Transcript Details

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Rare Kidney Disease: A Parent and Caregiver’s Perspective

Dr. Colbert:
Welcome to *Clinician’s Roundtable* on ReachMD. I’m Dr. Gates Colbert, and joining me to share her unique perspectives as the parent of a patient with kidney disease is Ms. Kelly Helm. She’s also the Executive Director of Patient Engagement at NephCure, a nonprofit organization dedicated to supporting and empowering those with rare kidney diseases, including IgA nephropathy, or IgAN.

Kelly, thanks so much for being here today.

Ms. Helm:
Thank you for having me.

Dr. Colbert:
To start us off, Kelly, can you share your personal journey with your child’s diagnosis and how it has shaped your perspective on health and family?

Ms. Helm:
Sure. My daughter was diagnosed with rare kidney disease about 15 years ago at the age of 3 when she presented with swelling in her face and extremities due to high levels of proteinuria. She initially responded to treatment, but that only lasted for a few months, and from there, she progressed rather quickly to end-stage kidney disease, at which time she required dialysis and a kidney transplant at the age of 5. Unfortunately, her disease returned in the transplanted kidney, so she started the journey all over again. And fast-forward to now, she’s 18 years old, and she actually just received her second kidney transplant a few months ago and is doing really well. And having a child with a life-threatening illness like kidney disease completely shifts your perspective on every aspect of life. We had to become medical experts and learn rather quickly how to properly advocate for her, as well as find new jobs that allowed flexibility to manage her medical needs and navigate insurance and specialty pharmacies, all while trying to keep some sort of sense of normalcy in our family life.

Dr. Colbert:
Yeah, it’s pretty amazing. I’m really glad that she’s doing so well now. What are some of the biggest challenges you’ve encountered as a caregiver and as a mother? How did those experiences influence your work with NephCure?

Ms. Helm:
Well, when you’re dealing with ongoing and progressive health concerns, there are many challenges that pop up, and the most difficult challenges that we have encountered as a family have been finding treatments that worked for our daughter and going through the insurance and financial headaches that came along with having to use off-label specialty drugs; having to learn to find a new normal when our daughter was in and out of the hospital constantly and immunocompromised; and then dealing with a plethora of comorbidities and mental health challenges really for our entire family in dealing with that medical trauma. So at NephCure, we work to have programming that reaches patients where they’re at in their journey to help them navigate all the systems and learn how to advocate for the best care possible.

Dr. Colbert:
Now, if we continue along your child’s journey, Kelly, how was she treated? And from your vantage point, what roadblocks keep patients from receiving improved care for kidney disease?

Ms. Helm:

Well, at first, we were left to think that our daughter would take a course of steroids and eventually outgrow her condition, which obviously didn't end up being the case; but once we found an adequate nephrologist about three months into her diagnosis, she was very lucky to have wonderful care. Although that didn't mean that there were always answers, we felt like she was in the right place getting the care she needed. Unfortunately, there are many roadblocks that impact patients' care, such as access to timely diagnosis early on in their journey. A lot of rare kidney disease patients are not diagnosed until they're in stage 3 CKD. And another roadblock is finding an informed specialist who frequently treats their rare kidney disease. Also, patients need adequate and ongoing education regarding their diagnosis and where they're at in their journey. And, finally, until recently, innovation in the kidney disease space was pretty stagnant, and now there seems to be a plethora of innovation but a slow uptake of these new therapies actually reaching patients, particularly in the IgAN space. This is happening for various reasons, such as low awareness, clinical management challenges with insurance needs and REMS programs, and cost.

Dr. Colbert:
For those just tuning in, you're listening to *Clinician's Roundtable* on ReachMD. I'm Dr. Gates Colbert, and I'm speaking with Ms. Kelly Helm from the nonprofit organization NephCure about her story as the parent of a child with kidney disease and the roadblocks separating patients with IgA nephropathy to improved treatments.

Now, what kind of support systems have you found to be most helpful for both you and your daughter throughout this journey? And can they have the same positive impact on patients with other kidney diseases?

Ms. Helm:
Well, we've been very fortunate to have a wonderful support system, from friends and family, but ultimately, connecting with other kidney patient families who fully understand the rare kidney disease journey has been paramount for our family. And for my daughter, growing up having access to other children who looked like her when she was on high-dose steroids and who were in and out of the hospital, someone who could relate to her struggles, was really important and also validated that she wasn't alone in her journey. And through my work at NephCure, I've had the privilege of seeing many patients connect to the kidney community for the very first time, and it often changes the trajectory of their journey and how they approach things moving forward. So hands down, having connections to others living with the same or even similar conditions is the most impactful support system patients can have.

Dr. Colbert:
To dive in some more on IgA nephropathy, what are some of its most important misconceptions that you would like to clarify for clinicians and the general public?

Ms. Helm:
I think there's many misconceptions, but in my opinion the most important current misconception is that IgAN has historically been viewed as a fairly benign condition that rarely progresses and can just be monitored rather than treated quickly and aggressively. So we hear from patients all the time whose doctors choose not to treat their proteinuria because they're asymptomatic and they're going about life at a fairly normal pace, and so they just monitor them until things start to get worse—or even patients who are told upon diagnosis that IgAN is the best kidney disease to have, and so patients are left feeling no need to treat their condition. However, new data now shows that even patients spilling lower levels of protein, even less than 1 gram, are still at high risk of progressing to end-stage kidney disease and oftentimes in the prime of their life, so it's important to shift that lackadaisical approach to create a larger sense of urgency in treating active disease so that patients can stop or slow the progression of their disease. Another misconception is that new FDA-approved therapies have to be used one at a time or either/or, rather than considering using them as combination therapy to lower the amount of proteinuria as much as possible.

And from the patient's side, a misconception is the assumption that their physicians have all the answers all the time, and when it comes to rare disease, that's not always the case. Physicians are extremely strapped for time, they're very busy, and when their patient load is 90 percent CKD patients, they aren't always able to stay up-to-date on the latest innovation and treatment options or even clinical trials for those living with rare kidney disease.

Dr. Colbert:
And before we close, is there anything else about IgA nephropathy and other kidney diseases that you'd like to share with our audience today?

Ms. Helm:
I love this question, and I want to take this opportunity to share that patients can greatly benefit from the support and educational resources outside of the physician's office. And there are often wonderful patient advocacy organizations who can help bridge the knowledge gap and help serve our healthcare community by serving patients, so I would highly recommend for physicians listening to

this podcast to learn which patient advocacy organizations might benefit both you and your patients.

And, finally, to close, I think with the extensive innovation happening in rare kidney diseases, such as IgAN, it’s very important to invest time into better adoption practices of that innovation and no longer accept the status quo of treating the way we’ve always done things because patient outcomes are really dependent on it.

Dr. Colbert:
With those key takeaways in mind, I want to thank my guest, Ms. Kelly Helm, for joining me to share her personal journey as the caregiver of a child with kidney disease and how we can better care and support for these patients.

Kelly, it was a pleasure speaking with you today.

Ms. Helm:
Thank you so much.

Dr. Colbert:
For ReachMD, I’m Dr. Gates Colbert. To access this and other episodes in our series, visit *Clinician’s Roundtable* on ReachMD.com, where you can Be Part of the Knowledge. Thanks for listening.