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Voice Over: This NASN school nurse chat podcast comes to us with support from a CDC cooperative agreement collaboration to support students with chronic health conditions.

Donna Mazyck: Welcome to the NASN school nurse chat podcast. This is Donna Mazyck. I'm executive director of the National Association of School Nurses. The focus of today's podcast will be some of the challenges and strategies that we see for collaboration between parents and school nurses, so that they can best support students with chronic health conditions. Joining us for this podcast are Lisa Kern, a nationally certified school nurse and supervisor of health services for Pasco County schools in Florida, and Michelle Grove, a parent to a child living with Type I Diabetes who attends school in northeast Washington. Both attended a workshop hosted by NASN in April of 2018 along with other school community members. That meeting focused on factors that facilitate or impede coordinated care for students with chronic health conditions. Welcome Lisa and Michelle.

Lisa Kern: Hi, Donna.

Michelle Grove: Hello.

Donna Mazyck: The challenges of care coordination between parents and schools go both ways. Parents and school nurses both benefit from more information and more communication, but it's never that easy in practice. Today, we'd like to hear your priorities and perspectives in helping children and youth be healthy, safe, and ready to learn at school. Michelle, let's start with you. What causes the most stress for you when your child goes off to school?

Michelle Grove: At the most basic level, making sure my daughter will be safe at school is my greatest worry. When she was younger and more dependent on the adults around her, I worried a lot that even a small oversight or error could turn into a life threatening situation. Type I Diabetes is manageable, but it can get scary in a brief moment. Now that she's older, probably my biggest stress is the fact that her condition can potentially affect her academic success, so we spend a lot of energy helping the school and our student understand how we can mitigate that impact.

Donna Mazyck: What do you want your child's school to know about her chronic health condition?

Michelle Grove: I think one of the most important things that I need my child's school to know that every person with an illness is still an individual. There might be common things that will apply, but it's really important to recognize and understand that

the needs of the individual students may vary greatly from kid to kid even if they have the same health condition. I really want to be sure our school also understands the mental burden of living with a chronic illness, 'cause the utmost nature of these conditions can really weigh heavily on kids and I think it's important that school lets her be as normal as possible. She needs extra care to be safe and healthy because of her diabetes, but really she's just a regular teenager and she loves science and soccer and her friends, and I really need them to not lose sight of that part.

Donna Mazyck: What have been some of the challenges you've had when working with your school to make sure your daughter's diabetes is being cared for?

Michelle Grove: Interestingly, it's sometimes the simple things that end up being the trickiest, the things that you really don't expect. Everyone has always understood her doctor's orders and have watched out for her safety, which is obviously important but when she needed to simply carry her bag so that she had immediate access to her medical supplies or her phone to use her medical devices, we had to convene an entire meeting and write it into her formal file just to get an exception to the school rule. It seemed like it should be pretty simple sometimes, but it proved really challenging until everybody was at the table and everybody understood why we were asking for those accommodations.

Donna Mazyck: Lisa, what school health services should every parent of a child with a chronic health condition know about?

Lisa Kern: I think every parent of a child with a chronic health condition should know that their child is safe at school all day, every day. Parents should know whether the registered professional school nurse is available. Is he or she there all day, every day as is the recommendation of the National Association of School Nurses and the American Academy of Pediatrics? If not, parents need to find out how their child's care will be managed. Who be responsible for their child when a nurse is not on campus? Has that person been trained to respond if their child experiences a health emergency? What happens when their child goes on a field trip or participates in a school sponsored activity? A collaborative partnership between parents, school nurse, providers, teachers, administrators and training staff is essential for safe care and management of students with chronic health conditions.

Donna Mazyck: Lisa, can you walk us through what you do when you learn there is a student coming to a school that has been newly diagnosed with Type I Diabetes or any other health condition?

Lisa Kern: I think the first step would be to contact the parents and schedule a meeting where the parent and the child would have an opportunity to meet staff that will be responsible for that child's care during the school day. I'd ask the parent to bring any medical recommendations or orders and I would provide any

necessary forms to the parent ahead of time. During the meeting, I'd listen and gather information about the parent, the child, and the provider expectations essential to developing an individualized health care plan for that child. This IHP would be shared with the parents and others who have a need to know. I'd also consider the need for an emergency care plan. Do I need to provide easy to follow steps designed to guide unlicensed staff and what they need to know and do in an emergency? My next step would be to train staff so that they know what to look for and what actions they need to take to keep this student safe every day. If this is a student with newly diagnosed diabetes, I'd need to be on campus to model care and monitor safe delegation during that child's first few days at school.

Donna Mazyck: So what can be challenging for the school nurse when providing care for students with chronic health conditions?

Lisa Kern: Well, I think the greatest challenges for school nurses is to find time to provide more frequent monitoring to ensure that safe delegation, to communicate openly and regularly with parents and providers, and to ensure that information received is clear and understandable. I think every school nurse would prefer to be on campus all day, every day instead of having to rely on delegation to unlicensed staff who are not medically trained to make critical decisions about a student's health. Nurses can teach an unlicensed person to take action, but they really can't transfer all of their critical thinking expertise to that person. In some situations, when that level of expertise is missing, outcomes may be negatively impacted. Also, since school nurses are practicing in an educational setting, we often lack the equipment, resources, and additional health staff that is available to most nurses in other health care settings. Our practice is autonomous in nature, and that can be challenging for some.

Donna Mazyck: Support for this podcast comes to us from the CDC cooperative agreement collaboration to support students with chronic health conditions. School nurses can learn more about this topic on NASN's website. Parents can learn more from the Centers for Disease Control and Prevention's Parents for Healthy Schools. Links to both resources can be found in the show notes. Michelle, I want to come back to you. Tell us, were you surprised by anything you heard from Lisa?

Michelle Grove: I wasn't specifically surprised. I'd been at this for quite a while. I'm pretty involved with not just my own student, but other families, but I wanted to emphasize something that I heard Lisa say which was as a parent, you can't make assumptions. Everyone presumes best intentions, which is great but you still need to know what to ask. You need to ask who is caring for my child? Is there a nurse there all day, every day? What if she joins the jump rope club after school? If not, who's going to be there to train and support her? Those are some things that I think especially for newly diagnosed families, it's important to know what questions to ask, and I appreciate that she focused on that.

Donna Mazyck: How would you like to be involved to make sure that your child's chronic health condition is managed at school?

Michelle Grove: As a parent, I always want to be a part of the team and again, that's something Lisa said was the parent and the child really need to be involved in that team. I want to help be an architect as we build those routines and her 504 floor plans. I want regular check ins, whether those are with teachers about how things are going or playground staff when she was little or her school nurse. When my daughter was in elementary, one of her nurses had a really great system that we used to communicate weekly, and that was really helpful but you mentioned other activities.

It's really helpful to give parents a lot of notice, to keep us in the loop when we can provide support for things like parties or field trips. When my daughter was younger, I went everywhere. I came to every party, and that was what she needed to feel comfortable and we needed to have her feel safe so that she could participate. Now that she's in high school, she's independent but it's also really great to be able to support the school with the resources we have and it's also to know that we can depend on them to connect us to the resources that are going to make her time at school and in activities and sports to be really safe and successful.

Donna Mazyck: What is one thing that you wish the school had asked you about?

Michelle Grove: Seven years after my daughter's diagnosis, this question really still grabs my heart because I wish they would've asked how we were feeling, a mental and emotional toll as a major diagnosis is really impactful on a family. Her school was cheerfully fabulous about getting a plan in place and having protocols and establishing a routine, but I really wish someone would've just stopped and said, "How are you?" And acknowledge that it was a really hard time for our family and a big adjustment in our life and that walking out that day and that handing over her care after taking her home from the hospital, that was a very hard thing for me. I wish a little more care had been spent on that emotional piece, not just the routine.

Donna Mazyck: Michelle, what key message would you like to send to other parents for sending their students with a chronic health condition off to school?

Michelle Grove: I think we keep coming back to the idea that this has to be a partnership. As a parent, you are your child's first and best advocate, and it's really important that you're at the table to make sure they're cared for and that their rights are being upheld. It really begins with that cooperative relationship with all of the people who are going to be involved in taking care of your child and supporting them at school. When we developed those relationships and this is especially a hard one as a parent who's so emotionally involved, it's important to remember that everybody on that team is a human being and it may not always be perfect, and

you all might have to be a little patient and work together and develop what tools you need so that you can all support your student as best as possible.

Donna Mazyck: Lisa, what key message would you like to share with all parents who are sending their children to school with a chronic health condition?

Lisa Kern: I think it's important for all parents who are sending that child to school with a chronic health condition to share that specific information, to be sure that the school knows about their health condition and in particular, that the school nurse is aware. I think it's also important for all parents to find out whether or not their school has a registered professional school nurse on campus all day, every day and if not, parents need to advocate for this level of care and to use their voice to shine a light on this need. I think parents should be vocal about their needs with their child's principal, school board members, superintendent, and even the media to advocate for this level of expertise, for not only their child with a chronic health condition but also all of the others. The reality is that your child's school nurse might be coordinating care across several different campuses. I think parents should be sure that they know who's caring for their child. Their support is critical to ensure the state's care and management of their child with a chronic health condition during the school day.

Donna Mazyck: Thank you Lisa, and thank you Michelle. Thank you for sharing from your perspectives.

Lisa Kern: Thank you, Donna.

Michelle Grove: Thank you both so much, I appreciate it.

Donna Mazyck: Parents and school nurses recognize the importance of collaborating to help students manage their chronic health conditions while in school. Parents want to know what school health services they can expect from the school. As school nurses lean into listen to and address the priorities parents have for their child, keeping the student at the center of this collaboration will lead to health and academic success.

Voice Over: This NASN school nurse chat podcast comes to us with support from a CDC cooperative agreement, collaboration to support students with chronic health conditions. Parents can learn more from the Centers for Disease Control and Preventions Parents for Healthy Schools at [www.cdc.gov/healthyschools/parentengagement/parentsforhealthyschools.htm](http://www.cdc.gov/healthyschools/parentengagement/parentsforhealthyschools.htm).