



Multiple Sclerosis
Association of America

**MSAA Podcast:
Navigating the Pediatric MS Journey
Episode 10**

Host: Marie LeGrand

With special guests:

**Yolanda Wheeler, PhD, CRNP, CPNP-AC, MSCN
& Elena McDaniel (parent of a child with MS)**

Marie LeGrand:

Hello, and welcome to the Multiple Sclerosis Association of America's podcast on "Navigating the Pediatric MS Journey" with our special guests, Dr. Yolanda Wheeler and Elena McDaniel. I'm Marie LeGrand, Associate Vice President of Mission Delivery, Health Equity, and Education for MSAA, and your host for today's podcast. I'm delighted to introduce our guests, Dr. Yolanda Wheeler and Elena, who will explore pediatric MS and how that affects children and teens, and also what parents and guardians should know and consider when talking to their healthcare providers.

Now, please note that this program is for educational and informational purposes only and does not constitute as formal recommendations. Please do speak with your doctor or healthcare provider if you have any questions or concerns.

Now, without further ado, I'd like to introduce our speakers. Dr. Yolanda Wheeler is an Assistant Professor and Nurse Researcher at the University of Alabama at Birmingham School of Nursing. In addition to her duties as a professor at the nursing school and various research endeavors, she has been a nurse practitioner at the UAB Center for Pediatric Onset Demyelinating Disease for 16 years, where she cares for children and their families with multiple sclerosis and other demyelinating diseases. She is a member of MSAA's African-American Advisory Board, a member of MSAA's Healthcare Advisory Council, a longtime volunteer and patient advocate with the Multiple Sclerosis Association of America and the National MS Society - making tireless efforts to ensure that patients and their families receive quality and equitable care.

We also have with us Elena, who is a student nurse, wife, and proud mother of three. She aspires to work in postpartum care and lactation as a registered nurse upon completion this summer. She is an active member and participates in community service activities with the Birmingham Black Nurses Association, and the order of Eastern Star. Welcome.

Elena McDaniel:

Thank you for having us.

Dr. Yolanda Wheeler:

Yes, thank you for having us on this podcast. We're excited to be here.

Marie LeGrand:

We are so excited to have you both here with us today to discuss this very important topic. Thank you so much for joining us once again, Dr. Wheeler and Elena. I would like to begin this conversation actually by having you, Elena, talk to us about your child and your family's journey living with MS. Can you talk to us a bit about your son?

Elena McDaniel:

Well, sure. My son, Jaden, he's now almost 17, he'll be 17 next month. He was diagnosed when he was 12 years old. And it began with him having sort of a droopy eyelid. We were just actually taking pictures, and so I was looking back at the pictures, and I said, "well, what's wrong with your eye? You know something's going on with your eyelid, what's going on?" And so, it just kind of began this snowball effect. We took him to the eye doctor who sent us to a specialist. And then the specialist referred us to another specialist and ended up with Children's [Harbor], and that's how we met Dr. Wheeler and Dr. Ness there. And they were phenomenal.

Immediately, they knew what was going on. We had no clue how serious it was. My worst thought in my mind was, "Oh my God, he's going to need surgery on his eyelid, like, what's going on?" but I didn't know that it was deeper than that. But as of date, that was his only hospitalization. Every now and then, he'll have different little breakthroughs where he may have numbness or tingling in an arm or foot or something like that. But with medication, everything's been managed very well. And it just kind of... we've been taking it day by day, you know, trying not to get overwhelmed, but just taking it one day at a time.

Marie LeGrand:

Wonderful. Well, thank you so much for sharing your son's and family's journey, living with pediatric MS, Elena. Dr. Wheeler, I was wondering if maybe we can take this opportunity to have you talk to us a bit about pediatric MS and provide us with an overview and background. We can start with what is pediatric MS, and how does it differ from adults living with MS?

Dr. Yolanda Wheeler:

So let me just provide a little bit of MS topic. Multiple Sclerosis, first off, is a disease that affects the brain, spinal cord, and optic nerves that make up the central nervous system. And it controls everything we do. The exact cause of MS is unknown, but we do know that there are sometimes triggers from the immune system that attack the central nervous system. The resulting damage causes damage to myelin, the protective layer over the insulating wires, like nerve fibers. And I use a common thing where I talk about an electrical cord. If you were to shave off the covering of the electrical cord, that's what happens with MS, it shaves off the covering of the nerves. So, if you were to stick that plug into, electrical wires into the wall, you'd get that electrical shock. And that's kind of what happens with MS. It removes the covering of the nerves, and it causes damage to those things that the wires are leading, what they call, the juice to, basically.

And so that's the most common term that I use, the topic that I use when I talk to parents to help them understand. So that this interruption of the signal and the communication causes the symptoms, these unpredictable symptoms, because it happens out of nowhere, it causes numbness, tingling, mood changes, memory problems, it can cause pain, fatigue, blindness, and sometimes paralysis. Sometimes these individuals have experiences that may be temporary, but it may be permanent. But we don't know at the beginning of these instances.

So pediatric MS refers to when MS occurs before or under the age of 18. Fewer than 5000 children and teens live with MS in the United States, and fewer than 10,000 worldwide. So, for children, there are some differences. Children with MS exclusively have what they call relapsing-remitting MS. It's like they have a symptom, the symptom that starts from the attack on the body and then, once their immune system calms down with the medications that we give them, sometimes they have symptoms and they don't even know they have the disease, and so their bodies go back to their natural state on their own. Then that's the relapse part of things. And so, you will have periods where you have relapse and then you'll have periods where there's a remission, where there's no active disease process going on. This means that they're in remission. And so, adults can have different types of MS, but mostly children, 98% of the children, have the relapsing-remitting form of MS.

Children also experience more frequent relapses than adults do during their initial period of diagnosis, and it's probably less atypical in the adult world. Studies have shown that children have recovered from relapses that are better than usually adults, but they also have those more rapid attacks early on. And so those are some differences that we see with pediatric versus adult-onset MS.

Marie LeGrand:

Okay. Now, are there other childhood disorders, perhaps, that are similar to pediatric MS? Can you tell us a little bit more about that and the challenges in providing an MS diagnosis?

Dr. Yolanda Wheeler:

So, diagnosing children with MS is more challenging than in adults because there are other childhood disorders that may have similar symptoms. We talked, I touched a little bit about symptoms, but these symptoms may look very well like other symptoms that other diagnoses present with, such as infections, other disorders of increased inflammation, such as lupus. Then you may have nutritional deficiencies, like vitamin D, or other inherited disorders.

Some children may also develop neurological symptoms such as confusion or lethargy shortly following a viral illness or fever. This is called acute disseminating encephalomyelitis, and it's different from MS because most often these symptoms only occur once. Remember, we talked about relapsing-remitting, but this only occurs one time. And so, it may be mistaken for multiple sclerosis.

Diagnosing MS in the pediatric population can be tricky for many other reasons as well. One is simply a lack of awareness of that provider that's providing the diagnosis. A child may be having some vague symptoms that may not necessarily be anything specific. Due to the rarity of the disease, there are not a lot of providers out there who are doing general pediatric practice, who are educated about pediatric MS. So, it may not be on their radar and the child may complain again that these nonspecific things, like fatigue, that may not be on the radar of that provider who is making the diagnosis. Again, I want to reemphasize that MS is a diagnosis of exclusion and that there's no one definitive test to diagnose MS, but it's a culmination of things. MRI, examinations, spinal taps, evoked potentials, and other laboratory tests that are pieces that we

use in a puzzle to make an MS diagnosis. So, we just need to look at those things in order to come up with the diagnosis. And it may provide a challenge for making the diagnosis when it comes to pediatric MS.

Marie LeGrand:

Well, thank you so much, Dr. Wheeler, for providing that information. So, since you mentioned symptoms earlier in the conversation, let's talk about that. Are there symptoms that are specific to pediatric MS, and does it differ from adults living with MS?

Dr. Yolanda Wheeler:

So, the symptoms of MS in pediatrics and adults are just alike. They are very similar to adults. Adult MS experiences, most certainly symptoms with MS can, like I said, present in various ways. We've had some patients have inflammation of the optic nerve where they can't see. We've had patients have extreme fatigue, we've had patients present with mood changes, they've had difficulty walking, difficulty talking, balance issues. But all those symptoms are very similar to the symptoms that adult patients experience with multiple sclerosis. Again, I can say that sometimes those symptoms are vague, and they start having symptoms pre diagnosis, and they're often, like I said, dismissed. And because of the vagueness of the symptoms, especially when we have most of the kids having been well before their MS diagnosis, haven't had a lot of illness, they know something is going on different with their body, but they don't quite understand, and so those symptoms can be very vague.

Other symptoms can include muscle weakness, bladder and bowel issues. People don't understand that the nerves that innervate from your spinal cord help to make your bladder and your bowel function properly. And so, they may have bladder issues, but they're not thinking, okay, neurological condition, what does that have to do with my bladder and bowel? And so those symptoms don't really connect because they've been well, and they hadn't had to experience anything like this or anything of this nature. And so, the symptoms are very similar that they experience with the adults. And so, it may be quite a long time before they actually get a diagnosis because some of the symptoms come on and they're vague at the beginning.

Marie LeGrand:

I see, okay. Now is there an age range for pediatric MS? Are there unique challenges when navigating school and activities, including sports, that parents and guardians should keep in mind?

Dr. Yolanda Wheeler:

So, the typical age range that I've seen in my almost 17 years of practice is between 14 and 17 years of age. That's usually the normal age for a pediatric MS diagnosis. Now, of course, we have outliers, and I say I've taken care of my share of outliers over the years. We've had eight-year-olds. We've had a couple of children that were misdiagnosed with other things, like pediatric stroke, because of the way they presented, that were misdiagnosed and then later had a clearer relapsing course and got re-diagnosed with multiple sclerosis. But typically, the age is around 14 to 17.

While most kids with multiple sclerosis have mild and manageable symptoms, some of them experience symptoms that are significant enough to impact their daily lives. When they have a relapse, it may take them anywhere from two weeks to a month or three months to get well. Some of them have permanent symptoms. So just imagine a child that has been well, most of their lives had had only a little cold or maybe a little virus and had to go to the primary care and

had to have a disease like MS that impacts their daily living, impacts how they think, impacts their academic progress, impacts how they may look in comparison to their peers.

For the most part, children with multiple sclerosis, if you were to put them in a room of their peers or their family that are their same age, you can't tell that they have MS. But MS may impact the way they think. It may impact the way they process information. Think about the symptoms of MS being silent symptoms. You don't know if somebody has blurred vision unless they tell you. You don't know if they are having learning and memory issues unless they express that. Most certainly things like writing, their handwriting, may change, their socialization skills may change. They are no longer looking like their peers. And so, socialization may become an issue. They may have difficulty with performing tasks that they used to be able to perform very well, and now they are no longer able to do those things. Think about the basketball player that has lost the use of his legs and now he's got to go back and face his peers. And so those symptoms may just impact their daily living. I also want to bring and address something, those siblings that they have. Those siblings may be impacted because more time is pulled from their time with their mother, their father, their caregiver to focus on the sibling that's sick.

Marie LeGrand:

Okay. Thank you so much, Dr. Wheeler. What should, Elena, and this is Elena and Dr. Wheeler, what should parents and guardians be aware of when seeking care for pediatric MS? Dr. Wheeler, we'll start with you.

Dr. Yolanda Wheeler:

Okay. What I would probably make aware when seeking care that there are providers out there that know about these disease processes and that if you have a child that's got a new pediatric MS diagnosis, you should seek one of those providers that are really equipped, have what it takes in order to get you on the road to success. I make that comment to my patients when they're first diagnosed. My goal is to help you get to success, not to failures, not to the "what ifs," but think about all the possibilities that you have. And so just making sure that they have, that they realize that there are resources out there that can help them navigate their life after the diagnosis.

Marie LeGrand:

Okay. Elena?

Elena McDaniel:

Just like Dr. Wheeler says, you know, I think it's important to surround yourself around the correct providers. You know, if you notice that something is wrong with your child and you're not getting the answers, keep going. You know, if you know that something's going on with your child and you're not, you know, it gets brushed off, you have to keep going, keep being an advocate for your child.

There's nothing worse than receiving a diagnosis for your child, but you definitely don't want to get the wrong diagnosis and then go through the wrong treatments and all this trial-and-error period. So, I call Dr. Ness and Dr. Wheeler our dream team. We have an awesome dream team, and it gets me emotional when I think about it because we had no idea what was going on, and definitely didn't know how serious it was. And so, for them to just... they just picked up the ball and kept going. And I think it took me several months before it really hit me what was going on because they've made it so easy. They picked up, they said, "Hey, let's do this. You

need to do this. You need to come here. You need to go there. I'll meet you when you get to the hospital." What doctor would admit you to the hospital and beat you there?

I mean, I remember my son getting... I brought my Kleenex because I knew I was going to need it... I remember when he got admitted, and Dr. Ness is the neurologist, and she called me. She had my cell phone number. I have Dr. Wheeler's cell phone number. And if I text her or call her, she knows who I am. She knows who my child is. And I can call her. I can text her any day. And I feel bad when I do have to call her. But she's there. She's there to answer my questions. They're there whenever we need anything. They are there. They're there to answer those questions and to take away any negative notations or thoughts that we may have because, you know, it's like a deer in the headlights when you're looking at your child's MRI and it's like, "oh my God," you know, as a parent, you want to try to protect your child from everything and anything negative that you can. But to have our dream team there, it was phenomenal.

And it literally took me a few months for it to finally sink in and it was like, "Oh my gosh," you know, my husband can't wait for me to kind of break down and have a moment, and I didn't, I didn't need to because the experts had it all in alignment. I remember Dr. Wheeler calling and getting our medication going because it was an expensive medication, and you can't just go to Walgreens and CVS and get it. She's like, "never mind, give me your insurance information. I'm on the phone and I'm calling and I'm doing this, "and it just took away a lot of that weight. And that uncertainty.

So having that dream team around you, I think was imperative to how we view childhood and adolescent MS. You know, we know, we hear Dr. Wheeler all the time, it doesn't define who we are. You know, we were able to go from the negative thoughts that try to enter our mind in the beginning, and I literally... I'm not going to say I don't have a worry, but I don't daily worry and mull around the "what ifs" in my mind.

Marie LeGrand:

Wow, that's so good. And I'm so glad that you touched on the importance of having a dream team because that can be so challenging for a lot of people, you know, considering that pediatric MS, typically the number of cases are smaller than adult onset MS, and so, you know, having that team around you, having that support system, especially when it's coming from your healthcare providers, from your neurologists and MS specialists and others, that can be so crucial and fundamental to the health outcome of your child. So, thank you so much for sharing that, Elena. Dr. Wheeler, I'm sure you've come across this question, and Elena, you may have asked this question as well, is pediatric MS hereditary, and will pediatric MS affect other children in a family?

Dr. Yolanda Wheeler:

So, that is an interesting question. So pediatric MS is not hereditary. When you think about hereditary disease, you think about sickle cell or cystic fibrosis. You know, there are risks and relative risks related to those diagnoses, if you have both parents who have a sickle cell trait, then the child has a one in four chance of developing sickle cell. Well, MS is not like that. We know that there are some genetic predispositions. We know that it's not transmitted, so to speak, like those other diseases from child are passed down from a family through generations. There has been evidence in history, there's been evidence in cases that have been reported, where MS has existed in families, but they don't know the specifics of why, because we don't really know the cause of MS. We know that there are genetic components to it. We know that it's related to other autoimmune disorders, as far as genes, and there have been genes that have been identified over the years that have been similar in other rheumatological disorders,

like RA, or rheumatoid arthritis, but there are some statistics that have been put out about first degree relatives with MS that do increase the person's risk of developing the condition.

Lifetime risk, for instance, in an identical twin. So, for a child who has an identical twin, there's a one in five chance that the other twin may develop MS. And I've taken care of some identical twins in my practice, and that other twin has not gone on to develop MS so far. One in twenty-two relative risks for a non-identical twin that will have MS, one in thirty-four chance of a sibling who has MS. I have taken care of some siblings. And then there's that one in sixty-seven chance of a parent who has MS. And I have some parents who have gotten diagnosed after their child was diagnosed with multiple sclerosis.

And so, there's not hereditary in that, you know, if I have this child, then surely their siblings are going to develop that disease. And I talk to my parents, I tell them, especially my parents who have younger children, or older children, "we're not going to do MRIs on everybody in the household. We're going to let the stories unfold, but we're going to keep it real and we're going to keep everything normalized, and we're not going to dwell on things." I've had parents call me and give me their child's symptom and I've had to talk them off the ledge, so to speak; say, "hey, I don't think this is MS related. I think this may be growing pains. I think this may be something else they're experiencing," because they do worry, and they have every right to worry about their other children. But I just kind of normalize things for them. I say, "hey, you know, I'm a phone call away. We're going to have a conversation. We're going to figure this out."

Marie LeGrand:

Elena, did that cross your mind when your son was diagnosed?

Elena McDaniel:

Actually, it did. I guess just being a nurse in school it's like, okay, I'm going through the family history. And of course, I went back, even in my mind to my grandparents who passed on. And it's like, you know, if you have family members who are older, a lot of technology and medicine has changed since they were younger. So, they may have had it and not have known it. But Jaden is in that number who, his dad actually was diagnosed, I believe it's a couple of years after his diagnosis. So, it kind of... I'm not going to say it put our mind at ease, but I think it helps Jaden to not feel like he's alone. And it's something that he and his dad kind of, you know, I'm not going to say they have a common bond over it, but it kind of helps him not feel alone. You know, he's not the only person that he knows personally who has MS, and they can kind of share and bond in their different experiences.

And even now, Jaden's treatment is like his dad's now. So he was taking the oral medications, having to take a pill every day. And just being a teenager, he did phenomenally well with remembering to take his meds every day. But now, he doesn't have to take a pill every day so he can get an infusion a couple of times a year, you know, and he doesn't have to worry about it. So, even with that treatment, it kind of gives him a chance to be a kid, be a teenager, and not have to... that's one less thing for him to have to worry about being responsible for. Just those couple of times a year, couple of days, he's in the hospital, hooked up to an IV and he's fine. And it's been working really well, really well for him.

Marie LeGrand:

That's good. That's good because I know even for adults it can be challenging remembering to take your medication on a daily basis. You know? So, I can just imagine, you know, for a child, for a teen, how challenging that can be. So thankfully, he has that option that's available to him

now. Dr. Wheeler, earlier in the conversation, you mentioned briefly that MS can affect brain function, and I'm sure there are parents, guardians who are wondering how pediatric MS affects children's brain development. Can you talk a little bit more about that?

Dr. Yolanda Wheeler:

So, I will say that MS in pediatrics, you know, happens in the most vulnerable time when brain development is still happening, you know, when it's still maturing for the most part. And so, depending on where the lesions are located, it may affect that lobe of the brain where attention may be affected. Trouble with memory. They may not process speed as fast as others. Recalling information may be an issue difficulty learning new information or retaining information on short recall. Visual-spatial - when I say visual-spatial, I see something, but I'm trying to put in perspective of where it's happening. Recalling information, they'll say oftentimes, I have information on the tip of my tongue, but I can't say it. Difficulty with processing information and even language. And so, all those things can be affected because their brain is developing and they're going through changes, and then with the damage that MS has done to their brains, to their brain matter, it may have any impact.

Marie LeGrand:

And Elena, maybe you can touch on that as well, because I think you may have mentioned that before.

Elena McDaniel:

I think that's actually when Jaden's diagnosis hit me. Literally at the end of the meeting, I broke down and cried, but I had to meet with all of his teachers and the guidance counselor at the school. We kind of sat down and I told them, "Hey, this is his diagnosis and these are a few issues that may or may not arise. I just want to let you know, you know, he may come to a time where he may need more time on tests or, you know, sometimes they have timed exams and assessments and things like that." So I just wanted them to be aware that if he gets to a point where he's a little slower and he's not completed his time, it's not that he can't do it, maybe give him an extra 10 minutes to finish this task or, you know, maybe he needs to move closer to the board because he may not be able to see, you know, as clearly.

Or something as simple as restroom breaks. You know, you have some kids who use that time to go play in the hall. And with him, if he was to have an issue with urgencies or really need to go to the restroom, I needed that teacher to know, "hey, this is not the time for you to say no walking right now. If my child tells you that he needs to go to the bathroom, he needs to go to the bathroom, and I need you to let him go, or we're going to have a problem." But it's just a way to kind of put things in writing so that if a problem were to arise later on, we have documentation stating, "okay, he's been tracking well here, but now we may need a little more support or accommodations or be, you know, a little more lenient with certain things." It's not to just push them along throughout the school system, but it's to accommodate them wherever the need arises.

Marie LeGrand:

That's good to know. And I'm sure parents and guardians who are listening in are thankful for that bit of information because, you know, again, it can be challenging to navigate the school system. And when, you know, school administrators and the teachers and the principals aren't aware of what's going on with your child, it can make it even more difficult for them. You know, and especially when they have to deal with peers as well. So, you have to factor that in as

another challenge for children and teens. So, it's good to know. And thank you so much for sharing a little bit more and providing clarity around the 504 plan.

So, we're going to pivot just a little bit here. And let's talk about transitioning. So, for children and teens, Dr. Wheeler, who are transitioning from a child neurologist to an adult neurologist, they will have unique needs, I'm sure. So, what should parents, guardians, and children and teens keep in mind as they are making that transition into a young adult living with MS while being independent?

Dr. Yolanda Wheeler:

So careful transitioning from adolescence to adulthood, or adolescent to teen to adulthood, may I say, requires careful coordination between the pediatric specialists and the receiving neurologist, as well as the child, the young adult, and the parent. Everyone needs to be on the team. There needs to be open communication between the healthcare providers. There needs to be times for meetings, there needs to be education on the part, provided to the team.

You know, I give my parents, I start out very early on, I say, "okay, mom, you're going to stay in the room today. Jaden is going to go over to the lab by himself, because Jaden needs to be able to learn how to walk himself to the lab. Jaden needs to be able to learn to sign himself into the registration desk. Jaden needs a copy of his insurance card." There needs to be education, extensive education, from the very time that they're diagnosed and they're real little, real young, immature. But there's a time that we have to start teaching them how to transition into adulthood. It can be a seamless process if they're given the proper tools that they need in order to do this. Age-appropriate education to teach them about their peers, their community support that is there in order to address not only the physical, the emotional and the vocational challenges they may have as they reach young adulthood.

And so, it's a lifelong process. It's a learning process. It's a process that has to be done so that they are successful, that they don't fall off the radar, so they don't lose access to care, and then their quality of life goes down. And so, I think the transition is so important and it needs to be coordinated and meticulous so that care can continue on and it can be excellent care.

Marie LeGrand:

Wonderful. Good to know. Elena, what do you think parents and guardians should keep in mind as their child is approaching young adulthood and being independent? You know, especially when you're, you know, you think about your child graduating from high school, going on to college and, you know, and I know with having nieces and nephews who are about to graduate from high school and, you know, you have one that is anxious to go out of state, as far away as possible. And you have another who wants to stay close to mom. So, what are your thoughts around that? What should parents and guardians keep in mind?

Elena McDaniel:

You know, and that's, we're coming up on that now. Jaden is a junior now. And just like Dr. Wheeler says, you know, he's able to check himself in and go get his blood work done. And, you know, I think that's something we've always agreed on, like, "go, go do it. You can handle it." So, his next infusion appointment, he will be by himself. He will drive himself there, check himself in. He knows where to go and what to do. So, I think it's important to allow them to become independent. We can't shield them from everything, just like any other child, you know, as parents, we want to, sometimes, to shield them from every little thing, but they have to learn, you know, it's not going to be detrimental if he doesn't sign his name just right or have his

insurance card. So, I think we have to allow them to experience everything in life that comes their way. You know, he's learning how his body responds to certain situations and allow him to set his own limits instead of me wanting to bubble wrap him and protect him from everything. He has times, you know, when he's like, "No, mom, I really I don't think I'm going to be able to do this. You know, I had this on my calendar today, but I'm really exhausted." And it's okay. Versus me saying "you're trying to do too much, you need to slow down, you need to take a break. You know, give yourself grace." And sometimes I do have to do that because he'll take on everything. I think we have to recognize and allow them to sort things out for themselves and when to intervene.

So give them that little... give them a yard, give them an inch, give them as much as they can handle on their own and then be there to kind of catch them if they fall, just like in everything else in life, you know, allow them to make mistakes, allow them to handle challenges on their own and be there to catch them if we need them to. Kids are much more adaptable and can adjust to things then we give them credit for. We just have to give them the tools, give them their tool belt and everything that they'll need to face life's obstacles but still be there for them.

Marie LeGrand:

Yeah, and I know, again, that can be something else that parents and guardians have a hard time to deal with. And you mentioned bubble wrap, wanting to protect your child, your teen, from any and everything in this world and that is difficult to do, you won't be able to do it all and being able to give them that room to grow and to become independent and, you know, what you both said in terms of starting at a young age and giving them the tools that they need so that they can become familiarized with having to be independent and showing their insurance card and looking at the paperwork and, you know, going to their doctor's appointment by themselves without, you know, mom and dad, without a guardian there. So, it's the little things that you both shared with us that will help, you know, children and teens become even more independent. And as you mentioned, it will make it easier to transition as young adults living with MS.

Dr. Yolanda Wheeler:

I was going to say, we even start by talking to the kids about symptoms. I want to hear the child's version and then I ask mom or dad, "Okay, give me anything you want to add," because it's important for them to be able to talk about their disease process with the healthcare provider, because they'll have to do that when they become of age. They'll have to be able to talk to the doctors about what's going on with them.

Marie LeGrand:

Yeah, and that's very true. So now we're getting to the close of our program. Do you have any final thoughts? Was there anything that maybe we didn't cover, Dr. Wheeler or Elena, that you feel is critically important for parents and guardians to know?

Dr. Yolanda Wheeler:

I want to say that there are resources out there for parents newly diagnosed with MS and their families, that are available from various organizations. I also want to encourage parents, caregivers, whoever that may be, to connect to other parents and other individuals dealing with a diagnosis. But the MS organizations that I like to include are, of course, the Multiple Sclerosis Association of America, MSAA, who's putting on this podcast today, as well as the National MS Society. You want to reach out and there are most certainly more and more resources that have come out over the years. But make sure that those resources provide factual information, that provide information that can be backed by sound research, backed by sound information. And

so just make sure you go over that information with your healthcare providers to make sure they recommend those various organizations that are out there that will help you to navigate the pediatric MS diagnosis.

Marie LeGrand:

Elena, as a parent, seeing the effects of MS on their child, is there anything else that you would like to share?

Elena McDaniel:

Just allow your child to live their life. You know, at the end of the day, they're children. They want to be seen equal to their peers. A lot of children, they don't want that extra attention and doting on them and just wanting to put them in that bubble and pack them away from everything. They just want to be treated as other kids. And as Dr. Wheeler listed the other resources, I remember hearing about the MS Walk that usually takes place in town here in March, and I started getting so excited and I wanted to register us for it. And then I backed out the first year because I felt like, "Oh my gosh, what if he sees a lot of people, you know, with different assistive devices, the wheelchairs and walkers and things," and I didn't want him to get in his mind that this has to happen to you. And I didn't want him worrying about, "When is this going to happen? Oh, my gosh, is this it, is this it?"

And so, I finally dispelled all that negative emotion that I was having, and we went the last couple of years, and he really enjoyed it. He met friends, he met elder people. And I talked to other families and adults, you know, and again, just medical treatments and technologies have advanced so much where you might not have to worry about things like that happening. And so I didn't want to impose my thoughts and my fears on him. Let them be kids. Let them live, let them participate in whatever they can, whatever they want to, and whatever you're allowing them to.

And I'm so proud of him. He is so active. He is in every organization he ever wanted to be in. He sings in the choir, he wrestles, he's on the honor roll, he's in... they have an engineering academy at school. He plays piano. He has a part time job. He helps at home with his siblings. So, I try not to limit anything that he wants to do. I'm going to push him to do it. The only thing he doesn't have to do is cut the grass. We are in the Alabama heat, and you know, that heat, it just kind of takes his energy. So that's the one chore that I've taken away from him because I used to have him out there, he would cut the grass, and then he'd come in and he is just done for like the whole weekend. So that's the one chore that we have to do at home.

Marie LeGrand:

And I'm sure he's okay with not having to do that. Alright, so finally, Dr. Wheeler and Elena, are there key messages to take away from today's program? And we can start with you, Elena.

Elena McDaniel:

Just like I was saying before, with going to the MS Walk, and Dr. Wheeler is partnering with Children's Harbor, so we have a camp every year, and we went for the first-time last year because of COVID shutting down everything. But we really enjoyed that weekend, getting to connect with other families, hearing other families' stories. And even Jaden, he's made some friends. You know, they text, they talk. And just knowing that they're not alone, they have their own little network and community of friends, and it helps to hear others and to know that even as a parent, I'm not alone. Somebody else is going through the same thing that I am. And to be able to encourage one another and just, you know, we can do it, we can make it. We have to let

them go a little bit, give them that independence as parents, and the kids kind of just connecting, knowing that, “hey, I'm getting ready to go off to college or I'm working this job.” So, it's encouraging for the parents and the teenagers, the adolescents, the kids to kind of have that community.

Marie LeGrand:

Wonderful, wonderful. Well, I think we are pretty much at the end of it. Thank you both so, so very much for sharing and providing such insight into pediatric MS, Elena, and hearing about your son. And I know that's going to be so helpful for, you know, parents and guardians who are listening in. And Dr. Wheeler, your expertise in pediatric MS will give parents and guardians the tools that they need to make informed decisions for their children. So, thank you both very much.

On behalf of MSAA, I would like to thank Doctor Wheeler and Elena, once again, for your helpful and wonderful knowledge and insight on this topic. I'm sure this conversation will, as mentioned, be helpful for parents, guardians, children and teens who are living with pediatric MS as they navigate seeking care and resources. This concludes our podcast and I'd also like to thank Gradwell House Recording for hosting us today and producing the program. Please know that this podcast, along with additional information on pediatric MS, can be found on our website at mysaa.org. Once again, thank you for listening and have a wonderful day.