

## January 15, 2021 Patient Education Webinar- Rare Across America and Advocacy

**Amethyst:** Hello, welcome everyone. This call is now being recorded, and I would like to thank everyone for being on the call with us this afternoon. And also, a big thank you to our sponsors, Genentech, Principia Biopharma, a Sanofi Company, argenx and Cabaletta Bio for making today's call possible. Today's topic is Rare Across America 2021 and Advocating for pemphigus and pemphigoid patients. Before we begin, I want to take a quick poll and just see how many of you have ever participated in an advocacy event? It could either be writing to your local official, visiting them in their local or DC office, and it doesn't have to be just with the IPPF. Maybe it was with some other organization that you've worked with. We are just take a quick poll to see how many of you have participated in some sort of advocacy events? And while we're doing that, I want to start introducing our speakers for this afternoon.

**Amethyst:** Becky Strong is the IPPF's Outreach Director and a registered nurse. She was diagnosed with pemphigus vulgaris after a 17-month journey that included seeing six doctors from various specialties. She continues to use this experience to shine a light on the average pemphigus and pemphigoid patient experience of delayed diagnosis and bring attention to how healthcare professionals and policy makers can change the patient experience.

Marc Yale is the IPPF's Research and Advocacy Coordinator. In 2007 he was diagnosed with Cicatricial Pemphigoid. Like others with rare diseases, he experienced delays in diagnosis and difficulty finding a knowledgeable physician. Eventually, Marc lost the vision in his left eye from the disease. This inspired him to help others with the disease. In 2008, he joined the IPPF as a Peer Health Coach and from 2016 to 2020 Marc served as the IPPF's Executive Director. Marc continues to work with people to improve their quality of life, and encourages them to become self-advocates. Marc continues to work with patient Advocacy groups.

Carolyn Fota became a Peer Health Coach with IPPF in August 2019. Carolyn was a newly retired U.S. Army Lieutenant Colonel Medical Service Officer when she first experienced the undiagnosed symptoms of Bullous Pemphigoid in October 2015 following a simple same day procedure. Carolyn experienced body wide blistering to include oral lesions for almost six-months before being correctly diagnosed and treated. Carolyn has actively participated in Rare Disease Week on Capitol Hill since 2017 she has written articles for IPPFs magazine, Mid-Atlantic Support Group Leader, Representing IPPF at various events and meetings and last year serving as a Peer Health Coach.

Fred Wish is a PV patient who lives at the Jersey shore. He retired from full time work in 2010 and owns a writing and editorial service company with his wife, Loretta. Fred has volunteered at many IPPF events including helping educated dental professionals at the Greater New York Dental Meeting and he participated in Rare Disease Week in D.C. last year.

Hannah Yale is Marc's daughter and is a first-year student at St. Mary's College of Maryland. She is double-majoring in Public Policy Studies and English. Hannah is a member of the Young Adult Representatives of RDLA and has attended Rare Disease Week on Capitol Hill every year since 2017. Welcome everybody.

**Amethyst:** Based on our poll here it looks like most of you have not participated in any advocacy events so this is a great opportunity for us to share with you about how the IPPF is involved in advocacy and how you guys can get involved as well. Before we start our questions, I'd like to go over a few housekeeping slides... (Discuss housekeeping Rules)

**Amethyst:** It is now my pleasure to introduce our advocates to discuss Rare Across America and Advocacy. Welcome, everybody! We're going to jump right in here. And this question is particularly for Marc since he is the advocacy coordinator. Marc, what is advocacy and why is it so important to the IPPF?

**Marc:** So advocacy is really being able to share your voice and share your story. I mean, when I think about advocacy, those are the two things that really come to mind. And at least for everyone that's on the call today and for our other esteemed speakers, it's important because it allows us to really create a lot more disease awareness about our disease. So many of you know there are many rare diseases, approximately 7000 rare diseases and pemphigus and pemphigoid are two of those diseases. And, as patients we've all experienced that physicians don't know about this disease or know how to treat it. So it's important to be able to advocate and spread awareness so that more doctors can understand what it is. And then, also that our legislators and regulators understand what it is and understand what patients are going through. This will allow us to be able to pass legislation and pass regulations that are more favorable for us, allow us to have better access to therapies and treatments and again, just allow greater awareness towards the disease.

**Amethyst:** Wonderful, and in what way can the IPPF community become involved in our advocacy efforts?

**Marc:** Well, there's lots of ways to become involved. Many of you saw just recently we distributed an email and a survey regarding our awareness ambassadors. So we're actually relaunching our awareness Ambassador program. And this ties in directly to what I just mentioned as far as awareness is concerned. We really want to make sure that we put pemphigus and pemphigoid on the map, so to speak, and that more people know about these diseases. And a great way to do that is to become involved in the Ambassador program. And, within that Ambassador program, people have the opportunity to not only write letters regarding particular legislation or write to regulators about regulations, but they'll also have the opportunity to meet, of course, now virtually with their legislators and with their regulators. So, the IPPF has lots of ways where we can involve people that are interested in becoming

advocates. And we really look forward to people joining our efforts because together we will have a strong voice. Singularly, it's just one person, but together, we put all our voices together, we can have a strong voice and really make a difference.

**Amethyst:** Great. Definitely. And I think that kind of ties into our next question. Rare Across America and Rare Disease Week that normally is hosted in D.C. is hosted by RDLA, what is RDLA and how does the IPPF work with that organization or other advocacy organization?

**Becky:** RDLA, stands for Rare Disease Legislative Advocates and it's an umbrella organization where patients of many different rare diseases can come together and an advocate as part of the Every Life Foundation and RDLA. They do a lot of education and a lot of training throughout the year. I believe they also have lobbyists that work for them full-time, professional advocates that are on the Hill and working in between our meetings. But really, the importance is getting that patient's story out there. We are truly the consumers and as voters we are the legislators bosses, right? We are the Senator and Representative's bosses and it's important that our voice be heard. And working with an umbrella organization, such as our RDLA, while the IPPF community may be small, a lot of other organizations are smaller, but when you get 900 or one thousand advocates, having legislative meetings on the Hill that brings a real power, and that voice becomes very loud.

**Marc:** So just to kind of expand on what Becky is saying. So already RDLA or Every Life Foundation, they are that umbrella organization, but they represent a number of different rare diseases. And of course, as we mentioned pemphigus and pemphigoid are just two of those diseases. So we've had the opportunity to work with them, to visit Washington D.C., to understand what legislation is important for people with rare diseases. But also, as Becky said, to really be able to share our voice. And in the past the IPPF has been working with this organization, RDLA, for many years now. We've had groups of patients from the IPPF visit Washington D.C. every year, over the past few years. And again, we meet with all of these people and we are demonstrating democracy. This is what democracy is all about. Is to be able to talk to the legislators and talk to the people that represent us, and have that dialog. And I think that that's really important that we continue to do that. That we share our stories and share a voice and talk about what's important to us and build those relationships with the people that we vote for.

**Becky:** Yeah, and going back, I'm gonna add, you've just kind of sparked something with me and it's those building relationships and having those conversations, some of them are repetitive but it builds a level of trust. It allows us to add conversation, instead of calling it a rare disease, it now affects Carolyn or Fred or Marc or Hannah, or me, right? We're putting real faces and real people's lives in front of legislators and showing them how they can truly make a difference. Whether it's signing on to legislation or its co-sponsoring, or joining the Rare Disease caucus just to become more aware of issues affecting our community. It's the rare

disease community, and addressing those issues that will address health care and health related issues for the community at large. It's really about building those relationships. It's about communicating. It's not about arguing or anything. You don't go in there offensive, it's very much a respectful conversation to have, and that's how things get done. Unfortunately, in the government, it happens a little bit more slowly, sometimes, than we wish, but it's truly those relationships and conversations that are at the basis of every law and every act that gets passed.

**Marc:** I know Carolyn and Fred and even Hannah have been to the Hill a few times now. Maybe you guys could share why you think advocacy is important?

**Fred:** Without advocacy you just get ignored. I don't think anybody likes to be ignored, but especially when you have a cause such as working on behalf of pemphigus and pemphigoid. You have to let people know, and you have to let people who are empowered to make decisions know, what it is you're talking about. It is one thing about our RDLA and IPPF, they are able to use their professionalism, their strength. They've been doing this for a long time. And the IPPF is a wonderful organization, but it's a small organization. And without that boost that you get from RDLA's training and professional approach, we would never be able to do what we've been able to do. So I'm really happy with that association, with that relationship. But, advocacy in general, if you care about an issue, and there isn't anybody on this call who doesn't care about pemphigus and pemphigoid, you need to do what you can to try to make people aware and to spur further research, further treatment. Eliminating, or cutting down on the time from appearance of symptoms to diagnosis, these are all things that we talk about. But, until you bring those issues to the people who could actually do something about it on a national level, you're not going to get the attention you need.

**Carolyn:** I think the group has really shared some outstanding thoughts, in that we will only become relevant to our nation's leaders when we sit across from them and we share our stories. We tell how the disease has impacted us, and impacted our lives, and our health, our careers, our education, our finances, how deadly it is to us, and that's what they remember. Our Congressional and Senate leaders and staff are very respectful and they do listen very intently and they want to listen to patients and families. They're not as interested in lobbyists as professional communicators, or people like that, they want patients sitting in front of them and they really do care. As a person who has been there, RDLA provided outstanding training and so did the IPPF. IPPF's support while there. Sitting in front of them, it's a very professional discussion and they asked great questions. Not hard questions, but questions like what's a day in a life like for you? How has this illness affected you? What do you want me to remember? And they'll look at you, and they'll remember. I had one congressional office, I went back last year, and the young lady said, I remember you, How are you doing? And they do remember you. You're important and you're an important voice, you're an important story, and you will bring relevance far more than you will ever realize. That's been my experience so far. It's been

good, it's been positive and I've grown and learned to communicate. It's been a very good experience.

**Amethyst:** I think I could echo a little bit of what Carolyn and Marc, and Becky were all saying. RDLA especially when we've gotten in the past for a Rare Disease Week, is a very powerful organization. And when you get into that room, and you get to meet all those other rare disease patients, and family members. Each year that I've gone, it's growing and it's powerful. It makes you tear up a little bit to see all of these voices coming together, to not only represent their individual patient organizations, but the rare disease community as a whole. So, I think to echo what everyone was saying, we're powerful, we have a very powerful voice, and everyone's story truly matters. They really care about what you have to say and how your everyday life is affected. I remember one particular legislator, one of our representatives here in Colorado. I went back a year later, and I was originally there with the mother, and her young son had a rare disease, and she gave him a postcard. It was like a baseball postcard. And the next year, that baseball card with the picture of her son was still sitting on his bookshelf. And she had another one to add to this collection. And he remembered her story and the son's story. So they want to know. And I think that's very important to remember as we just discuss today's events and advocacy. So Hannah, I have a question for you. As a family member of a patient, why do you feel it's important that even a family member participate in advocacy and Rare Across America?

**Hannah:** Well, it's really important I think to show legislators and even other people in the medical community that you'll meet a rare disease week, that family members are affected by the disease as well and then it stretches into every aspect of a person's life. Like Carolyn was saying, your finances, your career, everything and your family, too and your family can be seriously affected by this. Also, as a family member, you can provide a unique perspective on the disease that's very personal, but also similar to the perspective of a caregiver and I think that's an important perspective for legislators to hear. And, in some cases, as well, maybe your family member isn't able to advocate for themselves. I have quite a few friends, as well as my sisters in the rare disease community that we call ourselves Data Advocates, because we all go and advocate for our dads, who have rare diseases. So I think it's just really important to support your family, show your family members that you support them, and to provide that extra push to legislators, and say, the patients aren't the only ones suffering here. They're not the only ones who care. We all care, too. And we need this. And when you include family members and friends, and not just the patients that expands the number of people who are being affected by rare diseases exponentially.

**Amethyst:** Right, and the number of constituents, because, ultimately, you're a vote for that person, right? So, it's not just that one patient. It's their family and their friends, who are also voting for them, and hopefully voting, for the legislation as well. Great, very great. Well, this

year, Rare Disease Week on Capitol Hill is being replaced by a virtual event called Rare Across America. And there are a lot of events that will be happening and they're all virtual which I think is great during the COVID-19 crisis that we've all been dealing with for almost a year now. So with RDLA, Rare Across America is going virtual, how will you all be participating? And why do you think it's important to also participate in this virtual event?

**Fred:** I will be participating in Rare Across America and I've registered and we'll be taking 3 to 5 meetings with legislative staffers with the New Jersey lawmakers. I think it's important for a couple of reasons. First, is to re-establish those connections and make sure those connections continue. As Becky was talking about, or maybe you Amethyst, that you build up those relationships. People remember you from year to year and if it were to be, let go for a year just because we couldn't meet face-to-face, I think that would be a real problem. This way, even though virtual is probably not as good as a face-to-face meeting, in some ways, it can be. In some ways it may even be better, you may get a little more focus, a little more attention. But it's important just to keep the ball rolling. Just to give that wheel a spin and make sure that the legislators that we talk to and those issues that we want addressed. I'm assuming that we have a few new ones to talk over this year, are heard and they're heard early. We have a new administration coming in and I think in this case, the early bird really does get the worm. If we're able to get to our new congressmen, members of Congress and Senators early on in the administration and early on in 178th Congress we're going to get more attention. There's a lot of attention being placed on the 178th Congress nowadays anyway. But as far as the real work of what goes on on Capitol Hill, the sooner we can do this, the better, and that's what I think is important.

**Marc:** I like Fred's analogy. The early bird gets the worm, right? Or you know sometimes you will hear, the squeaky wheel gets the grease right? He's absolutely right. We need to be there at the beginning of this new Congress to say hey, look at as pay attention. These are our concerns, and these are the things we need to address. I think it's important to remember, especially in light of you know where our country is right now, that we're talking about policies not politics. They're two different things. We're talking about policies that help our community and help people with our diseases. It doesn't matter what your politics are. We're talking about the rules, the regulations, and the policies that affect all of us. I wanted to make sure that I mentioned that, because I think that's really important.

**Hannah:** I would also add that right now, during this massive public health crisis, some people in the rare disease community need these regulations more than ever. With COVID-19, people haven't been able to go do in person therapies and treatments have been postponed or canceled. And we need to push all of this as much as we can right now. And also doing it virtually will be a lot more accessible for some people in the rare disease community. I mean, doing meetings on the Hill is great, and it's exciting but if you have 5 meetings in a day, and you have to dart back and forth between the Senate buildings in the House building, it's a lot of

work. And it's tiring. And for some people, it's just not doable and this is going to make it a lot more accessible for people in the rare disease community to participate.

**Becky:** Absolutely.

**Fred:** That's very true and not everybody can get to Washington either economically or physically. They may have some challenges getting to the nation's capital to take part in this. A virtual event eliminates those problems. You don't have to pay for a hotel if you're talking to someone from your living room. You don't have to be walking four miles through office building corridors to get from one meeting to another. There may be some people who are just absolutely unable to attend in person who will be able to give their voice this year because of a virtual event.

**Becky:** You kind of took the words out of my mouth Fred but I was going to add to that too that just because there's a global pandemic going on doesn't mean that any of us stop having pemphigus or pemphigoid. And with the global pandemic there have been major strides taken under emergency orders that have allowed insurances or that has had insurance's pay for things like telemedicine, that before was pretty off limits. And so it's really important as a rare disease community with areas that people are having to travel miles, hours and days to get to a doctor to be able to keep some of those advances that are under the emergency orders, that would disappear once those emergency orders go away. Like Marc said, it's about those policies, right? If it's working now and it's such a benefit and it's a true benefit to the rare communities that something that a lot of us can speak of. And Fred's right, taking down the barriers just allows more voices to come to that party to show how important it really is for people all across America.

**Amethyst:** Definitely, and I agree. Like Fred said, it's new, the early bird gets the worm. We have 66 new leaders in our congress and so those are 66 new voices that have not heard about the IPPF and all of your story. So we hope to share with those members about what we do and how they can help all of us and you guys at home. Great. Well, thank you for sharing that, guys. So in the past for Rare Disease Week, and this year virtually for Rare Across America, there are a few different events that will be going on spread out over a couple of weeks. One of them is the Rare Disease Caucus, I don't know who wants to share their experience. What is the Rare Disease caucus and the caucus briefing that will be happening, and why is it important that we patients, caregivers, and family members attend this event?

**Fred:** I was just going to say it's numbers, for one. If you're in attendance, people know you're there, and they can see you. The last couple of years when we've been to the Rare Disease Caucus meeting, the room has been absolutely jam packed. And so the members of the Rare

Disease Caucus who attend the meeting can see that it is not just a rare number or small number of people who have an interest or a story to tell. So I think that's very important.

**Marc:** I was just going to kind of explain what a caucus is, and how it works in the bodies of Congress. So, a caucus in Congress are basically a collective group of members that are interested in a particular topic. So in this case, it would be members of Congress that are interested in the rare disease community, or people that have rare diseases, and how they can learn about those diseases and create legislation to help people that have these diseases. And so this caucus is what they call a bicameral caucus. So there's members of the House, as well as members of the Senate, that are part of this caucus. And every year, actually, several times a year, they come together and discuss things that are relevant to the rare disease community. So, whether it's the member themselves, or their legislative aids, their health legislative aids, they'll come to these meetings to really learn about what's important to the rare disease community. And at that time, people from the rare disease community also present to them and really try to educate them on what is impacting all of our lives on a daily basis and what type of things need to be addressed in upcoming legislation. So that's what that caucus is and what they do. As Fred said, the caucus, briefings and the caucus meetings that we've been involved in in the past have just been jam packed. It's really great to see that many people in Congress interested in what we have to say. Because they are, they're interested in what we have to say.

**Becky:** And it's also an opportunity, too, not during the caucus, when they're having discussions but before and after, offices frequently send staffers and a lot of times it's the staffers that you talk to when you go to your meeting. Either the health legislative aide or assistant. So, it's another opportunity to make a connection and to make a contact and to keep those relationships and conversations going. And something to relate back to. So, I don't know what this year's going to be like virtually, but an in person event, it's a pretty spectacular thing to be a part of.

**Amethyst:** Great. And just to clarify for everybody that maybe has never attended, the caucus briefing is separate, then the normal hill meetings or the meetings that they'll be doing virtually with their Representatives and Congress members?

**Becky:** They're generally about an hour or an hour and a half, so it's not that you're committing a whole day to it. It's just a little snippet of the day.

**Amethyst:** Great. Jumping forward, I'm sure we'll discuss this on a future call and any training that people will hopefully be attending as they become advocates with us this year, but one of the questions or one of the Asks that we typically have for our Representatives and Senators is to join the caucus, correct?

**Marc:** Yeah, absolutely. So, you know when we meet with them virtually, we ask them if they're not already part of the caucus, to join the caucus and learn more about rare diseases and the people that we represent. If they are already in the caucus, of course we thank them for supporting us and working with us on trying to really improve the lives of the 30 million Americans that are affected by rare diseases.

**Amethyst:** And there are 66 new members who are currently not in the caucus yet, so we hope to get them on board. Great, so moving on. One of the other components of Rare Disease week is Rare Disease Day and a visit to the National Institutes of Health, the NIH. So is this a worthy event to attend? And can anyone explain their experience of what they've experienced at NIH in the past?

**Carolyn:** Well, I can if that's okay? I had a wonderful experience at NIH, and over the past few years that I've participated, I've always looked to it. I think it's one of the highlights really, of the entire experience. Because you go into NIH and you receive briefings throughout the entire day on all matters of research and policy information. You really get to see the expert's standing in front of you and senior leaders within various fields. So it is very, very informative. Also, you get various different pictures throughout the week of Rare Disease week from a legislative point of view. Communications, training, advocacy, feeling more informed about, for us, dealing with blistering disease, bullous pemphigoid and pemphigus vulgaris and pemphigus foliaceus and a few others. But then at NIH, you're learning all about research. You are learning about the dollars, where are they going? You are talking to the leaders involved with that. So you really get to see just, really the breadth and the depth. For me, it was a wonderful experience. I got to speak to a lot of people within the research field funding, various leaders. I've found it very rewarding and I look forward to it every time as well.

**Marc:** I was just going to build on what Carolyn said. I think it's a great event because as she said, you really get to hear from the experts directly. So people that you might even see on television, you're going to be interacting with these people one-on-one and up close. I have to admit the first time that I went to that event, I was a little intimidated. I mean, here are the top experts in the United States, and I'm talking with them. I'm interacting with them. So, it was definitely intimidating. But once you get in there and you start to understand that, hey, these folks are just people just like me and they just really want to hear your story and understand how they can help, whether it be in research or advocacy efforts. That's huge. I've met some of the most incredible people during these events. Doctor Collins from NIH and Steven Hahn from the FDA. So they're really excited to talk to people like us and find out how they can help. They are in positions of service. They want to find out how they can help.

**Becky:** And how truly dedicated they are to the rare disease community. It's really interesting and I guess fortifying for me as a patient to know that Dr. Collins is on my side. That he wants

to know exactly how he can help and that our voice matters. And that's why it's important that we show up so we can have that voice.

**Amethyst** I think, speaking of intimidating, I know that one of the first times I did these events I was very intimidated as well, but one thing I think Becky told me is, remember, all of these people put their pants on the same way that you do every morning. They are people just like you and me, and I think that kind of helped me relax a little bit. It's true, they have families just like us, their mothers or sons or daughters just like you and me. It helped me feel a little more at ease. So, does anyone else have any good advice for somebody that might feel after hearing about all of this, wow, this is really intimidating. I don't know if I could do this. Any advice to encourage them and let them know it's really not as scary as you think it is?

**Carolyn:** It's really getting past yourself a little bit. Because I found the people at our nation's capitol, the staffers, those in Congress, those in the Senate, really were very friendly and very respectful. I was never drawn into any kind of political situation, no one ever asked me about that. It's always, tell me about you, tell me about your experience, what do you want me to remember? What is your ask? With RDLA you will get that coaching. And it's really, very simple. And also with IPPF you get that coaching. You're with the IPPF team, and we were checking, and we'll probably be checking in by phone more this time, but you're not alone. I found you might need to get past your own self, past judgement. Be yourself. And you know what, I was intimidated, but very quickly I had a whole bunch of friends around me. I met a whole bunch of friends. I learned a lot of things. I think I flubbed up a whole lot my first time but people were very gracious and very kind. I was never pushed or encountered anything. I walked away learning a lot. I was very grateful I could share with people, and also a certain amount of my own self respect, I could walk away and know that people know about me. You don't have to be afraid, it's okay.

**Fred:** Yeah, the only thing that I would add to that, or just kind of expand on is the best solution for intimidation, if you're feeling intimidated is preparation. And you are going to get first class preparation from RDLA and from the IPPF. You're going to be able to ask questions. You're going to be able to practice meetings in a non threatening environment. So, by the time you actually walk in the door of your Representatives office you'll be ready. It'll set you back a little bit but you'll be ready, You'll know what you need to do, you're going to be prepared. It really becomes a much less scary prospect than if you just took a trip to Washington and decided to stop in and see your Senator. You get a lot of back up.

**Marc:** Doing it virtually is probably not as scary as doing it in person.

**Becky:** I think that everybody went into public service because they have a sincerity that they really want to help and make a difference. And a lot of our stories really point to the areas where they can make a difference. You find very relatable points very quickly when you say that I have a rare disease. Nine out of ten times that I've been in a congressional office, somebody in that office has a family member that also has a rare disease. And that's an instant connection. It's an instant point that they can follow up on it. Like, hey, I saw the rare disease team going like, what did they want? What are they advocating for? So you can spread the message with them and reinforce in those offices too and really know that you're making an impact just by being there.

**Amethyst:** Definitely and I know we're kinda talking a little bit about prepping and sharing your story. What are the preparations that we will be having this year virtually? What does that look like? Will the IPPF have a separate meeting? Does RDLA have a prep session?

**Becky:** There are some prep special sessions. One that is extraordinarily helpful I've found in the past is "Practicing your Pitch" that is put on by RDLA. It's kind of the playbook of put your story together. If you're interested, they'll send you different prep sessions. And they'll go over some common legislative asks. But also the IPPF, Marc, I think you are planning to have some IPPFs prep sessions as well for anybody from our community that would be interested to discuss how specific asks relate to our community specifically, correct?

**Marc:** Yeah. So once you've signed up for Rare Across America, which of course we encourage everybody to do. And I think Amethyst is going to give you some information on that before we leave today. We will schedule a meeting to talk about what we are going to ask for. What type of legislative things are on the IPPF agenda and what are you going to ask for? So, we'll have a meeting that really talks about that, and we'll be able to discuss that. As Becky said, it's about practicing that pitch, practice, practice, practice. A lot of times you'll hear us call it, the elevator speech, right? Because sometimes you don't have a lot of time because there's many advocates that are sharing their story. So you have to be able to take your story, kind of condense it in the time that you would be in that elevator and have that speech prepared and pitch it, but also include whatever it is that you really want, what you're asking them for. So one of the things that I anticipate us, without getting too far into the weeds here this year, but would be talking about step therapy. Step therapy is where you are forced by your insurance company to try certain medications before you're allowed to try medications that may work better and be more effective. And that's a problem, not only for our community, but for lots of people with rare diseases. So we'll certainly be talking about step therapy this year, and until we can get some good legislation that prevents the insurance companies from doing something like that. So that's just an example of one thing that we will probably be asking congressional members for this year. And we will have a meeting to kind of practice all that and make sure that you feel comfortable talking to those people about this issue.

**Amethyst:** Great. Thank you, and I'm sure we'll discuss this during the prep session. But I think it's important to kind of note that obviously being virtual things might be a little bit different, but typically in an in person meeting, can somebody give like a quick overview? What happens in those rooms behind those doors? What are you saying? How long do you have? What's happening?

**Fred:** You don't have a lot of time. I was lucky the first year I participated, my first meeting, there was just me and one other person. So, we actually had eight minutes each, I think to present our stories, which is a long time in this type of setting. Normally there will be more people and you go around the table or go around the zoom boxes and everybody gets to tell a little bit of their story, very briefly, what your personal story is, and then present what you would like to see happen. Whether it's increases in funding or avoiding decreases in funding for NIH or FDA, whatever it happens to be. Or specific legislation or specific asks, like, please, would you consider joining the Rare Disease Caucus? You just kind of line those up, but those go person to person to person until everybody has had a chance to speak. If you have 10 people in the room, you don't have a lot of time to do that, and that's why the preparation that Marc emphasized is so important. So that you can get in there and within the space of 90 seconds sometimes you can get your entire story told. The meetings themselves can be a little crowded but they're always pretty well organized. You always find that whoever you're meeting with, whether it's a Representative or Senator, which doesn't happen very often, or a staff person, which is what's going to happen most often, you will find that they are interested. That they are knowledgeable, which is a good thing to see. So, it's a very, very productive type of atmosphere. I liked doing it.

**Hannah:** I think an important thing to note is that you and the other advocates that are going into the meeting are really in charge of the structure of how the meeting goes. And the best way to do that, we always follow the same plan because we always go in together, since we live in the same place and have all the same representatives. You go in, thank them for meeting with you, you do your introductions and tell your stories, and then that's when you go into your asks. And it's really important to, to do some research on your Representatives that you'll be meeting with before you go into your meetings, so that you can adjust your asks accordingly. So it's important to know are they already on the Rare Disease Caucus? If they are, I will thank them instead of asking them to join it. Because if I ask them to join it when they're already on the caucus, I will seem like I don't know what I'm talking about.

**Marc:** And you waste your time

**Hannah:** Yes, and you waste your time. energy wasted time. Then, once you've done all of your asks, you make sure to thank them again. If you have any kind of token that you're leaving with them, like the orange sunglasses or leave behind sheets that have information with all of your legislative asks on them you hand those over. If you want to take a photo, you ask to take

a photo and then you shake hands and you're on your way. It's all very easy, once you've got a system down.

**Becky:** And one thing that I was very afraid of, and I thought I would pass out, is if they asked me a question that I didn't know the answer to. And this is a perfect time to say, I don't know but I will get you the answer. And it's important that you make a note of that, and take it back to RDLA. They're going to give you a thousand contacts to be able to contact them on the day of. And it's really important, that one, you let our RDLA know so they can follow up and answer that question appropriately. Or send you the answer. But two, to get the contact information of the person that you're talking to, because they have literally handed you an opportunity to talk about the issue that's important to you, again. And so, to be able to say, hey, I followed up and I got the answer. Or I let somebody know and they will be contacting you and this is their contact information at RDLA. They literally handed you the opportunity to discuss it again. Now you have their contact information and when you're feeling gutsy a couple of weeks later contact them and say, I just wanted to follow up with you to make sure that RDLA Followed up with you. Did you have any other questions or concerns? Is the member considering joining the caucus or supporting the ask? And again, that's how those relationships are built and you're also helping to hold them accountable and to know how important it is for us.

**Amethyst:** Definitely. I think that's one thing that I've learned through the years is that the follow-up is very important. For in person meetings, they always hand you their business card. So you've got it right there with their email and you take that home and keep that somewhere safe and stay connected with those people. It wasn't just that one meeting that one day that one year, it's building those relationships and following up every few months. And sometimes it becomes a personal relationship where you start asking them how is it in, say, Southern Colorado where I live? Because I know that's where you from, or I know Becky sometimes she talks sports with her staffers. And they become friendly with one another.

**Becky:** A great question to ask is did you go to school in whatever state you live? If they happen to go to the same school as you, that's the best. If they go to a rival school like the big rivalry school in your state, that's second best. Whenever my university plays this one in particular, it's been four years now, but we always send emails back and forth. And, that leads me to say something else. When I first went to my Senator's office, she was actually the person in charge of the mail in the office. And now, she's one of the legislative aids, So, they move very quickly. In the course of the 4 or 5 years that I've been doing this, she has moved up quite high. And they also move offices. So it also provides a good in. She might not be working for my Senator anymore. She might be working for somebody else. And I can take that connection and then make a new connection as well. So again, those relationships prove again every bit and that's important.

**Amethyst** Wonderful. This question is geared towards Becky and Marc, since the pandemic have either of you participated in any other sort of virtual, legislative or advocacy meetings? And what was your experience with that?

**Marc:** Go ahead, Becky, I'll let you share.

**Becky:** So, it's essentially everything that it was in the in person meetings, it's just happening in squares like the Brady Bunch now. We're still having the opportunity to meet with people and to make those connections. A lot of the same faces are in those meetings, some of them have changed, that's to be expected, but we're still able to make those connections and tell our stories. They still ask the scary questions that you may or may not know the answer to, and I still tell them, but I will follow up with them. To me, it's been nice because you can be business on the top. For me, it happened in the summer, so I was business on the top, shorts on the bottom. So I was a little bit more comfortable than I would be in heels and dress clothes tracking across the hill. I sat at my desk and had my meetings, and I would get up and have lunch, and then come back for another meeting. But I think we were as equally as effective in person, as we are virtually, and probably had more people attend my last event, being a virtual event.

**Marc:** Yeah, I agree. So Becky and I both participated in an advocacy event on the Hill with the American Academy of Dermatology last fall. Just as she said, it was just as effective, if not more effective, doing it virtually. The IPPF generally participates in these types of events usually, three times a year. Rare Across America will be one opportunity, there will also probably be another opportunity in July, where, hopefully, we can participate in person, but, if not virtually. And then again in the fall. So, generally three times a year, the IPPF is talking to legislators and developing those relationships and working on really trying to make a difference for everyone in our community.

**Becky:** And the important thing, too, and I don't think we've said it, is there may be an opportunity when you don't get a chance to share your story. But just showing up and the sheer power of numbers that are attending those virtual meetings or in person meetings, is very important. So, don't get discouraged. We encourage you to be one of the ones to share your stories, but sometimes that's not always possible. And that's okay, because you're still showing up and being there.

**Amethyst:** I have two more questions, and then we will wrap this up. So, Marc or Becky, if someone's interested in participating in and other advocacy events with the IPPF, how can they become involved or stay informed about their opportunities?

**Marc:** Well, as the new Advocacy and Research Coordinator, they can certainly reach out to me directly at [marc@pemphigus.org](mailto:marc@pemphigus.org) and then I can get people plugged into whatever those opportunities are. As I mentioned, we have three events this coming year that we will be participating in, either virtually or in person. And then there's also other opportunities where you might have a chance to write your Senator or write your House Member, a letter sharing your story and explaining if there's a piece of legislation or regulation, that you want to make sure that they pay attention to or make a comment on. So, we'll have opportunities throughout the year where you can reach out to reach out to your representatives and really try to make a difference, not only for yourself, but for everybody in the community.

**Becky:** If you're a little hesitant of joining in a live event like this, the other option is on our website we have the advocacy tab, and you'll see the letters that the IPPF has signed on to. The advocacy letters with either other organizations or umbrella organizations. And you can research those. We all have local Congressional offices, yes, they have offices in Washington DC, but they also have those local offices. So whether you decide to send an e-mail or write an old-fashioned hand-written letter, which is very impactful on Capitol Hill because now you're standing up you're doing something different or you make a phone call or even stop by the office, depending on what their policies are related to COVID, those are all great ways to make an impact as well.

**Marc:** These are the things that most influence representatives, when they get ready to vote. Believe it or not, these things really influence how they decide what they're going to vote on.

**Amethyst:** I think one of the most important questions for today is, if anyone on the call wants to join us in our efforts for Rare Across America, how do they sign up? And is there a deadline to sign up?

**Marc:** Yes, there is a deadline. The deadline is actually the 22nd of January. And to sign up, you can go to the RDLA website and look for the registration for Rare Across America. And the website for that is [rareadvocates.org](http://rareadvocates.org), all one word. And you can sign up there. The IPPF will be putting out information via E blast, as well as on social media. Do we have that on our website, Becky, I can't remember.

**Becky:** I don't know but I did see Patrick, our Communications Director send out an E-blast and I've seen it on social media.

**Marc:** Or you can just reach out to me, [marc@pemphigus.org](mailto:marc@pemphigus.org) and I will point you in the right direction. I'm always happy to help, and we need your help. We, we want you to hear your voice to be heard. The more of us that can join in and participate in this important activity, the

better. So please join us. I know, obviously, there's all of us on the call today, all of our speakers will be participating, but we want you. We want you to join us.

**Amethyst:** Great. And just to reiterate the deadline is the 22nd.

**Marc:** January 22nd to sign up, and then all the events will occur, the last two weeks of February, culminating in Rare Disease Day, which is the last day of February.

**Amethyst:** Wonderful. Well, thank you, everyone, for joining us, that was a very quick hour and thank you for all you guys for being on the call. I'd also like to give a huge thank you to our sponsors, Genentech, Principia Biopharma a Sanofi Company, argenx and Cabaletta Bio for making today's call possible. Before we go, I just want to do a quick poll, and then I have a few announcements as well. I'm after hearing today's call, are you the audience interested in participating in Rare Across America 2021 or any of our other advocacy efforts? We hope that you are. If you will take a quick second to answer that and as you're doing that, as a reminder the deadline for sign-up is January 22nd, which is next Friday. And to emphasize what Marc said, you can visit [www.rareadvocates.org/rareacrossamerica/](http://www.rareadvocates.org/rareacrossamerica/) that's how you can sign up. And based on our poll here, it looks like a lot of you are truly interested, so we hope that you guys will go online and register. You can make a note that you are associated with the IPPF, and we will connect with you guys for further training, and we will also see you during our meetings. Very exciting stuff!

**Amethyst:** Also, if you interested in helping accelerate research the IPPF is participating in GlobalSkin's Global Research on the Impact of Dermatological Diseases project, the Phase 3 – Patient Data Verification Delphi (the Delphi). GlobalSkin is calling on adult dermatology patients representing all disease conditions to participate in the study. By participating in, you will be helping to design a new and credible measurement tool (questionnaire) that fully explains the impacts and challenges that people living with dermatological conditions experience. Studies like this are a great way to help advance medicine and treatment for pemphigus and pemphigoid patients. If you are interested in participating in the survey, please contact me, at [amethyst@pemphiugs.org](mailto:amethyst@pemphiugs.org) and I will send you the link to participate in the study.

The IPPF has been looking towards the future and how we can continue to help you and our community. We need your help to grow our community of Healing Heroes. Healing Heroes fund the future of the IPPF community by making sustaining, monthly gifts to support our mission of improving the quality of life for all those affected by pemphigus and pemphigoid. No amount is too small, even a \$5 or \$10 monthly, which for me is a Starbucks or 2 a month, goes a long way. We truly are a small organization and even a \$5 donation makes a huge impact for us and our community and continues to allow us to provide for the greater good of our community.

If you have not registered for the IPPF's natural history study we encourage you to do so. The IPPF Natural History study is a patient registry sponsored by the National Organization for Rare Disorders (NORD) and the US Food and Drug Administration (FDA). You can register today at [www.pemphigus.iamrare.org](http://www.pemphigus.iamrare.org). This online data system collects, stores, and retrieves patient data for analysis in research studies. The more data we can collect, the better the information we can give to researchers, the sooner they can find better treatments, earlier diagnosis, and one day – A CURE!

Our next Patient Education Webinar will be in February with our IPPF Peer Health Coaches to discuss your questions about living and managing your disease. This is a great opportunity to get tips and tricks from our coaches from anything from bandage and wound care to their experiences with medications.

Lastly, If you have a question that didn't get answered on the call, or have additional questions please email Becky Strong, at [becky@pemphigus.org](mailto:becky@pemphigus.org), or call (916) 922-1298 x:105, and we would be more than happy to help. This call recording will be sent out with the survey following this call so please take the opportunity to let us know if you enjoyed the webinar. Thank you so much for joining us, and we hope that we will see you for Rare Across America 2021. Have a great night thank you so much.