

Managing Life with PKD

Danielle Rose: Welcome everyone. I am Danielle Rose, I'm with the PKD foundation. I'm the hospitality host for the managing life with PKD session. And before we get started, if you have any questions, you can type them in the chat box. And we'll address those in the Q&A at the end of the session. We ask that you keep your microphone muted, so that we can have great, good quality audio, and I'm going to turn it over to our presenters for managing life PKD.

Ashley: All right. Hi, my name is Ashley Montgomery. Can you hear me? okay, Danielle?

Danielle Rose: Yes.

Ashley: Great. I am living in Northwest Arkansas. And I have a daughter Abby, who is now five years old, with ARPKD and eight-year-old daughter Megan, who is unaffected. Little bit about myself and my story. When Abby was 18 months old, we had her check-up with our physician. And he noticed that she had a distended belly. And so that put us on our course of trying to find out what might be wrong, it took us about six months to get a diagnosis only because initially, they thought that it could be something wrong, cancer wise, or a virus. And so, there was a period, because we didn't initially have a CT scan, we only did ultrasound with that they were kind of grilling other things out. So then, when nothing changed over those, about four months of the summer, we were referred back to the Children's Hospital from our cute bio paediatrician.

And that's when we underwent further testing and found out that she had a ARPKD. And so, we've navigated 18 months until now she's going to be going into kindergarten, this fall, day-care and kind of those early toddler years, and how we communicated with our day-care providers, how we communicated with families and our daughter, daughters, as they grew up in that age of communication, where we had to be kind of careful what we said what we didn't say, and we wanted to be honest, but we wanted them to be able to handle that information. So, I'm happy to be here today and to talk with all of you about that.

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Alix: Thanks, Ashley. Sorry, it took me minutes to come off mute, to find the button. So hi, everyone. I'm also one of the speakers today. My name is Alix Petrelli. And I have a 10-year-old son with ARPKD. So, we live in the Northern Virginia area. And I have two boys. I'm also a military spouse, and my older son is impacted with ARPKD, but my younger son is unaffected. My career is change management. And so, I try and utilize that skill set whenever I can and offer my professional services to the PKD Foundation, or as I'll talk to in a few minutes about any of the ARPKD researchers if they ever need some of those skills, I'm always happy to offer those and help out just to kind of move any kind of research further for our kids. My son was diagnosed at the age of five. So, he was in kindergarten, which is sometimes a little unusual.

I know that there's a lot of younger kids and also babies in utero that are diagnosed, but we found it at five. We had no idea. My son was wetting the bed quite a bit. And we had done a couple of things to try and help them and it wasn't working. So, I just asked the doctor if there was anything else we could do. And they said Well, we'll send you out for some more tests. And lo and behold, we were not expecting an ARPKD diagnosis but that is what we got.

And so is now 10 and doing well. I'm hoping to help talk about today is just this stage of life. So, elementary school years and navigating the aspects of ARPKD while you're trying to navigate the rest of parenting and this stage of life, and just the complications and the wonderful things that go with that, and also some of the challenges as well. And so, I'm really happy to be here and talk about our experience as well. So, I'll hand it over to Michelle.

Michele: Hi, I'm Michele Karl, I live right outside of New York City. And I have three boys who are 22, 19 and 16. And my oldest and my youngest, the 22-year-old and the 16-year-old both have ARPKD. We're also a little bit different story in that we did not find out about ARPKD until my youngest was born. So, at 34 weeks, I had no amniotic fluid, and we delivered, and he was diagnosed formally with ARPKD at four weeks of age, and our older two or three and six at the time, thought to be healthy. And we did a sonogram of

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them. And our six-year-old showed sister's kidneys, but at the time, he had no symptoms. And it's been a long, 16 years of knowing about PKD and navigating the schools and doctors, but my boys are both very stable and doing well.

Ashley: All right, I'll take over. This is Ashley, again, with the day-care perspective. Some of the things that I really worried about when we found out our diagnosis was that my daughter was 18 months old. And so, there wasn't a way for her to communicate what was wrong. And so that was really scary. And there wasn't a lot of control that I could take over the situation being that I was working. And she had to be in day-care. And so, one of the things that really gave me comfort was that I was very open with our day-care staff about what was going on. And I wrote them a letter and just asked them that they have it on file, that they give it to any of the caregivers that were going to be rotating through her class, at our day-care that we used, it was not uncommon to have two primary teachers, but possibly three or four other teachers that would be rotating in and out and taking care of her during the day.

And so, it was really important for me to, for people to know what our situation was, so that they could help me keep an eye out for issues. And so, in the letter I was, I tried to phrase the information in a way that any lay person with no medical background or experience could understand. And so, I told them what she had, I told them how that presented because you can definitely tell by 18 to 24 months old that her abdomen was quite large. And so, I explained why that was I explained where the cysts were. And what that meant that she couldn't concentrate her urine, so she needed to drink a lot. I talked with them and wrote about how we were monitoring her sodium and potassium and what our physicians had given us as limits. And I even went so far, and this was maybe a little bit more for my comfort.

Because during that time, you can't control anything, but you can kind of try to choose there, help them choose what they're fed. So, I talked with our day-care providers, and of course, they kind of had a list and a routine of their meals. And most of their meals were prepared meals there wasn't there wasn't too much that was homemade. So, things like Stoker's lasagne for

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lunch or preparing snacks. There were a few homemade items that maybe were a little bit difficult to figure out the sodium content but chicken nuggets, all of those things I could research or go to their kitchen and find out how much sodium was in those foods. And so, in that letter, I mentioned those amounts that our doctor had given us recommendations and just asked, I didn't want them to police her.

But if they were having pretzels as a snack, I might bring in extra apple sauces or something and just kind of just give them that that information. Maybe she doesn't need a full serving and pretzels to use that you know more than her sodium allotment for snack that day to try to push other items if she was still hungry, and that really gave me comfort, to know that we, as a team were kind of doing our best. And the other things I mentioned in the letter. Because, again, a lot of the caregivers came in and out, but also a lot of the caregivers were young. And so, there, there might be an 18-year-old changing diapers that doesn't know what blood in stool looks like. And so I gave those descriptive terms of we need to monitor for blood in her stool, and this is what blood and in a diaper may look like.

And then just had reassured them if they had any questions to take a picture of it and sent it to me. And I would let them know if they needed to be worried at all. And so that really gave me a lot of comfort, it was a lot of anxiety. Those first, I would say a year or so after a diagnosis, when we kind of got into more of a routine and and felt comfortable with it and more comfortable with our caregivers. But that really helped us a lot. The other thing that we talked about with our daughters at the time, and as my daughter as she was learning her language, being that day-care age was we talked with her and her sister you know about these are the reasons why we you may there may be some special rules for her.

And we talk we describe, we do say her liver and kidney issues, and we call it tummy troubles. So, there's a lot of acknowledgements in our house that we can't do this or that because of her tummy problems. Or we have to go to the doctor so much because of her tummy problems. And so those are things that I think I've seen other parents' question about how do they talk to their

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young children about ARPKD and there's a lot of information that you could overwhelm them with. And then you could also try to protect them. And so, we as a family have, I feel like has kind of gone middle of the road, which has worked well for us, and have been learning to cope with that.

The other things that I wanted to mention kind of with our stage of life was because we were a young child's family, we were not sure yet, where we were in the family planning process, we'd had our second child. And so there had been hopes for a third and discussions about that. But then when we got our diagnosis, we were thrown for a loop like most parents are, we were completely overwhelmed by it stressed out about it. And just dealing with that aftermath. And so, one thing that I like to share with other moms is too, even though it's overwhelming at the time to try to think about that and have your options open. And so, one thing that we came to the decision of in probably about two years ago, is that we wanted to see what the process might be for IVF. And to see if we could have a child without ARPKD.

And so, we had not gone through the genetic testing for ARPKD, because our physician said it looks like a duck. It sounds like a duck, it's a duck. This is most of this is absolutely ARPKD. And so, we had never gone through that genetic testing. And so, by the time that we had made that decision, I was I think 39 at the time. And that process is a long process. And so, one thing I'd like to kind of throw out there for new parents who may see this and are not quite sure of what their family planning might look like is early on, go ahead and be sure and do the genetic testing would be my recommendation. Because at least you'll have the information and that choice down the road is not hindered by that. And the genetic testing for us took about eight months or so. And so, it was a prolonged period. And then the appointments that we had with IVF physicians before anything started took many months.

And so, there's a lot of time involved to get to the point of making the decision of whether or not to move forward. And so that's something that I'd kind of like to throw out there and just make sure you're having those conversations and thinking about that, and encouraging you to explore that, so that you're fully prepared when the time comes to make that decision. The third thing

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that I wanted to mention and talk about was just an emotional outlet for yourself during those early years. During our toddler time of diagnosis, there was a lot of emotions anyway with the diagnosis, having small children, the stress of work, all of those things. And I realized now how much I would have benefited from talking to someone, someone a professional.

When we received our diagnosis, a lot of family and friends had comforting things that they wanted to say and tried to give support and the ways that they knew how, but oftentimes, it wasn't what I needed to hear. And it wasn't phrased in the way that I received well, and so I realized now that it would have been easier for me to talk with a professional and to talk to someone because carriers are hard anyway, being a parent is hard anyway, and then being a parent of a child with a serious disease is very hard. And so those has just been my few of my suggestions of, of what we went through in these first three years, four years of our diagnosis. What we're dealing with now, as Abby's going into kindergarten, is just how to transition all of that.

And so, having the conversations about what kindergarten looks like, what does she have any needs that we need to address with the elementary school? Do I need to be as involved as I was with the day-care providers now that she has a little bit more, control and verbal skills of what her issues are? So, she can tell me if she's in pain, she can tell me if she sees something in her stool, she can tell me if she feels badly.

So, those are things that we're dealing with now, and, and hopefully going to learn a little bit from Alex about that how to deal with those situations. But we made it through we've had a stable course, throughout 18 months till now five years old. Abby is healthy and happy. We see the physician, our specialist physicians, about twice a year in Kansas City, we're in Northwest Arkansas. And so, we've chosen to go to the Children's Hospital. That's in Kansas City, Missouri, and are very happy with our care and hoping for continued health and growth for Abby.

Alix: That's awesome. Ashley and I received her nodding as you're going through because I agree and have done so much of what you have talked about. And

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I just think that you've raised some really good, great points. So, I think that's awesome. I don't know, hopefully, I'll have some good points. It sounds like you've got a lot of it covered too. We also so again, my name is Alex and I live in Northern Virginia. And my older son Ian, is now 10. And he has ARPKD. I also have a seven-year-old who is not impacted. But he was a very supportive younger brother. And we approached it very much like you did, Ashley where we wanted to talk about, we wanted to we wanted our son to understand at an age-appropriate level what was going on because the internet's out there, he's going to hear it.

At some point, we wanted to kind of ease him into this and so we call it special kidneys. So, he has special kidneys. And that's why we have to go to the doctor more than the kids and when I think when he was diagnosed at five, of course, it was just a huge shock for us and how do you even go about explaining something that we were trying to grapple with and wrap our brains around? So, we brought it down to a very basic level and I have boys, so the kidneys make pee. Right? That's what they do. The liver kind of helps weed out stuff so you they make poop When they got it, they got there was like a very basic elementary school. That's what those organs do. And then we just said, you know yours, when we talked about it, we said yours don't work like everyone else's.

And so, we need to take extra special care of them. Doctors can't see them because they're on the inside of your body. And so, a lot of times, that's why we have to do bloodwork, I think blood work is just the hardest for everybody. Nobody likes it ever. But we say that's the only way that the doctors can find out what's going on. And that's how your doctors talk to your kidneys. And so just in a very basic level, that's how we talk to him and his brother about it. We don't want his disease to define who he is, because he's so much more than that all of our kids are. But it's also something that we didn't want to ignore. And one of the big things and especially now that he's 10, and as we've kind of moved through this is, we would like him to have agency over his body.

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And understand that it's also part of his responsibility to take care of his body. So, one of the things that we try and do as a family is we just try and normalize some of the extra things we do like lots of water. So right now, he drinks two liters of water a day. But it's not just him, everybody, we all have fancy, like colored water bottles. Nobody leaves the house without one, right. So, it's not just him maintaining this thing that's pretty much good for all of us. And so, we talk about smart choices like Ashley was talking about, it's not necessarily pretzels, and it's for extra snacks. It's what's the best, best thing that you can choose whether it's fruit, we've we're trying different types of vegetables.

I wish he would like carrots, he doesn't he like celery. I don't know what kind of kibble he does. So, I'll take it. But any really just kind of reintroducing, introducing in different ways. And just talking about making smart choices. Elementary school is the age of birthday parties, and snacks and treats. And there's all of these things. And so, what I try and do because I think as a mom, and a lot of you probably can relate to this as just as parents is that, like you're the one that has to say no. And I think when you have a child with a rare disease, and you're just thinking about and focusing on their health, you want them to be normal and participate in other things, but because of safety reasons and health reasons, you're the one that draws the line and saying no. And sometimes that for me, it's like why can't I be the fun one.

But what I ended up doing was if we knew that we were going to a birthday party, let's say I would talk to him beforehand about where we're going and what we're doing. And they say would say hey, there's probably going to be pizza, we're only going to have one slice of pizza. Or if there's, potato chips on the side, let's skip the potato chips. And when we can have an ice pop when we come home. And so, putting those parameters in place where we're not completely segregating in keeping them separate and not letting him do the things that are fun. I mean, and enjoyable. But we are kind of setting those parameters. So, we don't have to, because again, I think we had three birthday parties last month, I mean, it just kind of adds up and when being the person

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that has to say no, or like put those parameters that's never, that's never fun position to be in.

But as a parent, it's our responsibility. So, talking to him about why we make those changes why we're making those choices, and just to kind of imprint on him, why we're doing it. And what's interesting as every now and again, I'll hear him talking to a friend or his brother about those choices, or the things that we've discussed. And I know he's listening. So, they are and slowly but surely, it's nothing drastic, but it's just the little changes that we're making. So, that it's kind of like a unified effort between all of us, in our in our family to keep them healthy. And when we were doing we were talking about Ashley, Michelle and I what we wanted to discuss in other points of what we wanted to share with other parents. Something that was just important for me and things that I really feel strongly about is research and clinical trials and clinical studies.

And so, when my son was first diagnosed, I like to think of is what do I do? How do I how do I help what how do we change this? How do we when is there going to be a drug ready? When is there going to be something how do we how do we make a difference and so being part of the PKD Foundation has been really helpful in that regard. And I've also reached out to different doctors who research ARPKD. So, specifically Dr. Guay Woodford, and I know that she has a seminar, I think after this one, and she's going to be talking about some clinical trials for her. So, definitely check that out, I encourage you to do as well just to just to learn and just to hear information. But Dr. Dahl has a study, Dr. Hartung has a study going on. And I think that participating in the studies really helps me and my family feel like we're doing something to help move the needle, and helping these amazing doctors find out more about this disease.

Because when it's rare, as you all know, there's a lot of doctors out there who they can't tell you, they don't know. And so, if there are doctors that are willing to research this, then let's help them do that. And they need us and our kids to participate. And sometimes some of that stuff is virtual, I've participated in a couple of things where it's just a couple of questions. So, it's

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not even done looking at our kids. If you're not on the Facebook pages, the ARPKD or the PKT in children's chapter, I highly recommend you guys sign into that there's a great wealth of information and support out there. And I do share information about studies that either we've participated in, or studies that are ongoing. So, even if there's one that I shared for ad PKD. Last week, and so being able to participate in these really makes me feel like I'm doing something, and my son, we actually turn it into little trips, when we go up there.

And we actually have a really good time together. So, it isn't just a focus on the disease. It's a new city. And it's something that we can do together. And he knows he's helping the doctors. And so that makes us feel good. And like we're being I needed to do something. And this is one way in which we do that. And I also just as we're I know, I don't want to run out of time, because I do want to hand it over to Michele. But one of the things, again, is just talking to other parents, other moms is just I initially, really just wanted to put in a bubble and just protect him. And I realized that I was kind of limiting him if I did that. And so, I really want to build resilience within him. I encourage him we talk, we even at this age to ask questions to his doctors, so that it's not just me, and he's sitting on the chair and just waiting to be looked at. I want him to be an active participant in his health.

And I know that's me sounds strange, even at 10 years old, that we're already doing those things. But it gives him I think it empowers him to take care of his body and to know that he's doing the things that he needs to do for himself. So, with that said, I'm going to pass it over to Michelle because again, Michelle's got older boys, and I've called her she's been a wonderful resource, as well. But she can probably speak a little bit more about what that's like and moving on to the high school and college years.

Michele: Thank you, thank you. And both of you, you both had such great points, things that I forgot that happened. For us it was it was interesting when our son was born, and then our older son was six at the time when we had to tell him that he had a kidney disease, it was easier for the baby because he always had it. And so, we just really started talking about the baby and that his

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kidneys were different. And then one day luckily my oldest his name is Max, Sybil, are my kidneys different. And we said yes, since I've went on. And it's an interesting ride. It's going through elementary school, middle school, high school, and now Max is just graduated from college. And it's definitely different experiences each time. I think the biggest thing is stressing in starting in elementary school is to get your child a 504 plan and have it continued with them.

Even if they're stable, even if they're doing well get that 504 plan in place at your school. I know that we're kind of short on time today. So, I won't go into all the details, but we have perfected our AR 504 plans over the years. So, I would be happy to discuss with anyone you know what you need, what I think you need in your five outputs for plan and how to do that. But another thing is that what helps is to have that fiber floor plan and make sure that they have the teachers all have the plan ready for substitutes and that there's a picture of your child. We had an experience once where my youngest was in third grade. And the substitute got him confused with another child because there wasn't a picture and wouldn't let him go to the bathroom. And it was a lot and he actually started having a lot of anxiety about it with substance it's coming in and different people telling them different things at school about going to the bathroom or getting water and feeling different than the other children.

So, 504 is definitely a big one. And even when they get to high school, I still email all of the teachers at the beginning of the year, my boys, I love how Alex is having her son asked questions. Now, my boys are very shy at school about talking about their kidney disease, they don't want their friends no, they're good friends, no, but they don't want the whole class knowing. So, I send an email at the beginning of the year, just outlining a few things, telling them I'm available to talk anytime. And that the boys don't are a little bit shy about it. So, they don't want to discuss it. Some important things on the fiber for like, sometimes they have you take tests and other rooms to give you extra time. But my boys didn't want that. Because academically they're doing well, they're stable in their health.

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So, even though they had a five, a four, they, the school kept trying to pull them out to have their tests and other rooms so that they would have access to the bathroom and water. And so, we had to talk about that. And I had to listen to my boys and what they felt comfortable with. I think like Alix said, it's so important to have them start asking questions to the doctors, we talk about how doctors, you have to be respectful to the doctors, but sometimes you could go to the doctor, and they might not have the information, or they might not be the right fit. So, you can question what they're telling you to do. You can break up with that doctor and try and find another doctor, you can bring in paperwork and say this is what I learned.

And now that Max is an adult, and he's 22, we're still with pediatric nephrology, urology, they're letting him graduate from college versus actually staying one more year in college for masters. So, they're letting him finish one more year of college before he transitions. And I think that's great. But also, they've given him their email addresses. So, he can email them and ask them questions that he might not feel comfortable asking in front of me. We're pretty open, and we talk about things and I'm not going to be blinded that oh, my child's never going to do what he shouldn't do in college. And so, he does drink alcohol. And we've talked a lot about it, he actually had some blood work this week, that wasn't so great. And so, I think it's going to be a wakeup call for him and awake, a wakeup call for all of us and talk about it more with his doctors, because the alcohol could have played a part in some of this.

So, I think, we don't want our children to do things that they shouldn't do as far as drinking alcohol or eating these foods they shouldn't eat. But I think in my opinion, just to be very open about what it's going to do to your body, if you do choose to do those things, and how we can choose differently and how they can talk to their friends about it. Because I know for my oldest and even for my 16-year-old, it's hard to be different with their friends. And have to say I can't eat that, or I'm not supposed to do that. And ways around it. I say to my oldest get a drink that looks like an alcoholic drink and just hold it

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all night. And then you don't have to explain anything and just slowly sip it, they don't know.

And so, trying to give them ways that they don't have to look different, but they can still deal with their disease. And also, like Alix said, the studies, we've done so many studies over the years, and my 16-year-old especially hates doing them now and he really doesn't want to and at his age, he doesn't really understand how it's for the benefit of other children. Even then right now, if it doesn't benefit him, he doesn't want to do it. But I would if you can do as many studies as you can because not only is it benefiting other children and hopefully benefiting your own children. It's giving you connections to a lot of amazing doctors that you wouldn't have connections with before so the doctors that Alex talked about Dr. Guay Woodford, Dr. Arum Hartung and Dr. Dahl, Catherine Dell are three of the leading doctors with ARPKD nephrologists.

And when you do their studies, especially Dr. Dahl and Dr. Hartung, they have the two studies right now. You have access to their email, and you can email them with questions. If your doctor doesn't know as much you can connect the doctors with each other. And then also, for me, it also makes me feel like I'm doing something when they were first diagnosed, I felt very helpless, helpless. And it just was I had a lot of anxiety surrounding it. Not that now I don't have anxiety surrounding it.

But I have learned a lot over the years to just stay in the moment and not worry about the future not worry about transplants as much as I was and having access to these doctors has helped and also, I feel like talking to other families has really helped me feel like I'm doing something good for this disease. So, I and my information I think is up but I'm always willing to share my cell phone and my email and talk to anyone because we've now been doing this for 16 years and we've come a long way we're both my both my boys are pre transplant so we have not hit the transplant, yet which is great for them. But I'm happy to talk to anyone about their experiences and also help connect you with others who might be in the same situation as you. So, I'm not sure if there were any questions that Daniel had.

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Danielle Rose: Do not see any in the chat. But anyone who is feel free to shoot them on over and are these lovely ladies, we'll be happy to answer them. I can't believe, Michelle, that your boys are so old. Because I know them so along.

Michele: How long has foundation Danielle?

Danielle Rose: It's been eight years.

Michele: Okay, I can't believe my boys are as old as they are now. It's flown by.

Danielle Rose: Oh, yes. Okay, there's one here. Thank you to all the speakers.

Alix: And while you're reading that, I'm just going to second something that Michelle said that I think is so important. And it's for parents that maybe starting out on this journey is that doctors and we've gone through a couple of doctors that we just didn't, I just didn't connect with, in the sense that I'm always polite. But there are sometimes there are doctors that doctor that I swear hit every panic button I had as soon as I walked into the, into the room. And I just was like, I can't work with this person, I need a different doctor that's going to just be communicate with me in a different way. And so, we have doctors and nephrologists that we see regularly. But then we also go out to some doctor who would for the for like, every couple of years just for a baseline as well so that we're connected with her.

So yeah, Michelle, I think you said it is like, it's like breaking up with a doctor, that's okay. As a parent like to make sure that you've got a team and really look at it as a team of people who are there on that. I think it's a really critical thing that I that I felt when we were building our team.

Michele: My son transitioned to his adult primary care but not the specialist yet, but it's he's learning a lot with that transition. Our center isn't so great about helping us transitions. We've been doing it on our own. But like he forgot to tell his doctor a bunch of things when he recently had a telehealth visit with her. And so, I think it's good that we're you know, we're talking about it now. Another quick thing I wanted to say as a parent is have a notebook, write

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down everything. Because when you get to be my age and have been in this for 16 years, you forget a lot.

And it's good to have everything written down either in your phone or in the notebooks, go back and say oh yeah, I remember we saw that doctor and they told us this and also having your child fill their pillowcases, I kind of made the mistake of not starting it early enough. And you know, then they were kind of lazy about it. And my 22-year-old will often say to me like three days later, oh, I'm out of medication, and borrowing his brothers at the wrong dose. So, things like that to help them advocate for themselves.

Danielle Rose: The comment came in was just from one of our researchers from the University of Arizona. He just appreciated listening to the everyone tell their stories and how it's both important and motivational to everybody in shaping new treatments and techniques. And he Michelle he encourages Max to get a hold of some liquid death water for those parties. The cans look very much like a beer cans, but this may help me in some discomfort in those social settings.

Michele: Thank you.

Danielle Rose: Great, I'll just have some resources here. As always, from PKD foundation and Facebook groups.

Marcos: Hi, one question.

Danielle Rose: Yes.

Marcos: I'm from Mexico, I have three girls, and they are all diagnosed with PKD I have PKD, I already have a transplant. But do you know if for example your kids, some of them may not develop the PKD really disease or malfunction for the kidney at some point or because I know my father had the PKD but he never suffer about the kidney disease or malfunction is like they have just the assists, but really never develop now so I have the hope that maybe some of them may not develop or do you know something about these days about the development in your case and maybe for the future?

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Michele: Well, so our children happened to have the recessive form three of us that are talking. So, that's ARPKD and you and your children have ADPKD. So, definitely a little bit different as far as sometimes how the progression goes. And they do say that typically families with ADPKD do have the same progression. But sometimes a family member might have a little bit of a different progression, I would definitely say try and connect with one of these doctors like Lisa Guay Woodford, because she's a very good resource, or Dr. Dahl or Dr. Hartung, which we can get you the information. Are you also before I forget are you in our Facebook group PKD and children parents' group? Definitely join there. And but I'm sure you can connect with somebody at the foundation to get my personal information.

And I can help connect you more. Because with a ADPKD. There are also there's also tolvaptan, or GNRQ which is a medication that slows the progression. And there are other things that a lot of other things on the pipeline that they're working on, even just water intake and prolonging the kidney health and diet definitely makes a difference, especially with ADPKD. And so, I would definitely connect with other families and with and I'm happy to connect you with any of the doctors, but I think that I've heard a lot of great success stories with ADPKD. If they have other family members who have never needed a transplant.

Michele: Okay, thank you. Thank you very much, Michelle.

Danielle Rose: I have one more question here real quick. So, this is for Alix, asking, may ask what you mean by the physician hitting the alert or panic trigger? What were the recommendations or actions that raised your concerns?

Alix: Yeah, so one of the initial nephrologists that we saw with diagnosis. So again, we were coming into this with we'd never heard of ARPKD we'd never heard of PKD period. And so, one of the first things that this doctor told me is they said, you know, your son's kidneys are huge, and they're full of cysts. And now like looking back the way that I am, this was just for instance of like, one of the first things first of all, huge is a relative to one more time and later on I was like, well, well, what is huge meat, like I'm envisioning these huge,

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like football sized kidneys, and it was only like, a centimeter to what they were supposed to be. And so yes, while that's large, and definitely something's up, I mean, huge.

The terminology that this doctor was using was very alarming. In addition, full of cysts, I think what I would prefer it is, there's definitely something going on with your son's kidneys, they have cysts in them, but there's your son's kidneys are still functioning, normally based on all the tests that we're running. So, not just all of the things that are wrong. I've said to multiple doctors speak to me like I'm resilient, speak to me, like I am going to go home and live my life, and not just go home and live in fear of the one day that his kidneys are just going to start to fail. What are things that we can do that are proactive and mean something as simple as drinking a lot of water. We didn't start drinking two liters, the very next day, we kind of progressed into it. But I need to know that as a doctor, you have a plan, and that my participation as a parent is involved in that plan.

And so that way, we have a path forward together. And I can tell you based on the path that you're laying out the things that we are able to do as a family, the things that we struggle with, and so that there's communication back and forth, and not just here's all the things that you need to be worried about. I call it the list of doom. Dr. Stein of just telling you the list of very bad things of all the terrible things that you just need to be afraid of. And that's how I live my life. It's not how I want my son to live his life. I want him to understand that he has to take care of his we can be proactive about his health, and we can work together as a team. And that's really what I was looking for, rather than just kind of the alarm bells of all the things that are wrong. I know that there's something wrong, I get it. We're on it.

But that doesn't mean that we have to kind of cower in fear and just wait for bad things to happen. We can be proactive and live our lives and be happy. And so that's really what I meant by that.

Danielle Rose: Well on that note, I will say thank you to Ashley, Alix and Michelle for sharing your stories and experiences. We really appreciate you and don't

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forget to take the survey it's in the chat there. And you can also find it in the PKD conn site as well. But thanks. And enjoy the rest of PKD conn.

[Audio Ends] [01:05:00]