

## Advocacy

Sydney Shepherd: We are talking about what is an advocacy network. A lot of times when people think of advocacy, they think of one of the front lines with their picket signs, protesting hot topic issues, a lot is happening in Congress right now. But advocacy can look very different. It's most multifaceted and you can, you know, partake in advocacy from the comfort of your own home.

But today, I'm going to talk about the ACN and the work that they are doing to promote legislative change, specifically for the PKD community. And I'm joined by my colleague, Patrick Mead, who also works for curious strategies, who will be chiming in here and there we are a partner of the foundations and love the work we were doing with the ACN and promotion of legislation that will affect the PKD community.

Next slide, please. All right. So, this is just a disclosure, I'm actually going to just remain silent just to let you guys know, no medical advice will be shared during this presentation. But just take a look at this so, that you're aware of this, which is really important.

All right, we can move on to the next slide. All right. So, wanted to introduce ourselves. Again, my name is Sydney Shepherd, I am an account supervisor with care strategies. We are a partner of the foundations. I have about six years of experience working to build grassroots programs and in the promotion of different policy issues, ranging from hospice to cardiovascular issues.

This is work that I thoroughly enjoy because again, a lot of people don't really understand how policy works and how you can promote legislative change. And there are so many opportunities to engage in it. And I also love learning about all the different stories and how specific diseases and illnesses affect people's quality of life and looking for long-term solutions that can help them improve that quality of life. I'm going to kick it over to Patrick if you want to introduce yourself.

Patrick Meade: Yeah, absolutely. Hey, everyone, lots of people that I've met on this call and lots of people that I hope to get to know better. Thanks for joining

## Advocacy

us tonight. As Sidney mentioned, I'm an account executive with pure strategies. I've had the pleasure of working with the PKD foundation for going on two years through their advocacy champions network and the recently launched peer Ambassadors Program. And we're really excited to share a little bit about the foundation's advocacy network with you here tonight.

Sydney Shepherd: Thanks, Patrick. Next slide, please. All right, so, what is the advocacy champions network? So, our advocacy champions, again, who have joined us for this call today, our top tier advocates, they've when you think about advocacy, there are different levels. At the bottom you have people who engage maybe tweet about public policy issues might talk about the living donor protection act or other hot topic issues connected to the community, then you have your advocates who might actually be more involved by maybe sending an action alert, trying to encourage other PKD community members to message their members of Congress and legislative staff. And then you will kind of look at that top tier. And that's our ACN. Again, thank you guys for joining today. Our ACN is dedicated to building relationships with members of Congress and a legislative slate of slack staff. And what they do is basically host events and invite members of Congress, I believe, I don't know if Patty was able to join today.

To participate in events. They are building relationships with their members of Congress and legislative staff and promotion of public policy issues. They regularly engage in public policy training. So, you know, how can we best promote policy issues? How can we leverage different social media platforms? How can we leverage our social networks to engage lawmakers and promotion of public policy issues?

So, basically, these are our supreme or top-of-the-line advocates, who, you know, are just dedicated to building a stronger PKD community and engaging lawmakers on behalf of their state and districts. Next slide, please. All right, so, we have some of our again, our ACN one, this webinar today. I am going to start from the top of my screen with

introductions and I think I see Greg So Greg, would you like to introduce yourself fairly quickly?

Greg Mainolfi: Hello, greetings. Let me take a sip of my water really quick. **Escape.** My name is Greg. I'm a PKD patient and advocate out of Baltimore, Maryland. I've been part of the PKD advocacy champions networks my second year I'm, I've been participating in the PKD foundation for many years. My mother is a PKD patient as well, it's me and her, she was a dinoho case. She's got a transplant under her belt, 10 years post-transplant this June, and my dad was a living kidney donor.

I've participated in another number of different research studies, whether that's taking different placebo-based research studies, or I've also done actual research my undergrad was in genetics, and I focused it on PKD. So, I was able to work with some doctors and researchers at the University of Maryland, which is pretty great. And then once I graduated from my undergrad, and for the past, coming up on six years now, I've been coordinating organ transplants in Maryland. So, I've been very involved with organ transplants, and as a whole and really very passionate about polycystic kidney disease and kidney transplants in general.

Sydney Shepherd: Thanks, Greg. And I think I see the Neb Next, I'm sorry, Nadine. Sorry, Tamara. Tamara sorry.

Tamara Y Walker: Yes. Hey, everybody. I am Tamara Y Walker, and I say my middle initial because I do have a relative with the same exact name and we live in the same exact city. So, we decided we ought to differentiate each other with our middle initial.

So, I'm Tamar Y Walker, I am an advocate and ambassador with a number of organizations and the kidney and transplant community. I share my experiences with PKD, polycystic kidney disease, dialysis, kidney cancer, and the removal of both of my native kidneys and a successful transplant from a deceased donor, thankfully, so, I'm about seven years about to be eight years out from my transplant. So, excited about that.

## Advocacy

And I'm so thankful that I was moved or uprooted from my hometown, to move over 300 miles away, just so, I can be near my supportive family to help me through this journey. And I wrote about my story, I wrote a book about it. It's called a medical bill from heaven with everything that I've been through, regarding PKG. And just like I said, dialysis, the transplant, and the removal of both the kidneys. And thank you for having me.

Sydney Shepherd: Thank you, Tamara. Laney

Lainie Esquivel: Hi, I'm Lanie. I am from Fresno, California. And this is my first year in the advocacy champion network. And it has been so much fun and so informative. And this time last year, I was sitting in this session learning about what the advocacy champion network was. So, it's very exciting to be looking back and saying, oh, I've learned, I've learned so much. And I'm really excited for what the future holds **joke** and I'm a PKD patient. I'm currently taking tolvaptan.

So, I'm going to pause every 30 seconds probably to chug a bunch of water. My dad is a transplant recipient, he actually was a recipient from my mom. So, that was a wild ride about five years ago last week. And I have experienced a lot of complications of my own most recently, sepsis from a kidney infection and I also had preeclampsia with my daughter so, with all of that I've really found that diving into advocacy work and trying to connect with others and just see kind of what good energy I can put into this community and into this world has really helped me kind of balanced and you know, deal with the things that come up so, I'm really happy to be here and really excited for what the future holds.

Sydney Shepherd: Thank you, Lainie. Kay.

Kay Gilbert: There we go. Hi. Kay Gilbert. I'm in Manhattan Beach, California. My then-life partner now husband was diagnosed with PKD in 1999. And with no family history, you know, that he knows up. So, we knew nothing. And his mother who had ties to Johns Hopkins told him about the foundation. So, the next conference he went to when we've been going to the conferences ever since and educating ourselves and we're

huge proponents of these conferences we have nagged and whined and pushed and funded them and we're so glad to see that they're back on track to doing them annually. I donated a kidney to my husband in 2015 and we're both doing okay. I mean, I see you, especially with COVID. Dangerous, we never anticipated with, people who are immune suppressed. But we are dealing with that taking advantage of all the meds that are out there for transplant patients. And I'm very happy to be involved with the advocacy network. I have been talking a lot about the living donor Protection act, because, you know, we live in donors need to be protected come on, should be a no-brainer. And, again, my husband and I have been pushing for years for the foundation, to reeling much more outreach to communities of **color**.

And I think that the fact that this is now a priority is really, really encouraging. And also, these virtual conferences, which we've sort of been forced into, but they are loud a lot of people participate who otherwise you know, they couldn't afford the time or the money to travel to a conference. So, I'm really hoping that as if, as one of the arms of the outreach program, there will continue to be an online portion of the conference even starting next year, when one hopes we go back to live conferences.

Sydney Shepherd: Thanks, Kay, thank you for that introduction. Let's see who's next. I think it is Michelle.

Michelle Hoffmann: My name is Michelle Hoffmann. And I'm from Leesburg, Virginia, which is right outside of Washington. I do not have PKD. But my connection to it is my husband, whose father had PKD. And out of eight children, he was the only one that had PKD. In 2015. He had a transplant he had a live donor; it was his youngest sister. And so, every year we celebrate our kid, his kidney anniversary, in on January 16.

And the day he had; this is the kind of an interesting thing the day he had his transplant was 50 years to the day that his dad died of PKD. So, what in his family was a sad day became a very joyous day because the gift of life was given. We are first I first volunteered with the foundation,

## Advocacy

and we did the walks for several years. And then two years ago, I became the walk coordinator for our area.

And then this year is my husband my first year as an advocate. And I found it to be very interesting. I've learned a lot about PKD. About services. I also learned how fortunate my family is because, my husband out of eight children, he's the only one that has PKD. And then, you know, he's had some complications, but nothing like other families have had. And so, I would say that our process has been a very smooth process.

He had his seen in 2020 to have his native kidneys out because there were complications. So, he's had some other things. But I really have realized how fortunate we are. So, anyway, I've learned a lot about the legislative process, because it's been a long time since I've been in school a long time since I've taken a government class a really long time. And even though I worked in a high school, and I talked to government teachers, you don't get into the nitty-gritty of how things work and how things get done. And so, that's been a very interesting process. So, I would encourage anyone that has an interest in PKD. Go for being an advocate. It's great, it's been a great experience.

Sydney Shepherd: Thanks so much, Michelle, and we appreciate your transparency. Jim Myers, I think Jim is on. All right, great. I think you have to unmute yourself.

Jim Myers: Hang on I'm here. How are you?

Sydney Shepherd: I'm fine.

Jim Myers: I'm Jim Myers. I'm from Hammond, Indiana. I'm a PK D patient, 42 years now. I've been a PKD advocate for over a decade on a part of the advocacy of champions. I guess if I had to pick my forte. It would be advocating on social media. In particular, something I like to do very much as I do educational broadcasts. For Kidney patients on stream yard, I try to do everything I can to raise awareness and to educate other people about our disease. I run over 80 groups on Facebook, and I'm on

## Advocacy

about every major social media platform that you can think of. So, that people call me Uncle Jim. So, please.

Sydney Shepherd: Thank you, Jim. And lastly, Karen. Karen Edwards.

Karen Edwards: Good evening. My name is Karen Salomon Edwards. I'm a patient, advocate, and ambassador. I'm the only one in my family with PKD. I'm a public health official, retired public health official. And public policy is critical for me as a PKD patient, and my advocacy as far as getting legislation passed, such as the Living Donor Protection Act.

Currently, I am working with some individuals in the state of Michigan. We will be meeting this Thursday with Zoom to develop a strategy where we can get the LTPA sponsored and pass in the state of Michigan. I must say that my kidney journey has been very challenging. That has been very difficult. The pandemic did not help it all resulted in me having depression Well, I had it before, but I guess the pandemic, worse than itself.

There are other health challenges that I have learned. Having PKD matter of fact, one of the sessions that I just participated in, I learned about how aneurysms, the high blood pressure, and the kidney is so critical. And then I reflect back when I didn't know I was ill nothing yeah, I remember that happening.

And even now, I participated in the training on cardiology as an advocate, and participant with advocacy champions, I think it's my duty to learn as much about that function of the kidney, and how it has impacted me. So, again, I'm very humbled to be here. And we're going to do this as far as getting legislation passed for polycystic kidney disease. Thank you. You're on mute. We can't hear you Sydney.

Sydney Shepherd: I was saying thank you, Karen. And I think Tim is actually last. So, Tim, you would think we would have a down pack by now with a new button. I'm good at it.

Tim Miller: Alright, can you hear me now?

Sydney Shepherd: Yes.

Tim Miller: Okay, great. Hi, I'm Tim Miller, and I'm here in Atlanta, Georgia. I've been a guest working volunteering for Well, I've had a kidney transplant, and it's going to be 19 years next week. So, I feel really good about that I had a very short time preceding it to do dialysis. So, I've got a good understanding of the whole process. My mother had, has had PKD, I have PKD, my sister has PKD, she just did her second transplant. And, and also my son has PKD.

So, I'm very invested now and, in the future, to see, tend to shepherd this through, you know, beyond this upcoming legislative session and to more and see how we can contribute. I think it's important as I guess we're all associated with this so much so deeply. You know and being a transplant patient and seeing what my sister went through, my mother went through, there wasn't anything back in the day with her.

That was a good 40 years ago, she really didn't have a really good robust dialysis treatment nor transplant, maturity, so, to speak with the hospital. So, I've seen it from a historical perspective, and I just, I'm so excited about what you do, and you guys are doing great. It's just, you know, the PR side. You know, the conversations, the legislative discussions that we've had, it's been really, really progressive and I think we're, we're really got some movement here. So, some momentum so hopes that gives you some aspect of what I'm looking for and I'm glad to be part of this, thank you very much.

Sydney Shepherd: I'm always happy to hear that you think the program is progressing. And I've, you know, we're only in our, I believe our second year now. And we're already at about 36 advocates or members of the ACN. So, this is just a small representation of the diverse experiences that many people in the program have had. Some people don't even have PKD, maybe a family or a loved one has PKD, but you're welcome to join if you're passionate about these issues.

So, I'm actually going to go to the next slide just to give you a larger display of our state coverage. So, as you can see, we are spread out from

## Advocacy

the east to west coasts, and about 27 states are represented. So, rural and urban communities, suburban communities, as well, this is really important when you're trying to make an impact across the political spectrum, you don't want to, you know, a program just to be focused on one party, this is a nonpartisan effort, it's really just about getting policies passed, that will be a benefit to our community. So, we engage lawmakers across the aisle. Next slide, please. So, this may seem a little disheartening. This is our district representation. So, each of these tiny locations highlighted in green represents a district that is covered.

And while this does seem pretty small, remember that we're engaging senators as well as members of Congress or House lawmakers. So, the impact is just as strong if you can find one champion in a small community, who knows what kind of advocate they will be for us on the federal level when it comes up for a bill to be passed through the house of the Senate for a vote.

And we've seen this, and we have our champions like Representative Debbie Wasserman Schultz, who has been a very strong champion of ours, as well as other members who you know, just have a heart for the kidney care community. And just another fact is about 37 different congressional districts are representative, which is pretty great. But we always want those numbers to be higher. Next slide, please.

All right, so what is one of the most important components of the ACA in it's about meeting with members of Congress, and now that, you know, the pandemic, although it was unfortunate, it's kind of revolutionized the way we meet with lawmakers, a lot of times, advocates would only, you know, write to their members, or maybe have a phone call.

But I think this whole process or a meeting with members has been sped up or revolutionized through different platforms. So, one of the activities that the ACN regularly engages in is meeting with legislators to discuss different policy issues. So, each year we compete for research funding, and we compete for different bills were competing against cancer groups

## Advocacy

we're in both are equally important. It's not always appropriate to say, labeled as a competition, but we also have to raise our voice so, that we're not lost in that crowd of that mix.

And that's when the ACN comes in. A lot of times, PKD is a foundation, a lot of times, lobbyists or different groups will engage lawmakers and support a policies, but the lawmaker might not care as much because it's not representing their constituency. They want to hear from directly from their constituents on issues that affect their day-to-day lives.

And that's when the ACN comes in. So, ACN champions have met with their members of Congress and standalone meetings. This year, they participated in about 65, less congressional meetings so far in 2022. And we're only about halfway through the year. So, that's really remarkable for a group of 36. And that number is going to uptick, I'm sure during August recess when members of Congress are back in their district trying to get a rally of votes because we're coming to the end of the congressional term. So, it's really impactful that we try to get, you know, the ball rolling, especially with bills like the LTPA, which had been around four or few congresses, and we're really trying to rally together to get this bill passed.

But along those lines, they participated in 12 Senate level meetings and seventh house level, house level meetings, and they also served as State leaders. During our inaugural advocacy day. I don't know if you guys are signed up for PKD action alerts, or just when the PKD newsletter or to receive the PKD newsletter, but this year we held our inaugural advocacy day where members of the ACN including some folks on the call promoted the advocacy day creative videos, and I still believe they're up on the website on Facebook if you want to Check them out.

But basically, they have all this experience participating in training. They know what meeting with a member is like, they know what meeting with a staffer is like. They understand the policy. So, they were able to serve as leaders and talk to other people who wanted to advocate

and kind of guide them throughout their meetings and their virtual advocacy day.

And I think that's a really remarkable component. For some of these, this was their first year being a part of their program. But they still stepped up to the plate. And it was extremely successful. And I think Patrick, he's going to drop a link to like the stats, and just an overview of how the event went, if you want to learn more about it, Patrick thanks, next slide, please. All right.

So, ACN members also have a membership and just a Facebook group. But it's an awesome way to communicate in terms of like, what's happening in their state, you know, strategies on how to engage legislators, sharing their stories. And you know, it's a great forum. I think one of the best components of it is understanding that there are people who have shared experiences and being able to communicate those shared experiences without judgment.

A lot of times people don't, lot of times people don't want to hear about your story. They've heard it before. But being in a community that understands you know or shares that same experience is really important. And that's another platform that the ACN and are able to do that one. And then again, just share tips and trips, trips for outreach. The PKD does a great job of providing resources or creating resources for the ACN to use during their engagement.

They're just not doing everything from scratch, but have like a springboard to start from. And then again, just engaging other advocates in the PKD community. Next slide, please. All right. So, another critical component, I think this is second to, I would say this is second to meeting with legislators is actually just emailing them making sure that members of Congress know when a bill has been passed in the Senate, and now it's their turn to pass it in the house.

Just understanding policies that the PKD community or more specifically, their constituents who are in the PKD community are in supportive of. So, the PKD action alert page is actually already open,

and it's up on the PKD website. And anyone can participate in action alerts, it doesn't have to just be the ACN. But the ACN do often encourage their, you know, their family and their friends and their network to complete these action alerts.

A lot of questions I get about action alerts, it's like, what are they? And you know, why is it a pre-written message? Like, doesn't the staffer think that this is kind of like, carefully orchestrated? And doesn't this seem inauthentic for me to just sit and send the same email as everyone else? And the answer is, no. While it does seem orchestrated, members of Congress do understand that that is pretty normal.

They actually just tally up how many emails they get on a specific issue and then presented to their boss and say, Hey, I got about you got about 100 emails today about the living donor protection act. So, you can customize the email, if you'd like to, if you have a personal connection, like maybe, you know, the member of Congress is your son's best friend, or whoever whomever, you can customize it as well using that platform.

And sure enough, it will be sent in, you know, sent to the health staff to make sure that they are able to send that to their member or their boss's desk. So, just wanted to put that out there, I get that question. A lot of times, but right here, I think it's critical that, you know, I emphasize the importance of acting as a collective. It's just one thing for one person to send an email per month.

But again, if you have 100 people, emailing a legislator about a specific issue, it's kind of, you know, goes to the top of the list and list and becomes more of a priority. So, just wanted to emphasize like, it's all about the collective here. I know that we all have busy schedules, but there are times when we call them the ACN to send them, you know, reached out to a member of Congress at the same time just to raise their voices in support of these policy issues.

Next slide, please. All right, so, here are just a couple of photos. I think it's just great to see like some of the work that we were doing virtually, you know, we'd love for everything to be in person but as I think it was,

it might have been Kay or Michelle mentioned it just makes life a little bit easier to be able to do things from the comfort of your own home, especially when we have all these different priorities in life. But that doesn't mean you can't be an advocate from home and participate and really help for legislative change. A lot of people have virtual jobs. And this is kind of not as hard as a job.

But it is kind of like a virtual, I would say a virtual working from home, activity or engagement. But these are just a couple of examples of times we met with lawmakers and staff during the virtual advocacy day, and just during different points in the year. Next slide. All right. So, one of another critical component, when you think of an advocacy program, or a very strong advocacy program, one component is government relations, again, ACN receives training, so, they understand the policies, they understand the bills, but another critical component is media.

A lot of times members won't pay attention to, news that's happening in another state, but they're always tuned into their local newspaper. And so, what we try to do is work with our ACN to get op-eds or letters to the editor placed in local media, and we often help the ACN in crafting that message, we definitely want it to be personalized, but we understand that sometimes it takes a second to get the wheels turning.

So, we're here to support them and that engagement, but not only is this a great opportunity, you know, for you to get on that your congressman or Congresswoman radar, but it's also the perfect opportunity, you know, for you to spread more awareness in your communities about this issue, who knows who you might reach a lot of times, especially in kidney care, you never know, some people, a story might resonate with them, and you never know who you're touching, it might prompt them to go get tested, and prompt them to do digger research, deeper research and to their family history.

So, that is another critical component of the program is working with media and learning how to build those relationships. So, these are just some examples of some op-eds, I believe that we got placed and then

we'll also be working later this year, probably this month or next month, or yeah, July or August to get some more op-eds and LTs placed. Next slide, please.

All right. So, I kind of already touched on this, but just a brief overview, what is the advocacy champions network, it's a strong voice to advance our advocacy goals. It's an opportunity for you to engage with lawmakers in a way that you may have never done before. And it's a year-round advocacy program. It's you know, you don't have to pay to get in.

This is all on you your level engages of engagement as determined by you and your workload and what you're able to carry. So, who are they? They are direct right now we're at 36. Hoping to get that number up, I would love to see representation in all 50 states, and I think many of the ACN would as well. But that is a long-term go we understand this is again the second year, but we've already made strides.

And we have representation in 27 states, which is remarkable coverage currently. If you're willing to put in about 10 hours a month to support the advocacy mission, this might be a program for you, it doesn't always add up to 10 hours, it might be five hours, we're not calculating your hours. Again, we understand that different priorities in life may take you away from the champions network, we just asked that they notify us but we expect during especially like, for example, last or in April, we had the virtual advocacy day.

That was probably a 10-hour month. Just because they were meeting other people from their states with PKD. They were meeting other people who wanted to become advocates and who were kind of nervous about the experience. So, just coordinating that, making sure they were able to speak and prepare for meetings, that took a lot of time.

So, just a heads up there. That's an example of like a higher month, but that 10 hours is probably on the high end. And then just if you're willing to be an advocacy leader within your community, so, we always encourage the ACN to offer feedback, like what do you think that you

## Advocacy

could get out of the program? What do you want to see a change in your community? How can we better engage your community, and that's part of being a leader? And also, just taking the initiative and making sure that this commitment is something that you follow through with so we really appreciate the ACN and the leadership or the leadership role that they're taking in. You know, engaging with lawmakers, which can be very intimidating for someone who's never done it before.

And then lastly, just how participating in these bimonthly education and training webinars, they sometimes we try to have them once a month now. But sometimes we might skip a month if you know we've had a heavy month like the virtual advocacy day was pretty intense. So, we just had another webinar in May, that was just recapping, but we try to do monthly webinars, we understand that not all the ACNs are able to make one.

And then also, we're going to create those close, dedicated, communications channels. So, you can talk openly about experiences you've had, working with members of Congress and legislative staff, and then just organizing for legislative action. And this is something that the foundation does a great job about just kind of mapping out this advocacy plan for the year. So, we kind of know what to expect. We know when appropriation season is coming. We know when we really need to advocate for more research funding, we know, these influx periods where we need more advocacy support. So, it's just about organizing, gathering us together so we can take collective action.

I think that there was in the slide after this. All right, just get involved. So, here is just a QR code. So, if you're really interested in, you know, joining the ACN, I think this is a great opportunity. I'm happy to answer any questions now about the program. But if you're interested in learning more, and you know, signing up to become a champion for 2023, or 2023, I think this is 2022, says 2022. But it should be 2023. You can scan the QR code, or Patrick will drop the link in the chat.

Dean Lotito: Thank you, Sydney. I don't have any questions in the chat window right now. But if there's anyone who has any questions, type them in the window while asking to know, we're good to go. We really only have about 12 minutes left in the session. But we're certainly up for any questions. I just want to comment that I took part of the virtual sessions as April and it was really, really good. I really enjoyed it a lot. And you guys were very helpful. So, I thought, you know, really satisfying.

Sydney Shepherd: Great, thank you. That's great.

Greg Mainolfi: I would just add a comment, like for those of us maybe that is on a session or maybe watching recorded later. Just I really love being a part of this. I mean, it seems like it seems intimidating to be, oh, you're talking to these members of these representatives of our states and legislation. And, how can I make an impact, and maybe it's going to be a big commitment. But you get involved you get you meet these wonderful people. And you learn a lot about this process.

And it just flows. I feel like it's not something that drags me down. And I look forward to our sessions every month. And once you actually get to check some of these things off, I did meet with members of Congress, I submitted an op-ed I was sending these emails, they're really satisfying to have something tangible that we've been able to put out into the world and make some actual difference in progress.

Sydney Shepherd: Thanks. Greg. Thanks so much. And I think that oh, yeah, go ahead.

Tamara Y Walker: If I may a saying I'm sorry, I really enjoy us coming together, we're coming together with just one common goal in mind and one common interest. And we're able to reach the I call the masses, people that I may not be able to reach on my own are elected officials, they're making laws and they affect us and by us, using our voice reaching out. And number one, just sharing our experience with PKD.

A lot of them have never heard of PKD let alone kidney disease, you know, and we're sharing our experiences, our journey, our stories with them. And to me, that's number one, educating them on PKD. And also,

## Advocacy

just, encouraging them to support PKD either research or PKD research, allocating these funds. This time I spoke about disparities in our communities.

And so, yeah, just sharing our experiences, letting our voices be heard. It feels really good to do so, I do agree with you, Greg, it feels really good to do so. And they need to know, elected officials need to know what's happening with us, like you said, their constituents, they need to know this. So, if anybody's listening, hey, come aboard and join us, like Sydney said we meet once a month. And that's virtually.

And we're hoping next year that we can meet on Capitol Hill, I'm hoping everything will be well enough for us to meet on Capitol Hill and share our stories face to face with the staffers and hopefully elected officials, so, come on board, it doesn't take a lot of time. We meet once a month, that's for one hour. And virtually you can meet like Sydney said in the comfort of your own home. Very convenient.

Sydney Shepherd: Thank you. Tamara. Does anyone else have any comments about the program? I didn't want to add one last thing, because I want to get an update. I think we had about six or seven new co-sponsors of the LTPA. Since the virtual advocacy day, so, correct me if I'm wrong, Patrick. I'm going to have the stats up, but they're there.

Patrick Meade: Yeah, I don't have the exact number right at the tip of my tongue. But I think that's about right. I think it's for who we specifically had advocates meet with on that day. So, that's kind of a tangible thing that we can look at the point at and say that's part of, what the ACN and PKD. Advocacy has been done. And unfortunately, that's a little bit of a lagging indicator. So, we expect there to be more co-sponsors over the next couple of weeks and months. And we look forward to highlighting that as time goes by.

Sydney Shepherd: Exactly. Thank you, and there will be a new update regarding that bill during our next call. So, just an update on that. I'm going to talk to Chris about it. But thank you, guys, all for joining.

Advocacy

*[Audio End] [1:02:36]*