



Coordinated Regional Council Transcript: Empowerment and Advocacy

This is a transcript of the IFSP Coordinated Regional Council Meeting on Sept. 16, 2021. You can find links to the YouTube video recording and the IFSP presentation slides at <https://tinyurl.com/IFSP-Archives!>

>> ERIKA: All right everyone, I think it is almost 6:30. I think as soon as I finish this sentence, the clock on my computer will change. Welcome, everybody! That was a great way to get us started. Yay, such an exciting energizing kind of setup for us. We don't have anyone for you to dance with, but I am Erika Jones-Haskins. On behalf of the IFSP staff, we are super excited to have everyone here tonight to talk about advocacy. This is a topic that our State and Regional Council members have selected. This is how we do these Coordinated Council meetings. The topics come from the community and the public and we help support them, and we're so excited to be here tonight. And so glad to see so many people here joining us this evening.

I am Erika Jones-Haskins. We have other folks from the IFSP staff that I'll quickly run through just so you guys know who's here, and then I'm going to turn it over to Carly Blake to set us up to let you know who's the speakers for tonight and that sort of thing. So also here with us tonight we have Rachel Vamenta, and Rachel does all of our beautiful communications work, especially our cool stuff you see on Facebook and also our newsletter. And we also have Cristin Sprenger who is here tonight. Cristin is our Western region peer support specialist, so she is there to help folks in the Western region be able to connect with other families and support the Council in the Western region, and we're happy to have her here with us tonight as well. And last but absolutely not least, we have Carly Blake who is here. Carly supports our work with our State and our Regional Council, and a lot of what you see in this meeting is all because of her love and attention. So Carly, I'm gonna turn your baby over to you and say thank you. And I'm so glad to see you all here tonight. I'll be with you throughout the evening, but Carly, take it away.

>> CARLY: Hi, I'm Carly Blake. Thank you, Erika. I'm gonna go ahead and get us started. Actually, Erika, if you don't mind walking through the agenda for us, I'm sorry it says "Insert here," I forgot to add their names. But I need to deal with someone being muted that needs to be unmuted.

>> ERIKA: No worries. I am glad to do that um so while Carly's taking care of some tech support stuff. Just to remind everyone if you have tech support issues, we have the chat that we will put things in periodically throughout the night.

>> JESSE: I think I'm unmuted now.

>> ERIKA: Ah, yes.

>> CARLY: (LAUGHING) Awesome, thank you.

>> ERIKA: We've got our chat, where you can ask your questions and things like that. We also have here tonight, if you need any help, you know, just use that when we have our breakout rooms. We'll have people in those breakout rooms who can help you get some of the answers you need. Just sort of our welcome, I've done that, our ground rules ... you know we try to be inclusive in this meeting, so if you have questions, feel free to ask them in the chat. If you have regional-specific questions, we will cover a lot of that in those breakout rooms. And we'll probably get back together just to sort of say at the end that we've concluded.

Just the overview of tonight: We're going to have a little bit of an overview of what IFSP is, if you don't already know. The hot topic right now for "What is IFSP?" is about the Funding Program. We're not going to cover the Funding Program tonight. If you (INDISCERNIBLE) the Funding Program is its own separate thing. There's quite a bit of information that we've put out on the My Life, My Community website about the Funding Program. if you need help with submitting an application, there's a really good video, and a great set of Frequently Asked Questions and Answers, and we will direct you to the My Life, My Community website to get that assistance. And there's also a call center, the My Life, My Community Program, that can help people with getting answers to those questions.

The other thing we have as well is we have a brief presentation from LEAP, and I'm going to let Molly explain a little bit more about LEAP and what they do, but it's really actually quite interesting. LEAP has had to do a lot of their work virtually in the past year or so like everybody, so it'll be interesting to hear how Molly speaks to that and how they're being able to help educate and inform people about staying safe and when the world has changed so much. We also will have speakers from the ALLY Alliance and I'm not going to get too much in detail because I think all of these folks are able to pretty much tell you a lot about themselves and what they're here to represent. We will have our speaker, who is Leslie Mehta, to talk about advocacy. Leslie used to be a Council member, a State Council member with us, and she has been able to go on her own advocacy journey borne through all kinds of lived experience and I think that you'll be inspired and really interested in the conversations. Then we'll have our regional breakout sessions. We'll come back to this

room for some questions and answers, and then we will just have you know a quick wrap-up in our journey. So I hope you guys are ready for an exciting and interesting night. I'm going to turn it back over to you now, Carly, is that good? Then—

>> CARLY: Yeah!

>> ERIKA: Take it away.

>> CARLY: Thank you. So I just wanted to go over some ground rules before we get started. Tonight's main session is being recorded. Please put your questions in the chat. We will answer all questions at the end of the meeting after the breakouts. This meeting is for the IFSP Regional Councils. If you have IFSP-Funding-related questions, please visit the My Life, My Community website's Funding page. Rachel will put this information in the chat for you all. And again, remember that tonight's meeting is public and recorded, so please refrain from sharing personal information. Just know that if you do, it is a public meeting.

So really quickly, what is IFSP? IFSP has these four quadrants where we do our work. Financial resources for individuals and families, direct supports individuals and families through social emotional support and training, education, information, and general referral, and supporting community action and additional support creation. If you've been to My Life, My Community, that's in this quadrant. That is us. If you have worked with the Family to Family Program at VCU or the Peer-to-Peer Program at The Arc of Virginia, again, that comes from us. And of course, our Funding Program, but tonight you are here joining us for our Coordinated Regional Council Meeting. So now I'm going to turn it over to Molly Dellinger-Wray from VCU's Partnership for People with Disabilities to talk a little bit about LEAP.

>> MOLLY: Hi everyone, thank you so much for asking me to talk. Carly, I will ask you to cut me off or give me a sign. Talking is my favorite sport and I love talking about this project, so I don't want to take up too much time or go on too much. I don't like a lot of acronyms, so I'm going to tell you first what LEAP stands for. LEAP stands for "Leadership for Empowerment and Abuse Prevention" and LEAP is we call it. LEAP for short, because you talk about all the time and you say, "Leadership for Empowerment and Abuse Prevention" ... that's a mouthful, and so we call it LEAP. LEAP was designed to help people become leaders, to empower people, and to help prevent abuse. And so if you want to go on to the next slide, Carly, I'll talk a little bit more about how LEAP got started and why it got started.

At the Partnership for People with Disabilities at VCU, we have really been working since about the year 2000, so it's been 21 years now in helping people recognize that people with disabilities are at very high risk for violence and sexual assault and bullying and

lots of unhealthy relationships when compared to people who are typically developing. And we really wanted to do something about this, and so we worked for a long time training people, school counselors and adult service providers and teachers about how to recognize and respond to abuse. But it was really important to us—to me--that we really reach people with disabilities to teach them that unhealthy relationships happen, they happen to everyone and it's okay, that you can learn some strategies to get out of them, and really learn some strategies to figure out what's a healthy relationship and what's not a healthy relationship. And so we developed LEAP to be able to teach that, and we decided we wanted ... we looked at all of the other programs that had been developed across the world and across the country, and if you want to go to the next slide, I can talk a little bit about how we figured out what we're going to teach.

We had a group of people who advised us, and on the ground floor of that group was people with disabilities and their family members. There may even be some people here that were on our advisory committee who helped us. And we looked at all these different programs, as I said, that happened nationally and internationally about what are other people doing? Because it was our thought that if people in Pennsylvania are doing this, then we'll just do what they did. And so we brought we reviewed a lot of these training programs and we brought them to our team, and they said, you know, “We like parts of this one, and parts of that one, and parts of this one.” But we really had to kind of make up our own program, we had to create our own program. So we had people with disabilities and their family members, we had disability advocates and service providers, we had people from the Virginia Department of Health, we had people from the Virginia Department of Social Services, we did a lot with the Greater Richmond SCAN and the Virginia Anti-Violence Project, and some special educators. So we had a very multidisciplinary team. I am the mom of someone who was diagnosed with a disability and I’m a special educator both, so I kind of wore many hats um when we were developing LEAP. And this is how we came up with what we came up with. So go ahead and go to the next slide, Carly.

So we decided the training would be only 4 sessions. We didn't want it to be too many sessions, and each session is about 90 minutes. It's very interactive ... nobody gets bored and typically no one gets bored and wants to leave. It’s very interactive. It's usually groups, I’d say, we said 10 to 13, it's really more like 8 to 10 is ideal, we've had up to 15 at the most. We've had as few as five. It’s taught by a person with a disability and a co-trainer. So we have teams that go out and teach it. And we work really hard with our lead trainers to learn not only how to teach LEAP, but also when you start talking to people about relationships and about healthy relationships, oftentimes it will help ... it will remind them of an unhealthy relationship or a traumatic incident that has happened in their life, and we want to be sure that our trainers are sensitive and know how to respond to that and get

people help if they want it. And so they have to do a lot of work to become a LEAP trainer, it's not impossible to do, it's fun and people really enjoy it. And so the first step is to take a LEAP class, and then practice the training with, I would say, with your family and your friends and your pets, and then have us come and observe you and make sure the training is being carried out the right way, and then they're certified. (PAUSE) So go ahead, we'll go on to the next one.

So that is how we came up with LEAP. Every part of LEAP, in every session we do this at least twice, and I'm going to ask for your patience and just do it with me now. I know everyone's microphones are muted, but LEAP has a power statement. And we really worked hard with a group, with a focus group of people with disabilities to help us come up with our power statement, and so I will say it. If you want to say it after me, that'd be great.

"I am strong."

>> TOGETHER: I am strong.

>> MOLLY: "My feelings are important."

>> TOGETHER: My feelings are important.

>> MOLLY: Love it! "I deserve to feel safe."

>> TOGETHER: I deserve to feel safe.

>> MOLLY: "I deserve respect."

>> TOGETHER: I deserve respect.

>> MOLLY: Thank you, guys! You are awesome. That is the LEAP power statement. And after an organization says, "We want to have LEAP! We want you to come and train these people!" then they get a poster of the power statement that they can hang up in their hallway so they can remind them of the LEAP power statement as we go through. So that's the LEAP power statement. Go ahead and go on to the next one.

I don't know if anyone's interested in this or not -- we knew that people had a really good time at LEAP and they really liked it and they thought it was fun, but we wanted to make sure that people were actually learning something and that's very important to us at VCU. And so what we wanted to do is we gave people a little ... we had them watch a little video of a relationship, of an interaction between two people, and said, "What do you think about this relationship? Do you think it's healthy or unhealthy?" And then we'd say why, and if it was an unhealthy relationship, they'd say what should the person do next. And what we learned is that most almost everybody knows what an unhealthy relationship looks like. Everybody knows if somebody hurts you or steals from you or is unkind to you, that

that's not healthy. But what we learned, what people really learned in LEAP was what should they do to get help, what should they do next, and really better able to describe why a relationship is unhealthy. Why, what is it? They learned some words some vocabulary words to describe why is that relationship not right, and so we're very proud that not only do people have a lot of fun in LEAP, but they also learn something. Okay. 2 minute warning. Go ahead to my next, my next slide and that's it, I'm winding up.

So this is my email address. I know Carly said not to share anything personal ... this is my dog. If you have questions, if you're interested in learning more about LEAP, or interested in having a LEAP training, I would love to hear from you. As I said, talking is my favorite sport and I got it in under 5 minutes, so bravo to me because it's something that I really enjoy talking about and it's really important. So thank you so much for having me.

>> CARLY: Yes, thank you, Molly for coming. If anyone has questions, this is her email. Unfortunately, right now we do not have time to take a bunch of questions, but if there is one in the chat -- I haven't seen any -- but if anyone has a question, I'll open the floor to one and then we'll move on. All right, Paul?

>> PAUL: I would like to thank Molly and all of her support through my years, our People's first group, some of our members, including me, actually went through this training a couple years ago.

>> MOLLY: Oh, I'm so happy to hear that! Did you enjoy it?

>> PAUL: Yes, I did. And actually, the late Alexis was my trainer first.

>> MOLLY: Oh, she was a great trainer.

>> PAUL: And it was on Warfield, actually.

>> MOLLY: Oh, Alexis was a great trainer. We really miss her. Thank you so much for sharing that, Paul.

>> PAUL: (Indiscernible) Anytime.

>> CARLY: Thanks, Paul. Okay, we have one question we have one question and we'll move on. What age group do you present to?

>> MOLLY: Okay, so that's a really good question. Thank you so much for asking that. We designed LEAP for adults, and some people think adults start at 18. Some people think adults start at 15. But we designed it for 18 and up. But we are very fortunate, because some people who work at James Madison University heard about LEAP and heard that it was really a good program and that people liked it and learned a lot from it, and they said, "We are working with some teenagers." And they're actually working on sex education. And

I'm always very upfront that LEAP is not sex education, it's about healthy relationships. It's not about dating, it's not about sex education, it's about healthy relationships and friends and staff and negotiating those relationships. But we have been given some time and information to work with the people at JMU to adapt LEAP, to make a new LEAP focused on teenagers. So I have been -- it's literally on my desktop right now because I'm behind on it -- but I am plugging away to make LEAP available for teenagers. So thank you for that question.

>> CARLY: Awesome, and thank you again, Molly so much. We appreciate having you.

>> MOLLY: Love being here, thank you.

>> CARLY: All right, so now we're going to turn it over really quickly to some of our partners with the ALLY Self-Advocacy Alliance, Shawn Kirk, Brittney Lee, and Jesse Monroe. They have been participating with their Regional Councils for a few months now, actually, since the beginning of the year when they presented to us, and I just wanted to give them the floor for a few minutes to talk a little bit about what the ALLY Self-Advocacy Alliance does. (PAUSE)

>> BRITTNEY: May I go first?

>> CARLY: Absolutely!

>> JESSE: Sure.

>> BRITTNEY: Hello, I'm Brittney Lee. I live in Richmond, Virginia. I have come from a local self-advocacy group called The Four Seasons, where I started at the beginning of my journey. I also became a member of the A Life Like Yours Self-Advocacy Alliance, where I currently serve as a co-chair. I am a leader for people with disabilities. As a certified peer mentor, I want to assist individuals in achieving their goals by giving them the right resources for an individual on a successful path to gain more knowledge. (PAUSE) I continue to advocate for persons with disabilities while serving on many committees, such as the Marcus Alert community-based service-- community-based service advisory committee, Individual Family and Support services. Self-advocacy is important to me because I wasn't able to get Dragon Naturally Speaking because I was denied Medicaid services. I wasn't able to have the services because of my use of 1 finger. That's why self-advocacy is important to me.

>> CARLY: Thank you.

>> SHAWN: I'll go next. Hello there, my name is Shawn Kirk and I live in Richmond, Virginia. I have a high functioning form of autism. I work in the community at Panera Bread.

When I'm not doing that, I am helping as one of three coaches on the A Life Like Yours Self-Advocacy Alliance. Also like Brittney, I'm a trained paid peer support mentor and help facilitated some of the focus groups put on by the Virginia Board for People with Disabilities earlier this year. I also spoke earlier this year at the budget hearings on behalf of people like my good friend Brittney, my good friend and fellow liaison Brittney Lee, even though I don't have or need services. Self-advocacy is so important because it helps people with disabilities speak up for themselves and learn how to make their own decisions about their own life. If you had told me back in 2008 that I would make a great self-advocate for myself and others, I probably would not have believed you, but look at me now.

>> JESSE: All right, hello everyone, my name is Jesse Monroe. I'm also a member of the ALLY Alliance. I have been doing self-advocacy for about 4 years now. I am with a local group in Norfolk, Virginia called Our Voices, which I'm their liaison for the Alliance. I'm also on the board of The Arc of Virginia, and of course I do some things with IFSP as well. All right. Advocacy is very important to me because I know when I was a younger man and a child how much my mom, how hard she had to advocate for me to get things I needed when I was a kid and to get on the Medicaid waiver that I'm on now. And I saw how and learned about how people particularly were struggling to get on waivers and how people with disabilities were just not getting things they need, so I felt like I needed to do that to give back to make sure everyone with disabilities has, you know, the things that they need. And so I think that that's why it's very important to me. And also, I live on my own, in my apartment, and I think everyone should have that independence, even people with disabilities. So that's why I do that, and that's why advocacy is important to me. Thank you.

>> CARLY: Thank you, Jesse, Shawn, and Brittney! I always enjoy you all participating in your Regional Council planning sessions um you are great representatives of the ALLY Alliance and your local groups as well, so thank you so much for sharing with us.

Now we are going to move on to the main speaker of tonight, Leslie Mehta. Leslie Mehta is an attorney and chief of staff and counsel to the CEO at the Richmond Metropolitan Transportation Authority. She has nearly 2 decades of legal advocacy experience. She holds a bachelor's in English literature from the University of North Carolina Chapel Hill and a J.D. from Howard University School of Law. Leslie was appointed to the IFSP State Council in 2019 and served until 2020. In 2020, Leslie launched pRETTyBrooke.com, where she interviews politicians, executives, thought leaders, and parents about disability issues. Only a year after its launch, pRETTyBrooke was nominated as a 2021 disABILITY Law Center of Virginia disABILITY Impact Award nominee. Leslie is also a board member at the International Rett Syndrome Foundation and the Children's Hospital of Richmond at VCU Family Advocacy Network. Leslie's daughter Brooke was diagnosed with Rett Syndrome in 2017. She passed away from Rett Syndrome complications in March

2021 at the tender age of 5. She also has a 2-year-old daughter, Blair. Leslie, her husband Tarun, and Blair live in the suburbs of Richmond, Virginia.

I'm happy to turn it over now to Leslie to share with us.

>> LESLIE: Thank you, Carly. I really appreciate it. And my first slide talks about self-advocacy, but in some ways, it was self-advocacy because I was advocating for the needs as a special needs mom. And I say "am," because I am always Brooke's mom, even though she has passed away. But I think these advocacy roles or suggestions are for anyone who is going through this disability rights journey, whether it is on the side of a parent, or caregiver, or the person with the disability. And just like with what (INDISCERNIBLE) Molly, Carly, feel free to give me a signal if I'm going too long. Can we have the next slide, please?

So I just wanted to start off a little bit by giving you a little picture of my family. So there I am with my husband Tarun. And Brooke is the older child there, she was probably about 4 years old in that picture. And my youngest daughter, Blair, who is now 2 years old. Next slide, please.

So in order to kind of give you a sense of my advocacy journey, I wanted to first give you a little bit of my particular background. As Carly mentioned, I am a lawyer by trade. I attended Howard University School of Law and I have a background in civil rights law. I've worked for a nonprofit, for advocating on behalf of California consumers. I was the legal director of the ACLU of Virginia, and I continue to be a leader in my profession now. And I say that to say that that kind of colors and highlights some of my advocacy, and some of the journey that I've had so far.

As Carly mentioned, I was on the IFSP State Council, as I believe perhaps some of you have been on or have some kind of affiliation with. And part of my journey, which I can go into a little bit more, is that I am now a board member with the International Rett Syndrome Foundation. And like I mentioned, my daughter has Rett Syndrome, so that's been kind of part of my journey and how I've gotten to do some of the advocacy work that I like to do. And I am also on the Family Advisory Network at the Children's Hospital of Richmond, and I can certainly talk a little bit more about that, as well. Next slide, please.

So to know a little bit more before we get into some of the details about the advocacy, and to know a little bit more about the journey, I wanted to talk a little bit first about Brooke. And so some of my journey obviously is specific and unique to Brooke, but it is part of a broader way of looking at how I got into disability rights issues. Brooke was born in 2015. Within a few months of her birth, my husband and I started noticing that she was not meeting her milestones, she was not rolling over, she wasn't crawling at the time frame that she should have been crawling. And so we started having discussions with our

pediatrician. So I would say that in terms of advocacy for oneself or for others, if you're trying to give advice to others about starting a disability journey or, you know, trying to advocate for the rights of others, one of the first things that people may want to do is certainly reach out to their pediatrician if it is someone who is, you know, a small child. And that was the route that we went. We started talking to our pediatrician, who recommended county testing. And we discovered through that process that there were developmental delays, although we didn't know specifically what her particular, we didn't have a particular diagnosis at that point of time. So ... but because of that -- this part may certainly be familiar to a lot of people -- we started working with speech and physical therapy and occupational therapy and on all of those things, and ultimately in 2017 Brooke was diagnosed with Rett Syndrome. And I saw in the chat that there is another Rett Syndrome mama out there, so shout-out to her! (LAUGHING)

And so Rett Syndrome is a neurological disorder. It affects about 1 in 10,000 girls and even fewer boys, so it's a rare it's considered a rare disorder. It renders people incapable of talking or having at least limited speech, and there are sometimes regressions even with the speech that one might have. Some are able to walk in a limited capacity. My daughter Brooke was one who was not able to walk. And then and there are other kinds of issues that come along with that. So she had difficulty with purposeful hand movements. She had the ability to do some of that, and she lost it over time. And Brooke, along with a lot of other kids with Rett Syndrome, had seizures starting probably around the age of three. She started to have seizures, and so that became another issue that we had to address during her, during her living years. So that was one of the things that we had as one of her conditions.

And as was mentioned before with Carly, Brooke passed away earlier this year in March. Some people with Rett Syndrome live well into adulthood and some pass away when they're young, and Brooke just so happened to be one of those who passed away in her sleep earlier this year. As part of her legacy, I continue to advocate and I'll talk more about what that looks like for me, particularly with pRETTYBrooke.com and my work through the International Rett Syndrome Foundation and the like. Next slide, please.

So in terms of advocacy, one of the things that I recommend to people kind of trying to start the advocacy journey, as I call it, because it's not just one isolated instance incident in time, or instance in time, rather. I suggest that you do educate yourself first. So for me personally, I did a lot of research about Rett Syndrome. That's why I was originally introduced to the International Rett Syndrome Foundation. There were social media platforms that I signed up for and regularly participated in, and I started learning a lot more about the prognosis, potential skill sets, limitations ... And I will say that one of the things, I wanted to specifically learn those things, but I also wanted to not let those things define

Brooke. Brooke is an individual like any other individual, and so I didn't want ... so I wanted to know kind of what the parameters may be for her, but I didn't want to, you know, have a particular set of expectations and only deal with those expectations. And those, I had to talk to the teachers about as well, in terms of, you know, "I know Rett Syndrome says this, this, and this, but there are instances in which Brooke may be able to do more than this, and then there might be instances in which we need to step back because she may not be able to do some of the things that you may typically think that a kid with Rett Syndrome can do." So we, you know, as with anyone, you have to think about people in terms of being individuals as well. And so the next thing that I had to start thinking about was specialty clinics, particularly for Rett Syndrome and this is a little bit more specific to rare disorders because, you know, in other situations, it may not be as pertinent. But for Rett Syndrome, there are no Rett clinics in the Commonwealth of Virginia. So for us, what we did was we went down to Atlanta, where there is a Rett clinic. We did that once a year as kind of a tune-up, in addition to the work that we ... the therapies and the specialists and all of those things here in the Richmond area.

And also as I mentioned, I reached out to organizations. And as someone mentioned before, I don't know if it was Shawn, but I had to think about things in terms of funding sources. So you know, we got denied originally initially for Medicaid. And we know that there are lots of different things that come up, you know, equipment and all sorts of things, caregiving services, and other kinds of aid that become may become necessary for some individuals. And what we had to do was find ways to get those sources, and so we did our own research in that way as well. And when we were denied Medicaid, what we ended up doing was having to list out, okay, what kinds of things do we really need to make clear to Medicaid so that we can get approved? And as a parent, I, you know, I look for the positive. I look for the things that she can do and she could do and all of those things, but sometimes you have to say, "Okay, well, I need to tell this entity what the issues are. She is great in this way, but what we need to explain to them is that she's not capable of sitting up in the bath, so we need a bath chair" and those kinds of things become really important. And in addition to that, I can talk about a little bit in more detail what I did, particularly with my legal background and lobbying and all of those things, is I also reached out to my state representatives. So I was ... I had applied for Medicaid a couple of times and was denied, even though she wasn't able to do some of the things that neurotypical kids were able to do. She was still denied services, so I reached out to our state rep, and he actually wrote a letter to Medicaid. And Medicaid, after that, the next time, we actually were able to get approved for Medicaid, and I don't think that that was a coincidence. (LAUGHS)

So anyway, in addition to that, we thought about, my husband and I thought about things in terms of the legal rights and educational rights. Brooke was in kindergarten when

she passed away, but we had certainly already done some of the ... we had done an IEP plan. And we actually hired an advocate for her to attend virtually with us the IEP because it was our first IEP. We didn't know what to expect, and for us that was a good way to go to get an idea of what kinds of things we should be asking for. And it was recommended for us to possibly do another tune-up with an IEP advocate later on when she was a little bit older. But that is another realm of advocacy that one may want to take if you have school-aged children. Next slide, please.

So once I decided I felt rather comfortable with educating myself about Rett Syndrome and things that might be helpful to Brooke, that's when I started the journey of trying to educate others in the way that I could. So here, I talk about educating others about Rett Syndrome, even when there are diagnoses that are not rare, there are instances when medical professionals or agencies or others that you're reaching out to may not know as much about the condition as you, as the individual with the condition, or you as a caregiver or parent, or that nature. So it you know it may be unfortunate, but you may be the one that's um educating someone else um about these things and so these are some of the ways in which I did. I talked to uh educated medical professionals. I told people about October being Rett Syndrome awareness month. I reached out to our local TV stations to talk about it. I talked to state senators and delegates, and that kind of led to my being on the board at the International Rett Syndrome Foundation, because then I started lobbying and trying to get more funding for Rett Syndrome in particular. And of course, teachers and day care providers, you know some of them may be familiar with things like Rett Syndrome, but they may have only known one or two individuals with Rett Syndrome, so sometimes the education needs to go in that way as well. Next slide, please.

So in terms of the advocacy journey, after I'd done all of that, I started directing my attention to sharing information that I knew. You know, as a lawyer in particular, that's one of the things that I like to do. I like to do my research and then you share the information! And so that's what I started doing, and pRETTyBrooke.com grew out of that. "Pretty" was because Rett is in the name "pretty" and I've seen a lot of other Rett moms use that, and so I started using pRETTy Brooke, and so pRETTyBrooke.com derived from that. And there I started doing product reviews on things that were related to disability, products or things that even if they weren't geared to that, things that might be beneficial. And then it kind of morphed into interviews. And so on my site, I talked to CEOs and authors and politicians and other leaders about issues related to disabilities in general, not just Rett Syndrome. And that includes my YouTube page and Facebook page of the same name, as well.

And then I've started doing speaking engagements like this as well, to talk to people particularly about advocacy. I love talking about advocacy because I think it is important to talk for people to advocate for themselves or for their loved ones on these issues. And I

started this page back in 2020 at the beginning, right before the pandemic started, and I'm proud to say that I was nominated by the disABILITY Law Center of Virginia this year for their disABILITY Impact Award. I was pretty proud of that particularly because I really, I'm proud of the work that they do. And I am proud to be to have been nominated for an award, particularly with us only being, pRETTy Brooke only being in existence for a year. So, that is really my journey. I think that's my last slide, right, Carly?

>> CARLY: Yes.

>> LESLIE: Okay, yeah. So that's kind of my journey in a nutshell, but I'm happy to talk further about it. That's my journey with Brooke and disability issues. Thank you.

>> CARLY: Thank you so much for sharing with us, Leslie. If there are any questions, stick them in the chat, but we are about to jump into our breakout rooms. I just want to celebrate this is the first time that we've been on time and we will have our full 30 minutes in our breakouts, so I'm very excited for that. I'm gonna go ahead and stop recording so i don't interrupt any breakout rooms here in a moment.

