that could affect us. Maintain your coping strategies. It's important to maintain daily routines and stay connected to friends and family members and practice self care. All of these things are vital regardless of the time period for those of us living with chronic healthcare conditions and the caregivers that support us and seek support. Talk to a therapist, join an IDF volunteer led connected group or one of the therapist led support groups that I happen to lead and lean on trusted friends and connect with supportive online PI groups.

This is really important. Our community is impacted by policy changes. And when those policy changes occur or their research and funding cuts, it's important that we stay connected to others who understand what we're going through. Next slide, please. So on this slide, I'm talking a little bit about some therapeutic modalities and that you can utilize to cope with these uncertain times.

So CBT ACT and DVT coping skills strategy. So CBT stands for cognitive behavioral therapy. ACT is acceptance and commitment therapy. NDVT is dialectical behavioral therapy. All of these modalities are research have been research and we know that they're effective for coping with chronic illness and rare disease.

So first, acknowledge it and accept it. Fighting uncertainty increases stress, except that some things are out of your control and focus on what is most impactful for you. The truth is, right now, we're all bombarded with a lot of information. Some is disinformation, and some of it is just content on an ongoing basis. And it is going to be stressful.

Part of living and part of being human is that we are going to be impacted by stress. So living in this world where we have access to content on an ongoing basis does set off the sort of the trauma response. And it can set off a cortisol fight or flight and and that is normal and is a part of the world that we're living to living in because of the access to information. So, focus on distress tolerance. Use self smoothing techniques like listening to music or a favorite podcast or watch a TV show for purposeful distraction.

Pause before reacting. Balance emotion and logic to make thoughtful decisions. It's very easy during this time period when we receive information on social media or hearing the news to react. And it's good to take a moment and center yourself and think about it before you react. Reframe negative thoughts.

Challenge a rational fears and replace them with balanced perspective. When we are triggered by a stressor, by a piece of information that feels upsetting and we have a stress response, the reaction often is to have a series of negative thoughts and they can be hypothetical scenarios that are fear based. And we want to make sure that we work on challenging those thoughts and not not giving purpose and to all of those thoughts that we have. Use positive affirmations. So balance that anxiety and fear I was just talking about. Ask yourself, is this Is this issue going to affect me? Is this something that is going to take place? Is this a hypothetical fear that I'm just worried about so that you can remind yourself that things are going to be okay? Behavioral activation. So engage in meaningful activities to reduce stress and uncertainties such as exercise, getting out into nature and creative expression.

We know that positive distractions are helpful in calming the nervous system. So using a positive distraction that's behavioral such as these different events such as everybody can walk outside their front door and get into nature. And creative expression is just getting yourself involved in something you love. It could be crafting. It could be a book club.

It could be reading about a favorite place that you would like to visit. It's just simple things that get your mind off the stressor at hand. Problem solving. Break problems into smaller steps and identify actionable solutions. So part of that could be, for example, we've had recent measles outbreaks that have caused a lot of anxiety in our community.

One way to approach that would be to say to yourself, okay, let me check the immune deficiency foundation. Let me check with my immunologist or physician treating me and to see how this may impact me in the future. Am I protected? And what we found out recently is that many of us are and we don't need to be living in a fear based circumstance when we confirm with our community and with our doctors that things are going to be okay. Next slide, please.

So these are some examples of just some simple exercise tools that you can use that are trauma informed. So grounding exercises. So the five four three two one method is to identify five things you see, four things you can touch, three things you can hear, two things you can smell and one thing you can taste. By doing this, we're engaging our sensory, we're spots to take our mind off of the stressor at hand. Deep breathing.

So box breathing is inhaling for four seconds, holding for four seconds. Exhaling for four seconds and holding again. This slows down our sympathetic nervous system, which is the fight or flight response, and can help us to remain calm in a moment. And then utilize sensory anchors, so this can be holding an object, listening to soothing sounds, engaging in a mindful moment or doing the butterfly hug. So for those of you who can see me, I'm gonna move my hand so you can see this is the butterfly hug.

So what you do, it's almost like, you know, you're kind of giving yourself a hug and you sort of press down. And this engagement can be self soothing to the nervous system and is evidenced based and research. Next slide. Healthcare communication guidelines with loved ones. This is really important during this time period because we're not only bombarded by the reactions of people on social media, but by people who are close to us. So many people in our lives may not understand or have certain opinions about different health care guidelines and different policies. So, share your perspective. Explain why a specific healthcare policy affects you personally. Highlight potential risks, access barriers, or health concerns related to that particular policy. Step boundaries, communicate when a conversation becomes too stressful.

Pause this discussion if it triggers a stress. It fit triggers stress or discomfort. You have the right to say to somebody. You know what? I'm really having a hard time with this conversation and this particular policy or this discussion really impacts me.

And would you mind if we just moved on to something else? Encourage education and

advocacy. So offer resources for loved ones to learn more, suggest ways that they can support and advocate on your behalf. Next slide. So these are some resources that you can use for mental health.
The immune deficiency foundation has a wonderful page that's dedicated solely to mental health. And there's a lot of resources on that page. And also the page from the immune deficiency foundation to get peer support. There's a wonderful peer support that's a one on one peer support program. There are the IDF get connected groups that are led by peers and then the therapists led support groups.
Next slide. These are my references. And this is my contact information to get in touch. Thank you so much.

Emma Mertens: Wonderful. Thank you so much, Jodi. Alright. Now we're gonna call all of our panelists back, and we are going to have a little panel discussion. Alright.
Welcome back, everyone. Thank you so much to our panel for sharing your insight and expertise with us this evening. As I mentioned now, we have a few moments for a brief panel discussion. And we're gonna go ahead and start with a question for Lynn. So Lynn, we know that advocacy day is right around the corner, as you mentioned, and it's always extremely well attended by our PI community, which is amazing.
Can you speak to some other ways that folks can engage with these issues throughout the year?

Lynn Albizo: Sure. Well, I've listed a bunch of different ways like, you know, responding to advocacy alerts becoming a health access advocate. But I would say that a way the the advocacy day is one day and that's great. And we were gonna be have a hundred and fifty strong. I'm so excited about it.
But, you know, policy happens three sixty five days a year. So, we actually need people year round at the federal and the state level So, you know, if you are interested in engaging, especially if you have a story, so if you, you know, participated in an NIH study or you, you know, you you receive Medicaid or you have, you know, a story to tell about how vaccines has helped you on these kind on these issues that are important or if you had an issue with skilled nursing facility, those we want examples. So reach out to us and we can set up virtual meetings with legislators year round. And sometimes we're looking for someone in a specific district because that legislator is very important on the right committee or a way for this legislation or this policy to move forward. So I would say stay engaged with us year round, sign up for advocacy alerts, you can join ourHA program, which focuses on state level advocacy, and we do a whole training for that and have a really great program around that.
We do state workshops. We do two or three every year this year. We were in Virginia in January. We're gonna be in Louisiana in June, and then we're gonna do a virtual one in the

fall, which we haven't chosen the state yet. So if you want to send us a recommendation as to what is why your state is so important or if there's an important issue in your state. We'll consider that. We're gonna make a lot of decisions about how we choose that. But those are some different ways you can get engaged.

Emma Mertens: Thank you. And I love that. These issues are definitely present at three sixty five. They don't stop, so definitely appreciate you driving that point home. Alright.
My next question is for Angie. Angie, in your role as IDF's community resource navigator, what is the top question you are receiving from the PI community right now? And also, what sort of resources or guidance do you offer those folks in response?

Angie Kotarski: Sure. So, I really get a number of questions that range all the way across support, but primarily insurance questions. Anything related to insurance from commercial insurance, Medicare, Medicaid, all of it? So I don't have one one can answer a response to to give to you here. What I would suggest is that you reach out to ask IDF so that I could discuss with you one on one your specific situation and we can find the best best help for you, the best way to move forward.
And again, that's you can use our portal online or you can email ask idf primary immune dot org.

Emma Mertens: Definitely. Thank you, Angie. Alright, my next question is for Jody. So Jody, in your portion of the presentation, you talked us through some practical strategies for communicating with loved ones. Who might not be on the same page on certain issues or certain occurrences in current times.
And you mentioned that by sharing your perspective and setting boundaries and encouraging education, these can all be great tools to help improve that communication. Outside of that general framework, I know you provided one example in your talk, but I'm wondering if you could provide some additional kind of sample language of what using those strategies looks like in action.

Jodi Taub: I need to unmute myself. I know these conversations are always difficult when we're put in a position where we're having we're feeling like we have to defend what and be protective about how we manage our chronic healthcare conditions. But I think it's important to come from a neutral framework and to also remember that these moments can be teaching moments for somebody else. And not everybody understands and isn't willing to listen. And so I think you start off with a neutral stance that, you know, I'm going to be calm when I'm reacting to the other person.
And then also to say to this person that you know, you know, I understand where you're coming from because you wanna acknowledge that we have different perspectives and everybody comes in with different experiences and how you know, how policy changes,

how medical care, everybody can react differently and say, I understand that this is important to you. However, if you don't mind, I'd like to share how this is impacting me. And then a general statement about how that research funding cut may have impacted you or a recent statement from, you know, from a federal official about vaccine hesitancy or something that can be impactful. And then from there, when you do, if that person is still interested and is still listening, then you can move to the next step to say, if you would like to learn more, I'm happy to share this with you. And some people will be interested and other people won't, but at least at that moment, you're trying to bridge some connection so that they can hear you and understand why this may impact you.
The truth of the matter is there will be some people who won't And so for those conversations, if somebody's saying something that's really hurtful, you can say, hey, you know, by the way, this really is impacting me. So I think this is an important conversation, but maybe not something that we can talk about now. Maybe we can talk about it again in the future.

Emma Mertens: Excellent. Thank you, Jody. And we'll close with the question for Jody. So Jody, during your remarks, you touched on some of the obstacles that we as a PI community are facing in this current time. But in an effort to center us on the strength of that PI community and our mission here at IDF, what are you most hopeful about as we look to the future?

Jorey Berry: Oh, I have so much hope for the future. I would never lose my optimism and I encourage anyone who may be feeling discouraged to know that We are here. You're not alone. I love everything that Jody shared. I've spent twenty five years in the nonprofit sector, and I am completely biased.
I know. I'll just put that out there. But I believe nonprofits for the soul of our society. We do the hard work that others either can't or are unwilling to do. And we are incredibly strong when we're united I also believe that I completely stole this from another organization, but I'm using it like it's mine.
I also believe that the most affected or the most effective. So we we have so much to be hopeful about Innovation in treatment and diagnostics. The promise of AI and big data in reaching the undiagnosed, which is a key priority for the immune deficiency foundation. The awareness that our documentary compromised. Life without immunity is raising about the eye and a shameless plug.
I believe it's Friday, April twenty five. We're gonna be hosting a live screening through Facebook. You can go to our website and you can right there on the homepage, you can find compromised if Facebook is not gonna be a way. You can watch it. We have ways you can watch it alone, but we're also hosting it hosting a screening.
So I encourage you. And that's it's getting so it's getting it's raising such great awareness

about our community and about primary immune deficiency. I mean, the last last year's PI conference showed us showed me the sheer volume and need of our community to come together, and we only plan to expand on that in twenty twenty six. And in between, before we even get there, this year, we're hosting our first our first ever medical and science summit and his focus on clinicians outside of immunology so that we can educate them about PI. And I guess I would just close by saying, we're strong, we're stable, the immune deficiency foundation has the ability, and quite frankly, some other organizations do not right now, we have the ability to continue our work and we will.
We're not going anywhere.

Emma Mertens: I love that. I think that's a great note to end on. So thank you so much, Dory. And I wanna say thank you again to our panel. We so appreciate your time this evening.
And with that, be before we wrap up, I'm gonna share a few of IDF's resources and some upcoming events. Primary immune dot org is your go to website for additional resources, upcoming events, and more. All materials are free to access, print, or mail directly to you. If you have a follow-up question from tonight's program, you can contact our board certified patient advocate who you met tonight through Ask IDF, and she will personally connect with you to tackle your question and direct you to appropriate resources. You can even take IDF on the road with our engaging podcast series.
You can find programs like bold conversations, undiagnosed and chronic twenties by searching for the IDF podcast in your podcast player. We also have a YouTube channel where you can find recordings from all of our digital education events, and today's program will be available in the coming weeks. Applications are now being accepted for IDF's twenty twenty five research grant program. This program supports research initiatives focused on improving patient outcomes and expediting the time to diagnosis for individuals affected by PI. To submit your project for consideration, download the application, which we are linking now in the chat.
And are you looking for ways to connect with others who are also navigating life with a PI? You might be interested in joining one of our many get connected groups. These groups are free to join, virtually tool and volunteer led opportunities to connect with others with PI all over the US. We offer location based groups, so in your city or state, but we also offer nationwide groups. And because we meet over Zoom, you can join any group day time, leader, category, etcetera, that works for you and your schedule.
And a few of our new groups include early career in PI and the PI book club. We also offer facilitated support groups for young adults, parents, and spouses and partners. It's a busy spring here at IDF, and we have a great lineup of programming and events in the work Later this month, we have our spring volunteer appreciation event, and we have that next virtual

screening of Compromise that Jodi mentioned. And in May, we will host a lunch and learn to discuss genetic variants in APDS. And you can find all of those events at the Events link, which we are sharing in the chat.

As we conclude, I want to once more thank our incredible sponsors for supporting our education initiatives here at IDF throughout the year. As well as our panel for sharing their time with us this evening and providing this crucial information to our community. We appreciate everyone joining us this evening and hope to see you back for future programming. I'm going to leave the webinar up for just a few moments in case anyone would like to revisit any of the links that were shared in the chat. But otherwise, take care. Thank you for joining us and have a great night.