Prioritizing the Role of People with Lived Experience in Epilepsy Research
A CURE Epilepsy Webinar
(Transcript)

Brandon Laughlin: Welcome everyone to today's webinar. I am Brandon Laughlin from CURE Epilepsy. Last year, CURE Epilepsy celebrated 25 years of funding groundbreaking research. Since our founding in 1998, we have raised millions of dollars to fund epilepsy research projects that support our mission, which is to find a cure for epilepsy by promoting and funding patient-focused research. CURE Epilepsy provides grants that support novel research projects and advance the search for cures and more effective treatments.

We are excited to bring you today our first webinar, part of the 2024 CURE Epilepsy webinar series, where we highlight some of the critical research that is being done on epilepsy.

Today's webinar is entitled: Prioritizing the Role of People with Lived Experience in Epilepsy Research. A very important topic to our organization that is actually ingrained in our mission. The role of people with epilepsy and their support system and research has been evolving over the past couple of decades as research and the corresponding care and treatment of epilepsy become more patient-centric. Involvement of people with lived experience early in the research process helps ensure that healthcare professionals treat epilepsy in a more holistic manner; not only by alleviating the impact of seizures and their debilitating side effects, but also by recognizing that everyone's epilepsy journey is unique.

In this webinar, attendees will learn specifically about the importance and impact of people with lived experience in the research of post-traumatic epilepsy. Attendees will hear about the Congressionally-Directed Medical Research Programs or CDMRP, a congressional appropriation that fills research gaps by funding high-impact, high-risk, and high-gain projects that other agencies may not fund. As well as, you'll learn about the CDMRP's commitment to community engagement. Additionally, people with lived experience, who are deeply involved in the CURE Epilepsy mission, will share their unique experiences in helping move PTE research forward.

Today's webinar, like all of our webinars, is being recorded for later viewing on the CURE Epilepsy website. You can also download transcripts of all of our webinars for reading.

This webinar is presented by Dr. Melissa Miller, a health sciences program manager with the U.S. Department of Defense. Dr. Miller is a biomedical science administrator with an innate sense of urgency to support research that accelerates clinical application of disease interventions. She oversees the Epilepsy Research Program within the CDMRP, and engages stakeholders across different research domains to identify and fund projects with real promise to improve the quality of life for those impacted by epilepsy.

Dr. Miller will also be joined today by two members of the CURE Epilepsy community who have been influential in their roles in helping provide their perspective in helping guide CURE Epilepsy-funded research in post-traumatic epilepsy. And they will be introducing themselves following Dr. Miller's presentation.

Before Dr. Miller begins, I'd like to encourage all attendees to ask their questions during the Q&A portion of the webinar. Keep in mind, you can submit your questions anytime during the presentation by just typing them in the Q&A tab, and our Chief Scientific Officer, Dr. Laura Lubbers, will try to get through as many as possible in the time that we have. Now let's turn it over to Dr. Miller.

Dr. Melissa Miller: Service members and veterans and the American public, meaning that the populations we aim to impact is incredibly broad and not restricted to just military or veteran populations. We're looking to serve the entire American public. So additionally, CDMRP funds research from around the world, meaning that we fund impactful research regardless of where the work is being done.

And just an administrative note, I've included throughout this presentation QR codes to maybe make accessing the URLs on these slides hopefully a little bit easier. All right, let's go to the next slide, please.

So the epilepsy research program is, as I said, one of more than 30 CDMRP managed programs, and it was established in fiscal year 2015. So we're approaching about 10 years of impact, just under. The program aims to develop an understanding of the magnitude of post-traumatic epilepsy within the military, and to expand research into the basic mechanisms by which traumatic brain injury produces epilepsy.

So it's important to recognize that although we are named the Epilepsy Research Program, our primary focus is specifically on epilepsy that occurs following a traumatic brain injury. The program's vision is a time when post-traumatic epilepsy can be prevented or optimally managed. And the way we will get there is through our mission to understand the mechanisms of post-traumatic epilepsy and associated comorbidities. And this is to improve quality of life, especially in service members, veterans, and caregivers. Next slide.

The ERP supports research that investigates topics to help us identify the mechanisms by which brain injury produces epilepsy. We also support studies into the prevention of post-traumatic epilepsy and concomitant comorbidities, such as psychiatric disorders, cognitive and physical deficits, sleep disorders, and fatigue, just to name a few. We also support research that develops innovative research tools or biomarkers to better detect, diagnose, or predict the development of post-traumatic epilepsy.

The program also holds broader strategic goals to impact the field, like increasing research capacity, by supporting early career investigators, or investigators new to the post-traumatic epilepsy field.

We also offer opportunities that encourage research collaboration in an attempt to improve communication and build bridges across research silos. We also aim to build upon successful research within the post-traumatic epilepsy field, but we also try to capitalize on success from outside of the PTE field as well, so that we may apply them to post-traumatic epilepsy. And in this way, we leverage impactful research synergizing our investment, and we don't have to remake the wheel.

So for your awareness, I've also included a breakdown of the program's investment on the right side of this slide, showing that the majority of our investment is really focused on identifying the markers and mechanisms of post-traumatic epilepsy development. Next slide.

An excellent place to learn more about the ERP program and the research we fund is through our page within the CDMRP website. And there, you'll find helpful resources. And if you could click, we don't need to do the URL, just click the... Yep, perfect. So we have resources that highlight our research outcomes. Next.

We also have things like our program book, which summarizes the program's history, current strategic goals and research outcomes. And then finally, we have products that highlight upcoming funding opportunities. Next slide.

So, so far I've spoken a lot about what we do at CDMRP, and specifically within the Epilepsy Research Program. So now, let's switch to do a bit of a deeper dive, to see how investment strategies are set and applications recommended for funding. So this is a snapshot of the milestones within the ERP's annual program cycle, which looks very similar to other CDMRP programs.

Every cycle begins with a vision setting or stakeholders meeting, where experts in the field, including people with lived experience, come together to share information about post-traumatic epilepsy and the research landscape, and develop an investment strategy for the current year. It's at this meeting that research priorities are set and funding mechanisms are selected, taking into consideration the current needs of the field and the priorities of the lived experience community. Next, applications are solicited and then reviewed through our two-tier review process. At peer review, applications will be evaluated based upon criteria like research strategy and feasibility, but will also assess the application's potential impact on both the research field, but also, its potential to impact patient care and outcomes.

So programmatic review, our final step, we'll then take those scientifically sound applications and make funding recommendations by ranking applications based not only on their scientific merit, but also on other programmatic criteria, again, like their potential impact.

I'm walking you through the major milestones of our program cycle because at each of these stages, whether it be planning, strategy, or review, scientists, clinicians, and people with lived experience, are working together to make decisions and review applications. Next slide.

Involvement of consumers and people with lived experience is a hallmark of CDMRP's processes. And these key stakeholders serve as full voting members on all CDMRP peer and programmatic review panels, helping to ensure that our programs are addressing the current needs of the community through the research that we solicit and ultimately fund. Additionally, more and more CDMRP programs are seeing consumers and people with lived experience participating on research teams. In fact, next slide, please.

The ERP is one of those programs that's now encouraging the involvement of people with lived PTE experience as part of the research team to provide consultation and guidance throughout the planning and execution of our funded research. Our goal for this requirement was not for another box for applicants to check or a hoop to jump through, but as a means to maximize the impact and translatability of the research that we fund.

The entire mission of the ERP is to improve quality of life of people living with PTE, and we believe that through equitable partnerships among the research and lived experience communities, we can most effectively accomplish that mission.

So what are the current expectations for community engagement for applications to the ERP program? Well, our program announcements now include an entire section dedicated to community engagement expectations, so that anyone interested in applying for ERP funding is provided a detailed description of our expectations as it relates to partnership with the lived experience community. We outline these expectations in an attempt to maximize equitable collaboration and minimize tokenistic engagement. It's in this session that research teams [inaudible 00:12:00] that establishes and utilizes equitable collaborations with PTE community members. And we then provide examples of established collaborative research approach methods for implementing them. Key features of these approaches include the recognition of the strengths of each partner and understanding. Each research team will look at problems from their own equally important perspective.

It's also expected that community partners will be engaged throughout the entire project, which may include needs assessment, planning, grant writing, intervention design, and implementation. And then finally, equitable collaborations are hallmarked by joint interpretation and dissemination of research results, to ensure that the populations most impacted by the research can access and understand that research. Our program announcements also provide literature references to learn more about collaborative research approaches that for those who may want to expand their understanding in this area. And we understand that partnership between the research and lived experience communities may be new to many people. So we try to provide as many resources as we can, to be transparent as possible with this new encouragement. Next slide.

So I could speak on this topic for hours, but allow me instead to hit on what I believe to be the top four best practices for community engagement from this specific funder's perspective.

So first, community engagement is not something that is done once and you're done. Research teams should consider and address all elements of their collaborative research statement during the planning and execution of the research project. And community partners should be engaged early and often.

Second, when writing a collaborative research statement, teams should be specific. Reviewers respond very positively to actual examples rather than general statements. And this will help to build shared understanding of the roles of each partner within the research project.

The third point focuses on training, asking specifically if training will be provided, and who will be trained, and how will that training benefit the project? This training can be related to the scientific topic under investigation, so science focused, but it can also relate to implementation of collaborative research approaches, multi stakeholder decision-making, and equitable participation just to name a few topics; all of which can add to a more rich engagement experience across the team.

And finally, remember that community partners can provide a diversity of input on research projects, and that engagement can take many forms. Attendance at a monthly or quarterly lab meeting is only one form of engagement, and you may find that the research project could benefit from other or additional forms of engagement. Next slide.

So to avoid tokenism, we need to have people with lived experience involved in all aspects of the research and development process, and have them engaged in a meaningful and impactful way. So even if you, as a person touched by PTE, don't have a science background, your input and perspective for developing healthcare solutions for the community is important, and special, and rare, making it incredibly valuable. So come help us set investment priorities. If you're equipped for it, submit a proposal. We have amazing researchers out there who just so happen to have PTE. But if you're not equipped to submit a proposal on your own, consult on a project, review grant applications to help us determine which projects would be most impactful to the PTE community. Or of course, if you're one of those with a pioneering spirit, you can volunteer to participate in a research project. There are so many ways to get involved in the research process, and the more voices we have, the more impactful our research outcomes can be. Next slide.

So if you take nothing else away from this presentation today, I hope that you can appreciate how integral those with lived experience are to the entire CDMRP process. And if you want to learn more about the folks who have served as peer or programmatic reviewers, or those who are consulting on research projects, the CDMRP website has a number of highlights that tell their stories. Next slide.

Great. So I want to finish by noting that you will have the opportunity in this session to hear from a few people who are part of the PTE lived experience community, and are participating in the PTE research field as reviewers, strategists, and consultants. They are living my earlier call to action, and I really hope that they inspire you as much as they inspire me. And with that, I'll end. Thank you very much for your time and attention.

Dr. Laura Lubbers: Thank you so much, Melissa. That was a terrific overview, and I know that people may have questions about different dimensions of that, and I welcome people to submit your questions in the Q&A tab; but I really want to introduce Jack Somers a retired captain in the United States, Marine Corps who served our country in Afghanistan. Jack serves on the steering committee of CURE Epilepsy's latest research project on post-traumatic epilepsy, which is funded by the ERP. So Jack, I welcome you, and would love to have you tell us more about your journey with epilepsy.

Jack Somers: Yeah. Well first off, thank you for having me. It's really an honor and privilege. And Melissa, that was just incredible. Even being a part of this and an advisor, and learning from so many brilliant doctors and research folks on this grant and project, it is just so cool to kind of hear the back end from you. So thank you for all that information. I hope people are inspired to even jump on board and do, maybe follow in the footsteps that I've been so blessed to be a part of.

Yeah. So a little bit of background. I was as a captain in the Marine Corps, and in 2010 I was in Afghanistan on a combat deployment. I came back, and actually ran the Turkey Trot on Thanksgiving. Crossed the finish line and just totally blacked out. I had some folks who were apparently asking me questions about my deployment. I didn't know what they were talking about, really had no idea what was happening. Ended up walking away, and kind of found my way back to my parents' house. Started recognizing a house here, a street there. And that was my first experience with having a seizure.

And over the next 10 years, I started having more and more seizures. They turned out to be absent seizures. Then I started having drop seizures and grand mal seizures as well. And during that time it was really interesting, because I didn't think of seizures as a long-term, having a long-term impact. I thought of them as really isolated events. I wanted to keep them isolated in my mind. Maybe that was a bit of pride, a bit of stubbornness. In my mind, I kind of wanted to stay Captain Jack, and I liked that. And so, I tried out a lot of different jobs and was fortunate enough to be fairly successful, I hope to say.

And from doing whether it was a fitness boot camp instructor, to getting into acting, and jumping in on Captain America too, and Teenage Mutant Ninja Turtles, and trying fun things to being involved in a startup, and helping service members relocate from base to base and going through the PCS process. But through this time, I kept experiencing more and more seizures, and each time it got a little bit more frustrating. And I fast-forward to probably 2017. I really had never heard of post-traumatic epilepsy. I wasn't aware that I had a traumatic brain injury. I just thought that it was generalized seizure disorder. And as they progressed and got more frequent and got more severe, I knew something was different. I knew that the seizures were impacting me cognitively. My memory was getting a little, it was not as good as it was before, and things were just changing for me. But I didn't quite know why this was happening.

My doctors were changing my medications, they were increasing my medications. Maybe some of you folks out there, if you have epilepsy, or if you have a loved one, you are probably, or you've seen the medication issues where you get more medication, or you change medications, sometimes you're on multiple medications, and that's a challenge. And I started to experience that challenge. And as time went on, from 2017 to 2020, I began to experience more memory issues, more cognitive functioning issues, executive functioning issues. And I started to create a lot of life hacks to counter those issues. I started making my mornings as simple as possible. Minimize the decision-making processes, make them have my shoes here, workout, same workouts every morning. Eat the same granola bar, do everything I could so that when I needed to make a decision later in the afternoon, I had as much decision making bandwidth as possible. And by 2021, '22, I had so many hacks that my life was difficult to manage. There wasn't a whole lot of, I couldn't react to many things, because everything was a hack. And I started to also experience back to back seizures.

And so, it was getting kind of difficult to manage. And at that time, in fact, CURE Epilepsy, through Brandon, and thank you once again, Brandon and I connected and CURE Epilepsy came into my life. And I was very hesitant to actually kind of come forward and say that the effects of my epilepsy had been, really started to challenge my personal and professional lives. It was affecting some of my relationships. My behaviors were starting to really change. Memory was becoming an issue. And through Brandon, and then through one of the former research director Lauren Harte-Hargrove, they offered this opportunity to join this research project, which is the PTE astrocyte biomarker initiative.

And this project, which looks at from a TBI to then that first seizure, which PTE, it looks to identify how can we stop that first seizure? What can we find that we say, "All right, that TBI, there's certain things that it presents." That we can then say, "All right, this person is likely to have a seizure."

And so, we can go in and we can provide some type of intervention to prevent, or hopefully prevent, that person from having that first seizure. Because that's the big one. If we can prevent a person from having that first seizure, then the second seizure is likely not to happen. And if that happens, if there's no second seizure, then there's no third, fourth, fifth. But it's that first seizure that we really want to stop. And I'm a good case, take it or leave it. But how that first one was not stopped, and now 30, 40, 50, 60 seizures later, or more, it's because we just couldn't quite stop that first one.

And this beautiful research study, with folks all over the world who are involved and I'm so grateful, so blessed, so honored to be a part of this, are completely committed, dedicated to solving this problem. Which is, you had a TBI, all right, the story's not over. Now, here's the problem that we can solve is, let's stop that first seizure. And that's what this research project is all about, and it's a total honor to be a part of it.

So that's a little bit of me, and yeah, thanks for having me, once again.

Dr. Laura Lubbers: Thank you so much, Jack, for sharing your story, how epilepsy has impacted your life. I know that's not easy to share, but thank you for doing that. And thank you for sharing your enthusiasm and your engagement with this project. And we'll come back to you with some more questions in a bit.

But next, I'd like to introduce Patty Horan, who is a long time supporter of CURE Epilepsy. She currently serves as a lived experience reviewer for the CDMRP epilepsy research program. Patty's husband, Pat, suffered a traumatic brain injury in 2007. It was also military connected. And he overcame his grave diagnosis and the devastating consequences of post-traumatic epilepsy, and is now nearly 10 years seizure free.

Patty, can you tell us about the journey you and Pat have had with epilepsy over the last decade and a half?

Patty Horan: Hello, Laura, Jack, Melissa, and everybody out there, thank you for having me. And yes, we've been on quite a long journey. Pat was injured in 2007, and so that's almost, what, 17 years I think, since he was injured in combat. So Pat served out of Fort Lewis in 2006, 2007. He was a platoon leader, also a captain like Jack, and he sustained a gunshot wound to the head on a night mission that summer. So Pat was actually very lucky that evening, because he was the only one injured in the incident, and they were able to medevac him straight to field hospital, within an hour he was in surgery.

He spent about 24 hours at that field hospital, and was then medevaced to Bethesda Naval. So it was about 72 hours. So getting shot in the head, not lucky at all, but everything lined up for Pat's survival is pretty amazing. So when he got to Bethesda Naval, I also flew out of Washington state to meet him. It was the longest probably flight of my life, wondering what I was going to find on the other side on the East coast. When I got there, Pat was gravely injured, and oddly, I mean, this is a weird thing to think about, but I was just like, "Please let his face be okay." It's odd when you think someone's shot in the head, you don't know what they're going to appear. But he actually had a temporal lobe injury, and it just went, a big gaping hole on the side of his head that was open.

So in the beginning, epilepsy was a word I heard very often, and it was a word that was extremely frightening to me because it would end his life. He was in intensive care, I would say really for six weeks. It was three weeks, in surgical wing for three weeks, but he was intensive care for six weeks. And the doctors kept reminding me, with every visit every morning, "If he has a seizure event at this early stage of his injury, he most likely will die." They were treating him with, I think, Keppra prophylactically in the beginning.

So as Jack had this experience, it did not happen in the early stages, thankfully. And a lot of service members have this as well, where there's this latent period, and this is also where a lot of our research is focused. So we moved on to rehab, we went to Rehab Institute of Chicago, which is fabulous, one of the best places in the world for brain rehab. We were there many months. And it was around Thanksgiving, I remember, a couple of days before, Pat got a flu shot. They were worried about him traveling back to the East coast for some surgery and we got a flu shot. And that evening, he had grand mal rolling seizures about four months post injury.

So you can see that latent period, that opportunity, four months, how can we intervene? And this is a lot of our research is focused again. And so Pat was rushed to Northwestern, which was right around the corner, and he was put on a drip to control the seizure. They wouldn't stop. They were rolling, rolling, rolling. And I think they had taken him off the medication to see how he would do, and he did not do well. I'm not sure exactly when the cover was removed, but they brought it back on after that.

He then, I mean, that kind of what I say was the beginning of the period to tame the beast. It's once they start, like Jack said, they don't really stop until you can find this perfect cocktail. And for a lot of service members, I think it's a big number. I think it's around 30% that do not get control over their seizures or epilepsy, even with any sort of drug cocktail.

So we spent two years trying to figure out what that special mix, the magic, the magic pills that would control Pat's seizures. So during these two years, it was such a crucial period for brain recovery. So he was having seizures, and there was postictal states, and hospitalizations, and cognitive regression, and all these heavy drugs on his brain. So I really do think it impacted his ability to recover. If he hadn't had epilepsy, I often wonder, I think he might've had much better recovery from his brain injury, even though his recovery is remarkable.

In 2009, we actually got a call from Susan Axelrod, because we had gotten care in Chicago, and she was desperately looking for service members that would share their story about epilepsy. Because she knew they were coming home with this awful diagnosis, and she wanted people to talk about it, help raise funds, and get awareness out there.

So we joined Cure pretty early, like in 2009. We've been great friends and supporters ever since. And overall, Pat today is doing well, as Laura said, but as she knows too, we are really fighting for quality of life every day. And this medicine, we switched to Briviact a couple of years ago, but it's the same lines of Keppra. And for these guys that have combat experience and they're suffering with PTE, that Keppra and Briviact really aren't great drugs. They cause rage, irritation, aggravation, and the quality of life is really affected. So this past month we tried to get off of Keppra, well actually Briviact, and literally 48 hours, Pat totally on Vimpat, a new drug, which also had its own slew of issues. He had a seizure after being seizure free for probably like eight or two weeks. So it's shocking to me how sensitive his brain is.

It's a great reminder too, of how we really need to stay vigilant. But we're still out here fighting for the best life that we can have within this disease. And I'm happy to be part of the research too, because it helps me feel like I'm contributing, and I'm also doing something in a situation that feels sometimes so out of control. So thank you for having me.

Dr. Laura Lubbers: Yes. Thank you so much for sharing that. You can hear the over time, the struggles, they come, they go, but it's always a challenge. And quality of life is such an issue. Pat is doing amazing, and we were so grateful that you as a family have been able to welcome a baby a couple of years ago, but still, the challenges persist.

So I want to next ask each of you a couple of questions, because science isn't your background. This is all new to you. So why did you want to participate in research as a person with lived experience? What compelled you? What was the [inaudible 00:36:18] to make this choice? Jack, do you want to start? Maybe I mean?

Jack Somers: Yeah. Sorry about that. I think the most important part to me was to serve. Ultimately, that brings me the most amount of joy. I hope that's not a selfish response, but it is. Serving the community is the utmost importance to me. And given I do have experience, and I have so much experience over the last 14 years, the opportunity to give back, and hopefully, if it's helping one person who has this, or helping one mother, father, wife, husband, son, daughter, anyone, a friend, who is a loved one of somebody who has PTE, then that's, then sign me up. Anything I can do from my position is worth it. And so, service is everything to me. And so, anything I can do from my position is an obligation of mine.

Dr. Laura Lubbers: History of service in many ways. And Patty, you've sort of addressed this, but how about for you?

Patty Horan: I guess I agree with Jack, and the fact that I've seen so much suffering in the veteran community is unbelievable. And if there's anything that I can do to reduce the suffering of people in this community, they deserve it all. I mean, they deserve our attention, our focus, and anything we can do to relieve some of what they're going through is worth it. This war is awful. But I feel like this contributes to not just veterans, but the society as a whole. Because we're learning how to better take care of our brains, and everyone's got a brain. And I think that it's just a really important mission.

And I will say, I am not a scientist at all, I have a business background. And it's very scary at first to get involved in the research. I have a little selfish reason to, just to be engaged with all these brilliant scientists, that actually can give me a better understanding of how to help my husband, how to support him. And understanding of what the broader picture of epilepsy looks like, and what's happening out there, as far as access to care, and just the latest and greatest medications, and what's going on in the clinics.

Dr. Laura Lubbers: Yeah. I know we've talked about it before. It is daunting without having a science background to step into a role like yours, where you are discussing with the science, with well-established researchers. And I'll ask you both this, but Patty, what were your greatest concerns when thinking about this, when you were engaged with this? And how did you overcome those concerns?

Patty Horan: I think in the beginning it was really, it's a totally different language. It's like walking to a foreign country, going into like, what are they saying?

So the good thing about the ERP is, you do get some time. Each person is given five projects to evaluate, and you get a couple of weeks, look over all of these. You do have to present them and speak the language, but you have a co-presenter. So if you mess up or if you didn't get it quite right, you have somebody else to swoop in and fix it up a little bit. But the whole panel discusses everything later too, so you're not alone.

And I think a little of it was just ignorance, because with the first panel I sat on, I was very overwhelmed. On the first break, I went outside, and I was like, "What am I here for?" But people were so gracious, they were so nice. They were so thrilled that I was there. They felt like they thought that my opinions were valuable, which was amazing, because these are some of the smartest people in the country. So it was very scary at first. And I fumbled through presenting probably the poor researchers that got me. But I did it. And every year it gets easier, and I understand the brain a little bit more. And I've made some great, I've met some great people with CURE, and just the people on the panel are just the best people. And Melissa, and it's been overall, a great experience.

Dr. Laura Lubbers: Great. Yes, you have a very powerful voice on that review panel, for sure. And you have changed the direction of science with focused on PTE, and that's really something to be proud of.

Jack, how about you? You're coming into this fairly recently, so what were your greatest concerns? And what did you do to overcome those?

Jack Somers: I mean, similarly to Patty, I came into it with, I would say, I was a little naive, but very excited to join this group. I didn't know a whole lot about it, but I was okay with that. I just wanted to serve and give back, and if they were willing to let me join, that was enough. I was just so excited that they were willing to let me join.

It was really the first advisors call that, like Patty, I was just blown away by they're going through their different milestones and what have you, and the verbiage, all of the scientific research that they had done. And I just didn't know the level of expertise that these folks had, and I didn't understand a lot of it, but conceptually I could get it. And so, in order to overcome it, I kind of just used that old, the acronym, keep it simple, stupid.

But I just had KISS, and I just said that the best way that I can overcome this is to just keep it simple. And when I did that, I just listened and I kept it simple, and all of a sudden, I understood what they were talking about. And it was incredible, because I learned that all of these folks, who just like Patty said, some of the most brilliant neuroscientists, and epileptologists, and folks in the world, amazing. At Cambridge, at Texas Tech, at UCA, research groups, they are trying to solve the problem that I have. And they could do whatever they'd like, but there they are, and they're passionate about it, and they're working on this all the time.

And it actually, it almost brought me to tears. Because I said, "Why are they doing this? Why are they working on this problem?" They could do anything in the world, and they're trying to solve the problem. They're trying to answer the questions that I've been trying to answer, and keeping it simple. Let me learn. Let me figure out just what they were trying to do. And so, I then didn't have to worry too much about all the words that they were using. I just got to listen to generally what they were trying to do, and it blew me away. It still does, every single time I listen to them.

Dr. Laura Lubbers: Yeah. Yeah. I had the privilege of being on that call, that first meeting of that research team with you. And it too almost brought me to tears when you shared, and it is one of the highlights of my year from last year. When you shared your thoughts and experiences, and the entire conversation changed, and these scientists were acknowledging your experience and saying, "Yeah, we need to think differently about this aspect of it." So your voice was really powerful. And that is another example of why this is important to do.

So recognizing that, that's a great segue into the last question I have for you both is, what do you feel is the value in sharing your voice? And what do you hope your participation achieves in doing this? So what's to the value, and what do you hope the outcomes will be?

And Jack, do you want to take that, since we were just kind of talking about that?

Jack Somers: I hope that I can use my experience to give back and help one person. I hope that I can serve again. I hope that I refuse to let my experiences be lost in translation, or be just mine. I refuse to let them go to waste.

And so, my hope is that they get leveraged, is that they're used in ways that we are just learning how to use them, and how they were used five years ago or 10 years ago is actually just the beginning. And that we learn how to use my experiences more and more, and in more efficient, more effective ways as time goes on. That's my goal.

Dr. Laura Lubbers: Great. Wonderful. And Patty, what do you feel is the value of sharing your voice? And what do you hope it will achieve?

Patty Horan: Well, a little bit more support for caregivers and the families. So the VA, the Veterans Administration, they need concrete evidence of what's happening in our households. They don't necessarily understand the toll of epilepsy in a household, on a life, especially uncontrolled epilepsy. So I feel like I contributed, at least to start looking at quality of life studies.

We have some of those in our portfolio, and I feel like I push for that. And I'm hoping that the data from those studies will be concrete evidence for the VA to actually compensate these families better, that have epilepsy. They will give them better services, better access to care, and also, home health benefits. Because some of them, and we were at this point in the beginning where I couldn't leave Pat alone for five minutes; but we didn't qualify for any of those services, because he's not injured enough, or the epilepsy didn't qualify him. So it's interesting. So I'm hoping that out of with my voice, the value will become, will be that veterans are better supported with epilepsy by the Veterans Administration, and there's a better understanding of the daily life.

Dr. Laura Lubbers: Very important points.

Jack Somers: Yeah. If I could just jump in there, Patty, you're absolutely spot on. And just more specifically with that journey, it has been so difficult to find those resources, to qualify for those resources. And with PTE, the cognitive issues, and the communication dysfunction that it creates, the behavioral problems that we have, strains the family so much. It strains the relationship. It can compromise the relationship. And if the families are not compensated, then you have financial problems that the family has to pick up. You have financial problems that the individual who has PTE is then incurring, because they might get fired. I got fired. And then you're unemployed. You are trying to walk through that, or navigate that issue, while your folks or your loved one is also trying to deal with getting a second job. But taking care of that loved one who has PTE, and before you know it, it can become a disastrous situation. And the last thing you want to do is say, "This is too much. I can't take care of someone who has PTE and try have a job and take care of the kids."

Patty Horan: It is too much.

Jack Somers: And it can become too much. And what can happen is, God forbid, but you go separate ways. And in some ways, I don't want to go too far into it, but the isolation that can be, it can create so much isolation. And that's right when the person with PTE and the loved one needs so much compassion, needs so much forgiveness and understanding, but the strain is so significant that it can be catastrophic on the relationship.

And so, I just absolutely thank you for being specific about that. It is spot on. I have personally experienced that. And it's thank you, because from the person with PTE, thank you for mentioning that. That is just like, that's perfectly said. So thank you.

Patty Horan: Well hopefully, the research will say it loud and clear too, and we'll be able to get, or the future service members will be able to get more support.

Dr. Laura Lubbers: Yeah. Yes. Thank you both so much for sharing these, your experiences. And even this last piece, which we don't talk about, but is so raw and so needs to be addressed. And it won't happen unless you have the opportunity to share your voices and experiences. So I want to thank you from the bottom of my heart for your transparency on that.

I know we're nearing the time of the end of webinar. Before we wrap up, I do want to go back to Dr. Miller, for her to share her hopes and visions for the future of lived experience participation, and how we go back to how can people get involved?

Dr. Melissa Miller: So I think my greatest hope for the near future is for more researchers and people with lived experience to have the conversations that we were just having. It's so important to have opportunities for these conversations, to force opportunities for these conversations, because without them, the researchers are doing their best, but they are not the experts in your experiences. And we need you to tell them, and guide them into what is the most important and impactful questions to be researching for policy change, for care change, for overall change. And that's what I hope really will impact the future.

And the way that people can get involved with the ERP is just going to the CDMRP website. We have a big banner on our website that says, "Get involved." And if people are interested in reviewing for us, in consulting on projects, let us know. We can help connect you to the necessary people. I'm sure, Laura, that your organization also has opportunities. I think there's a lot of opportunities, and we just need people, and their generosity of time to volunteer, and we can make a really great impact in this field.

Dr. Laura Lubbers: Yes. Thank you all. What a compelling discussion we've had. I thank you all for that. You're sharing your unique perspectives on the importance of sharing your voice and the challenges of doing that, and the support that you will find if you choose to do it.

I'd also like to thank those who have been online with us today to learn more about this topic. If you have any questions about the topic, or want to learn more about CURE Epilepsy, you can go to our website. You can email us at research@cureepilepsy.org. We would love to have engagement, and be able to support programs like Melissa's even more. So please do reach out.

And please do stay tuned for more information about our next webinars, which will be announced in our communications and on our website in the near future. So again, I want to thank you all for such a great discussion. Thank you for sharing your stories, the things that are hard to speak to. It's deeply, deeply appreciated. And I hope you all have a wonderful weekend. Take care.