NASN School Nurse Chat: Rare Diseases Podcast Transcript

Kim Hollander: One of the easiest ways to convey to a child is, when we look around the room, one out of 10 of those children potentially may have a rare disease and they may not even know it yet and that's a scary impact.

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Donna Mazyck: In this episode, we're talking about rare diseases with Kim Hollander, who is executive director of the Oxalosis and the Hyperoxaluria Foundation, and Gloria Barrera, certified school nurse and adjunct nursing professor at DePaul University, Capella University, and her alma mater, St Xavier University. Kim served as a board member for the National Organization of Rare Disorders, NORD, and sits on a number of industry patient advisory boards. Gloria is president elect of the Illinois Association of School Nurses and treasurer of the National Association of Hispanic Nurses, Illinois chapter. Welcome to School Nurse Chat.

Kim Hollander: Thank you so much for having us.

Gloria Barrera: Thank you. Happy to be here, Donna.

Donna Mazyck: School nurses find information on rare diseases on the website of the National Association of Rare Diseases, NORD, and today we'll hear from Kim and Gloria about the topic as it pertains to students, families, and school nurses. Kim, what qualifies as a rare disease and what are some challenges students with rare diseases face while at school?

Kim Hollander: A rare disease is defined in the United States as a disease affecting less than 200,000 people nationwide. There's over 7,000 rare diseases that affect about 25 to 30 million people nationwide. Rare diseases can be isolating and difficult for others to understand because of the lack of awareness and knowledge about the disease. This often leads to isolation for the patient and their family, and the urgent need to learn how to fit in with their schoolmates so that they are not looked at differently. I often say to patients that we hear rare diseases, but when a family is affected by a rare disease, it's no longer rare to them. It's their reality.

Donna Mazyck: Kim, in your work that you do every day, you're very familiar with Primary Hyperoxaluria Type One or PH1. Let's use that as an example as we just share about rare diseases today. What can you tell us about your experiences with PH1?

Kim Hollander: PH1 is a rare, life-threatening disease in which a genetic defect in the liver results in the overproduction of oxalates. It's a chemical that is created in our

body. Over time, the accumulation of oxalate causes irreversible damage to the kidney and can ultimately result in kidney failure and the need for dialysis as a bridge to a dual kidney and liver transplant. The majority of patients are diagnosed in early childhood or during adolescence. The most common symptom are kidney stones that can recur time after time, with some patients experiencing 10 to hundreds of stones in their lifetime. Symptoms from kidney stones can include severe flank pain, urinary tract infection, painful urination, and even blood in their urine. Since kidney stones are not common in children, it's typically the symptom that alerts the family that something is wrong. We call this a red flag.

Donna Mazyck: Well, Kim, when you speak about that, can you tell us how PH1 affects a student's school life? We hear some of the acute issues that they deal with. How does it affect them at school?

Kim Hollander: One of the things with PH1 that is unique, we call this super hydration, and it's critical for patients to drink an excessive amount of water. Children must drink about two to three liters of water a day to reduce the formation of stones. A lot of times this requires the student to be excused for frequent bathroom breaks, which is frustrating for the child while their peers may view this as a privilege. Children with PH1 are often prescribed crystallization inhibitors and in some instances, vitamin B6 therapy, meaning that they will need to visit your office on a regular basis. In addition, absences from school is a normal thing for a child with PH1 and can make it challenging to stay on top of their schoolwork.

Donna Mazyck: Some of those concerns that you mentioned are things that students with various rare diseases will face. What else might a school nurse need to be aware of, Kim?

Kim Hollander: Parents often have a strong communication exchange with the school nurse, but they typically struggle to communicate those concerns with the teachers. My suggestion is to work with the school nurse and maybe even the principal, to improve the whole communication process. In addition, we highly recommend that caregivers should work closely with you and to teachers to create care plans. An opportunity to speak to the school counselor should also be considered to address the emotional aspects of having to deal with a rare condition and help a child to talk about it with others, their friends, teachers, and also classmates.

Donna Mazyck: Kim, you've given some actionable things that can happen in a school to increase that communication and to make it better for students in their day to day time in school.

Announcer: PH1 of a Kind is an animated video series for kids, their caregivers, friends, and communities about living with Primary Hyperoxaluria Type One. Watch and learn more at ph1ofakind.com.

Donna Mazyck: Gloria, can you walk us through what you do when you learn there as a student coming to school who's been diagnosed with a rare disease?

Gloria Barrera: Hi Donna. Yeah, so the first thing I do when there are students coming to my school that have a known rare disease is to introduce myself to their parents or guardians. That initial contact is vital to assess what nursing services, if any, they may have received at their previous school. So for example, if they're transferring in or are an incoming freshman, I review their previous health records, just to identify what the priorities of care are. So once those nursing needs are assessed for the school setting, I always check to see if they are protected under a 504 plan or an individualized education plan, and then review it along with any existing emergency action plan and/or the individualized healthcare plan as Kim mentioned. So before the student even steps foot in the school, my priority is to gather all the necessary information needed to meet this child's healthcare needs specifically.

Gloria Barrera: So Donna, we know that there are 400 million people suffering from a rare disease globally, and as a school nurse, I am committed to being a lifelong learner. So if the disease is new to my knowledge, which it may very well be, I review the literature to educate myself and to feel empowered in providing exceptional nursing care. My first go-to websites would be, of course, NASN, Global Genes, as we already noted as well, and then developing that rapport with the student and having a plan in place for meeting their specific medical needs throughout their academic career, as I mentioned, is my first step. Next would be to focus on educating staff. So for example, a previous student of mine had sickle cell anemia and I presented to staff members on sickle cell anemia, but specifically how to keep the student safe by understanding rapid recognition of a health crisis in accordance with their individualized healthcare plan and emergency action plan.

Donna Mazyck: You've really drawn a picture for us, Gloria, of how a school nurse can help students be healthy, safe, and ready to learn and in school. Can you tell us what types of questions that you want to hear parents asking? Those parents who have children diagnosed with a rare disease like PH1 or other diseases, what should they be exploring with their child's school health office?

Gloria Barrera: Parents are their children's biggest advocates. As such, you want to be confident that a nurse is available to your child. I think it's one of the most important questions and that just is, does my child have access to a full time registered nurse at school every single day? Unfortunately, Donna, right now in our country, the answer is not always yes. So going back to my previous example with the student with sickle cell anemia, their parent's questions for the school health office would be centered on nursing interventions, the emergency action plans in place, and also accommodations such as unlimited access to the bathroom, water for hydration, and temperature control.

Donna Mazyck: So there are very specific things that can happen and a school nurse leading that health services team is really the key for helping the students be able to do

what they need to do for their health and for their learning. I appreciate that. Kim, I understand you've worked as an educator in schools. From that perspective, what advice do you have for school nurses who are talking with teachers and other school staff about diseases? For example, PH1 or sickle cell or any other disease?

Kim Hollander: I think Gloria hit the nail on the head. You need to be proactive in reaching out to students and their families before the school year begins. Advise them to consult with you so that you can be prepared in the event of a medical emergency. It's really, really important to develop a strong relationship with the family and student to help them. If we're looking at PH1, we want to make sure that the child is drinking the necessary amount of water per day. It also requires multiple visits to the nurse's office to take their meds. Make sure that the student's classmates understand the child's condition. With different age groups, this poses a potential problem, because as the child gets older, they sort of want to conceal the disease. They may not want their classmates to learn about it, but I think it's really important that the teacher and the child's classmates understand about rare conditions.

Kim Hollander: This is incredibly important. When we look around the room and one of the easiest ways to convey to a child is to look at 10 people in a row. One out of 10 of those children potentially may have a rare disease and they may not even know it yet, and that's a scary impact. But I think the more education we can provide around it and awareness with rare diseases, the more it helps the family and the student get through their rare disease and have a more positive experience. In addition, educational resources are growing, especially in PH1. There's a great video for even young kids to older children called PH1 of a Kind. This video series helped completely understand that body, how things are moving, and what actually causes PH1. OHF also has a number of resources at ohf.org to help learn about PH1. We're constantly creating and working to better those resources. So it's really about encouraging open communication and I think that's key to making the process smooth.

Donna Mazyck: Gloria, you spoke a little bit about how you provide education and awareness to the teachers in a school pertaining to students who may have rare diseases. What's your experience in working with other school staff to support students with a rare disease?

Gloria Barrera: So my experience with school staff has always been one of a team approach when supporting students with rare diseases. So teachers are with students much longer than I am during the school day, and I depend on them as vital members of my team to alert me of any changes to the student's healthcare status. Other members of the team include student support staff, which we kind of already mentioned, the counselors, social workers, school psychologists, PT, OT, and speech. So my overall goal as the school nurse is to keep students with rare diseases healthy, safe, and ready to learn in school.

Donna Mazyck: Absolutely. Gloria, do you have any key takeaways for our colleagues who support students with rare disease?

Gloria Barrera: Yeah, I would remind them that they're not alone. They have a team at their school and are part of a larger community of school nurses that they can lean on for support. So if they're not already members of NASN, I would, of course, encourage them to apply and become a member. I would also tell them that it's okay not to have all the answers. This is not a test. Research the rare disease and use your experience in the nursing process to just provide exceptional nursing care to that student.

Donna Mazyck: Gloria, you mentioned some of the resources that you use. Could you remind us of those resources that you believe would benefit the most when assisting a student with a rare disease?

Gloria Barrera: As a nurse, I benefit from Ebsco, PubMed, ANA, of course NASN, Global Genes, and other organizations specific to rare diseases such as OHF, just to guide my nursing practice and provide that exceptional care to the students.

Donna Mazyck: Thank you, Gloria. Kim, where can our listeners go for more information and additional resources on PH1 and rare diseases?

Kim Hollander: There are a number of resources about the PH1 community that nurses can take advantage of. Since I represent the Oxalosis and Hyperoxaluria Foundation, I would say the starting point would be at our website at OHF.org. We have excellent information about all forms of Hyperoxaluria, and it really has proven to be a sounding board to patients, families, and their physician for many years. In addition, for our younger audience members and for your students, I would recommend using ph1ofakind.com. This is an opportunity for your students and their classmates to review a four part animated video series that was made in partnership with Alnylam Pharmaceuticals.

Kim Hollander: For nurses and other healthcare professionals that might be on the team for health care for your students with rare diseases, I would specifically go to aboutph1.com and that's going to look at the importance of genetic testing, management, and clinical manifestations of PH1. For rare diseases in general, I would certainly look to NORD and Global Genes, as I think their both an excellent resource for general purposes in rare diseases. They'll cover all 7,000 rare diseases. There may not be information in every single disease, but they'll have amazing toolkits which you can download and even share with teachers to distribute to their schoolmates. So also really great resource and a good takeaway.

Donna Mazyck: We really appreciate you, Kim and Gloria, for spending some time with us today to unpack what it means to have a rare disease for a child in school and how we can make it better for them and make sure that they're able to access their learning. Thank you for being with us today.

Kim Hollander: Thank you.

Gloria Barrera: Thank you.

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