

Autism Support of West Shore

A place where everyone fits



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The Blessings in Our Golden Years

The names in this story have been changed to protect our child

Our retirement plans were in place. A medium-sized motor home and tour the country! We had planned our golden years well in advance and were looking forward to them! We never expected we would be parents a second time around.

Our two daughters both had special needs. We spent much time looking for safe and comfortable placements for them. Our oldest daughter, Michelle, had schizophrenia. She had both visual and audio hallucinations. She is now in a very nice foster home and is comfortable and stable,

Our other daughter, Angela, is cognitively impaired. Her most difficult issue in life is she has never been able to recognize strangers. Anyone that said “hi” to her and smiled was in her mind a friend.” We were guardians and set her up in a lovely apartment complex that was less than a mile from our house.

She faced an unexpected pregnancy. Fortunately, we were friends with the intake worker at Probate Court. He guided us through what we needed to do so our daughter could keep her baby. The intake worker encouraged us to put together a plan to protect the child.

Our friend from Probate Court made out Power of Attorney papers that would be signed by one of the baby’s parents the day it was born, guardianship papers were filled out with the exception of dates, to go before the judge soon after the power of attorney papers were signed. We were guardians for six months. When the baby was 9 months old, we adopted him. When we settled into the fact that we were going to be “senior parents” we found a group called, “Second Time Around.” We began attending it once a week for hints and education about parenting as seniors.

Our daughter had had a difficult pregnancy and an ultrasound indicated that our little grandson Luke had lost the diastolic flow in his cord blood. At birth, he weighed 2 pounds and 11 ounces. He had a rocky stay in the NICU, to say the least.

We signed up with a program called Early On. They provided support and therapy for premature babies. We noticed that Luke didn’t like any of the therapists looking at his face. He seemed to avoid eye contact with everyone outside of our home. Our pediatrician told us to tell people not to look into his eyes but to look above his head. I mentioned to the doctor that I thought Luke might be autistic. He neither denied it nor admitted it.

At about 8 months, Luke began rolling around the floor and even down the hall. We all took turns crawling on our hands and knees to show him how. Once he crawled backwards down an entire flight of steps, grinning all the way. We had heard it was common for an autistic child to show off a skill then not repeat it for a long time. He also spoke a few words, but again only one time.

We built a house in Florida, only 20 minutes from Disney World. We began exposing Luke to many adventures they had to offer. We quickly learned what restaurants were too noisy for him and avoided those. We also noticed he became very upset if one of the characters in costume surprised him from behind. We continued to take him twice weekly and he gradually adjusted to the costumed characters, but not the loud noisy places, nor the parades.

When Luke turned 4, we took him for testing and school placement in Florida where we lived. The testing labeled him with a school diagnosis of Autism with Oral Apraxia. However, no classes for autistic children were available in the state.

We decided to homeschool him, after all how hard could that be? We went to a huge home school convention in Orlando. We purchased hundreds of dollars' worth of educational items. He was very excited when we walk in the door with several shopping bags. We laid them down on the floor. As he opened each one, we sat in amazement as he conquered each teachable item one by one.

By now we were beginning to put the puzzle together. One afternoon I was typing on my laptop in the breakfast nook. Luke was 4 years old. I left for a bathroom break and when I came back this is what I saw, "Where is my father." Luke could make a sentence. Luke could spell correctly. Luke knew what a family unit was and knew the person we called Poppy was grandpa, not father! He was much smarter than we thought.

Due to our American Sign Language training, Luke knew sign language at a very early age. He could sign all the verses of "Jesus Loves Me" at age 3, plus many other songs and communicated with us using sign language, and gestures. He also could read many words. We used 3 x 5 cards and labeled everything in the house. We took the cards down, shuffled them and gave them to Luke. We asked him to match the words on the cards with the things in our home. He was 4 years old and he could match every word with the correct item.

We began calling around to different states and asking about autism programs. We were originally from Michigan and they had two programs that were excellent. One was in the Ann Arbor area. After experiencing living in the Orlando area, we didn't want to live in a large town. The other was in Holland. We liked the sound of a smaller community and on the shore of beautiful Lake Michigan.

We visited West Ottawa's Education Administration building. It was summer so most departments were not fully staffed. However, we were put in touch with the school psychologist. He did some testing with Luke and wanted to interview us. He suggested that Luke sit at the computer while we talked and then we would see what he did on the computer. After our interview, we checked out the computer where Luke was sitting. The psychologist said, "My goodness, he is on the Internet. Has he done that before?" "No, never."

Luke had a medical diagnosis of autism, but needed an educational diagnosis of autism from Ottawa County, to be placed in an autism-based classroom. When we moved to Holland, we checked back with the administration office and found that Luke had been placed at Ottawa Area Center.

We drove him to school the first two days. He was very excited. However, when we picked him up after school on the first day, we were told, "He doesn't belong here." The next day they put him in another classroom. We again picked him up after school and were told that during recess he had unlocked the gate to the playground. No child had ever done that. Still, he didn't have an educational diagnosis of autism.

It was extremely difficult and long process, along with much advocating to get an educational diagnosis on the autism spectrum. We had four IEPs the first semester and visited schools with special needs programs.

He didn't fit any of them. Finally, a team of educators from the administration building called and wanted to come to our house to talk about Luke's needs for education. They asked so many questions, observed Luke and said there was no doubt that he met the educational diagnosis for autism. Finally! We decided to let him finish the first semester at OAC and start the autism program at Sheldon Woods.

Our new adventure in an autism classroom was exciting. We took Luke to visit. We found there were three other nonverbal students in the kindergarten class. The teacher was not certified in autism, but worked under the wing of a person in the special education department in administration, who was certified in autism. She asked a million questions and so did the aides in the classroom. They were well informed about their new student. The teacher didn't use sign language but had a book of signs to refer to.

As we toured the school and the kindergarten room, we noticed each student's name above a Velcro strip, which held little pictures showing their schedule for the day. After each task was completed, the student took the appropriate picture off the Velcro strip and placed it in a basket. We explained that Luke could read and asked for words to be placed on his strip. She never did use words, but gave him pictures like the other students. We were saddened that she was unwilling to test Luke's skills with words; despite the many times we talked to her about it.

When Luke started first grade, the school had hired an amazing and skilled teacher certified in autism, Andrea Dekker, to take over AI program. She was willing to try using words rather than pictures for Luke's schedule. Sure enough, he had no trouble reading the words and following his schedule. Luke drew very close to her; it was as if he knew she believed in him. He also grew particularly close to one aide who prompted him and pushed him a little to do more and more. His education was headed off to a great start.

In second grade, because of the growing number of autistic children another teacher was hired, Kelli Miller. She also was certified in autism. We were on an awesome start in school with gifted teachers and aides!

As the number of students with autism grew, they needed a larger space than the tiny room at Sheldon Woods. The AI program was moved to Woodside Elementary. They were given a spacious room that had an accordion-folding curtain that could turn one large room into two smaller rooms if needed. The class was divided according to grade. The kindergarten, first and second graders were grouped together, and the third, fourth and fifth grades were grouped together. Luke now had his whole week's schedule on one piece of paper taped under his name.

Luke began not wanting to associate with the AI students. He saw himself as a general education student. One day in third grade he walked out of his AI room and joined the general education classroom. An aide was sent with him to follow and just be there for him. When it was time to go home, it often took two adults to get Luke out of the room. He had learned to brace himself in the doorway.

Fourth grade was the same. He didn't want to be associated with the AI students. However, to keep his autism certification, he had to report to the AI classroom first thing in the morning and before leaving school in the afternoon. The academic work in general education was a little difficult for Luke, so his workload was scaled down so he wouldn't feel overwhelmed. He picked a locker next to the fourth graders.

In the spring of fourth grade Luke had surgery on his spine. Rods were placed from T6 to L2. He received cards and pictures from every classroom and staff at Woodside Elementary! What an awesome heartfelt love from his school.

Fifth grade was a repeat of grades 3 and 4. He sat with the general education students for lunch and spent the major part of his day with them.

Something else was changing. Luke began developing a hump of scar tissue at the T6 vertebrae. It caused him to walk bent over looking at the floor. His surgeon wanted to wait to operate again for one year after the first surgery.

The second surgery involved removing all existing rods, screws and caps currently in his back and replacing them with new ones extending up to T2 and down to L3. During surgery, the doctor was carefully scraping away at the scar tissue that had created the large hump on Luke's back. While scraping at the scar tissue, the surgeon accidentally scraped his spinal cord. All his limbs were connected to sensors. If the spinal cord is touched, the sensors beep. The sensors on his legs went off. He had lost all the nerves and muscles in his legs. The protocol was for the surgical team to step back and wait 30 minutes for the nerves and muscles to come back. Seventy percent of his nerves returned but none of his muscles returned. He was sent for a scan and then to PICU. That night his lung collapsed and he had to be placed on a ventilator. When he stabilized and could breathe on his own, he was transferred to Mary Free Bed.

The doctor had warned us that Luke might be in a wheelchair for a "very, very long time." Settling in at Mary Free Bed is where we watched as the most amazing therapists we have ever seen. Luke received even more cards, posters and gifts than the year before. His teachers, aides came on a regular basis to visit him and always surprised him with thoughtful gifts that kept him busy and his mind off his paralysis. Two months later he walked out of the rehabilitation hospital with a walker. We give God all the glory for his healing.

Luke was home schooled through West Ottawa school system for a few weeks. When he returned to school the first day, he rode in his wheel chair. As his aide, Vicky, pushed him past each classroom, the students saw him in the hall and began a contagious clapping that was heard throughout the school. We aren't sure who wore the largest smile, Luke or his special aide who pushed him.

Luke finished elementary and we all thought he was ready for middle school, also called "the transitional phase before high school." Middle school had some big bumps to overcome. Luke had an overbearing aide with a very loud voice. He began to shut down. Also, his resource room teacher was on maternity leave during 6th grade and again during 8th grade. She was Luke's source of calm, kindness and fun. Several times we were called to school while she was on leave because Luke didn't want to move from his resource room desk. His aide asked, "Why don't you punish this child for his stubbornness?" We asked, "Why haven't you asked Luke what was bothering him?" Thankfully, we made it through the rocky road of middle school!

Luke is now in high school. He continued with physical therapy. Some might say that we have sacrificed our golden years for Luke. But we have never felt it has been a sacrifice at all. He has the most joyful heart and we are blessed daily by his presence. He is not ordinary but an extraordinary gift to us during our golden years. There has never been a regretful moment, for we received the greatest gift of all; our moments are filled with joy and laughter.

God has given our journey to us and He makes no mistakes. He knew we didn't need a motorhome, for He had something much more enjoyable planned for us. We praise him for His gift of trusting us with the care of Luke. It isn't just what we could do for Luke, but also what he could and has done for us!

Research Opportunity

Have you heard about SPARK? SPARK is already the largest autism research study, but they are just getting started!

What is SPARK?

They are a growing community of individuals, families, and researchers on a mission to speed up the understanding of autism. Our **aims** are to:

- Collect DNA and information through surveys from **50,000 people with autism** and both of their parents.

- Share that data with **researchers**.
- **Make breakthroughs** that were never before possible.
- **Return our findings** to you.

SPARK is sponsored by the Simons Foundation Autism Research Initiative (SFARI) and Michigan Medicine is one of more than 30 participating hospitals and clinics across the country. Participation in the study is entirely up to you and will have no effect on the medical care you receive.

Who can join SPARK?

- Are you the parents of a child with autism spectrum disorder (ASD)? Join us!
- Are you a person with an ASD diagnosis? We need you.
- **All ages are welcome!**

Why join SPARK?

- Find possible **genetic causes** of autism in your own family.
- Power future autism research for **years to come**.
- Join other autism **research studies**.
- **Get updates** on the latest autism research.
- Connect with a **community** of *[number of clinical site's members]* SPARK participants in our region!

How do we join SPARK or find out more?

Registration can be completed entirely online and from home at www.SPARKforAutism.org/Umich, or by scheduling an appointment with the Michigan Medicine study team. We are standing by to help and answer your questions at 734-232-0196 or Michigan-SPARK@med.umich.edu.

By joining SPARK, you will be making invaluable contributions to advancing the understanding of autism. Together, we can improve lives by helping to accelerate research!

Save the Date

October 1-2, 2019 Emergent Literacy Instruction for Students with Significant Disabilities and Complex Communication Needs

Students with significant disabilities can and do learn to read conventionally with supportive print- and language-based experiences and interactions. Not unlike students without significant disabilities, this learning for students with significant disabilities begins with emergent literacy. Students who are emergent literacy learners should be provided many frequent learning opportunities that provide instruction and practice with functions of print and print conventions, phonological and alphabet awareness, and expressive and receptive language skills. This training is based on the work of Dr. Karen Erickson and Dr. David Koppenhaver.

<https://www.altshift.education/event/emergent-literacy-students-significant-disabilities-0>

Intelligent Lives

October 21, 2019

Time TBA

Watermark Church

13060 US-31, Grand Haven

Oasis Community will be showing the movie Intelligent Lives at Watermark Church. All are welcome.

7th Annual Michigan Autism Conference

October 9—11, 2019

Preconference workshops on October 9.

Radisson Plaza Hotel & Suites, Kalamazoo, MI

The mission of the Michigan Autism Conference is to disseminate information and training on scientifically validated, behaviorally based treatments to parents, caregivers, and professionals who work with and care for individuals with autism spectrum disorder, and to promote awareness and training of closely related conceptual, scientific, and ethical issues. This mission aims to increase functional skill development and decrease behavioral excesses to ensure individuals with autism can live enriched high-quality lives.

www.michiganautismconference.org

IEP Webinar Series

October 18th IEP 101

November 1st PLAAFP Statement

November 15th IEP Goals and Objectives Autism and Anxiety

1:30PM-3:00PM Sign-in opens at 1:00PM

Hastings Public Library

227 E. State Street, Hastings

With Debbie Rock

Do you have a child with an IEP? This series will look at how the important parts of the IEP build on each other. Each week there will be time to network with other families as well as speak with our Parent Mentor. Attend one session or all. <file:///C:/Users/elenb/Desktop/documents/ASWS/articles/conferences/IEP-Series-2019-10-Hastings.pdf>

Autism and Anxiety

October 21, 2019

6:30 – 8:00 pm

Herrick District Library,

300 S. River, Holland

Autism Support of West Shore will be hosting Dr. Kaarin Anderson-Ryan as she speaks about Autism and Anxiety. This presentation will provide information about anxiety and how it relates to autism. We will go over some of the causes and signs of anxiety, and will review information about anxiety disorders. We will focus on the overlap between anxiety and autism, including specific features of autism that can be connected back to anxiety. Different techniques for assessment and for overcoming these challenges will be presented, along with opportunities to discuss and ask questions. This is a free event. This event is open to the public

A Special Low Sensory Performance of Frozen!

Wednesday, October 23, 2019

7:30 pm

Enjoy a theatre evening where the script and entertainment never changes, but the environment does. Reduced sound volume, adjusted lights, and an opportunity to learn about the show ahead of time make productions a more pleasant experience for individuals with diverse sensory needs and their families/caregivers. Limited tickets to allow for more space for attendees. Reserve tickets by calling the Grand Rapids Civic ticket office.

AAoM Navigating Autism Today Regional Conference

October 25, 2019 10:00 a.m. — 3:00 p.m. The MTG Space

4039 Legacy Parkway, Lansing, MI 48911

Autism heroes from around Michigan will gather to discuss, connect and learn through participation in breakout sessions, panel discussions and interaction with a diverse mix of autism-focused exhibitors. The conference is FREE for all families. Professionals are asked to pay \$50 per person attending. Register at: <https://aaomconference.org/register/>

Peer to Peer Statewide Training

November 5-6, 2019

8:30-3:30

Kellogg Hotel and Conference Center

219 S Harrison Rd, East Lansing

<https://www.gvsu.edu/autismcenter/start-events-49.htm>

Building Your Future Transition Expo

November 6, 2019

4:30-7:30pm

OAISD Educational Services Building

13565 Port Sheldon. Holland

Students in grades 9 – 12 and post high school parents, guardians, family members, teachers, school staff and others interested in helping transition students in life after high school.

Special Needs Guardianship

November 11, 2019

6:30 – 8:00pm

Loutit District Library

407 Columbus Ave, Grand Haven

Autism Support of West Shore will be hosting Judge Mark Feyen as he speaks about Guardianship for special needs children. What is it? Who needs it? How do you get it? Is your child soon to be 18 or do you just want to know what is potentially in your future? This discussion will answer your questions. Judge Feyen sits on the Ottawa Probate Court and hears cases on Probate, Guardianship and Estate Planning.

ASWS Holiday Party at RebounderZ

December 1, 2019

6:30 – 8:30 pm

7500 Cottonwood Dr, Jenison

ASWS is going to kick off the holiday with our annual holiday party at RebounderZ of Jenison this year. This is a private party for our families with children on the autism spectrum. Come out for fun and family time at RebounderZ. Register for this free event at www.awsw.org

ASWS 2019 Golf Outing and 19th Hole Party

Wow! What a wonderful day for the ASWS 2019 Golf Outing and 19th Hole Party fundraiser

at Oak Ridge Golf Club in Muskegon! Judging from the smile we saw on Saturday; everyone had a great time. Another HUGE thank you to all our golfers, sponsors, donor, supporters, committee members and Oak Ridge Golf Club and Bella Maria staff who helped make this year's outing a success! We couldn't have done this without you! We appreciate all your generous donations and support which will help bring smiles to local children and families affected by autism.

Check out all the photos at https://www.facebook.com/pg/asws2/photos/?tab=album&album_id=2059054904193968



Resources

Friends Connecting People with Disabilities and Community Members

Angela Novak Amado, Ph.D.

This manual is to help people with disabilities increase community membership and belonging and for promoting relationships with community members

■ It is written for agency staff but can be used by anyone such as individuals receiving services, families, and support coordinators, etc.

■ Many strategies were developed with people with intellectual/developmental disabilities, but the strategies are useful for anyone

■ Not everything will be useful for everyone — use what is useful to YOU!

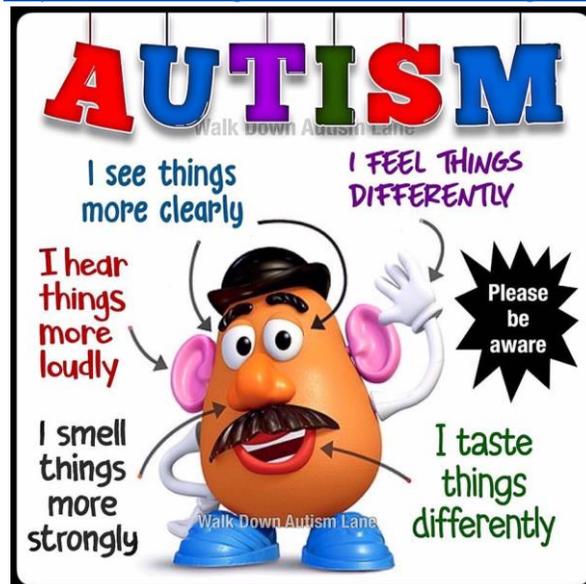
■ For additional information or training on this topic or any material in this manual, please contact — https://rtc.umn.edu/docs/Friends_Connecting_people_with_disabilities_and_community_members.pdf

Angela Amado Research & Training Center on Community Living 150 Pillsbury Dr SE, 105 Pattee Hall University of Minnesota Minneapolis, MN 55455

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Phone: +1 651-698-5565

Michigan Alliance for Families has a DVD available: "Making the Most of *Early On*®", designed to help parents better understand and access the system of supports and services for children from birth through age three. This video is divided into six topics and is available with Spanish subtitles, Arabic subtitles, or English closed caption.

<https://www.michiganallianceforfamilies.org/dvd/>



Advocacy and Awareness Come in Unusual Places - Headline - Amy Schumer Won't 'Cope' if Son has Autism Like Her Husband

Actress Amy Schumer floated the interest balloon in a docuseries about her pregnancy and birth in an Instagram post featuring a sweet picture of herself and son Gene.

But one fan replied on her Instagram, "Not really, honestly." Others felt the same. Though it's what she said next that brought a reply from Schumer, 38.

"I think you're great, I just feel like it's self-serving and overdone," the commenter wrote. "I'd like to see a documentary of you discovering your mate is diagnosed with autism and how you cope with the possibility that your child will be on the spectrum...."

Schumer wanted to back the truck up when it came to the word "cope."

Schumer responded: "how I cope? I don't see being on the spectrum as a negative thing. My husband is my favorite person I've ever met. He's kind, hilarious, interesting and talented and I admire him. Am I supposed to hope my son isn't like that?"

Schumer has been open about husband Chris Fischer's ASD, a "developmental disorder that affects communication and behavior," according to the National Institute of Mental Health. Autism advocacy groups have lauded the comic for bringing visibility to people with ASD.

The poster later apologized for her "poor choice of words."

Hundreds of fans praised Schumer's response.

"Your comment set my hair on (fire emoji) It's called love, joy, downright perfection! My darling grandson is on the spectrum and he gives off more light than the Sun!," one person wrote.

Another wrote: "this might be the greatest response in the history of Instagram comments."

Schumer, who gave birth to her son Gene Attell Fischer May 5, added in her response to the Instagram poster that she's a mom and has this parenting thing covered, thank you very much. "I will pay attention and try and provide him with the tools he needs to overcome whatever challenges come up like all parents", she wrote. "I'd be disappointed if he liked the Big Bang theory and Nasar not if he has ASD."

Solutions for Smart but Struggling Students

A FREE 5-PART MASTERS SERIES TO OVERCOME OBSTACLES AND UNWRAP YOUR CHILD'S GIFTS

JUST BECAUSE YOUR BRIGHT CHILD LEARNS DIFFERENTLY DOESN'T MEAN THEY'RE BAD, BROKEN OR DUMB (EVEN IF THEY FEEL THAT WAY) Your child may be '**twice exceptional**' or 2e:

2e kids are highly intelligent or advanced in certain areas (one exception to the norm) and at the same time, behind in certain areas like focus, learning, social/emotional or behavior (the second exception to the norm).

The problem is not your child or YOU! The problem is:

Most school and medical systems focus solely on remediating weaknesses when, in reality, what really works is developing strengths, interests and talents, in addition to skill building challenge areas.

Most teachers receive zero training in working with 2e kids and don't know how to personalize their learning or accommodate the unique way their brains learn.

Parents feel alone, scared and frustrated by the lack of services, support and information for their bright and quirky kids.

<https://brightandquirky.com/smart-struggling-students-registration/#signup>



Lights up. Sound down. Enjoy the BIG SCREEN experience in an accepting environment.

Showtimes start at 10:30 AM

Lights will dim, but remain on
Volume will be lowered.

Movies begin at show time with limited previews

Shown in 2D with open captioning

Cheering, calling out, or even strolling around the theatre is welcome!

In partnership with Family Hope Foundation, Sensory Showtimes make movies extra welcoming to guests with special needs, including autism. So, come relax, be yourself, and enjoy a movie at Celebration Cinema.

Upcoming Schedule

October 5: **ABOMINABLE**

October 19: **THE ADDAMS FAMILY**

November 30: **FROZEN 2**

December 21: **JUMANJI 2**

Celebration Cinema Grand Rapids North

Celebration Cinema Grand Rapids South

Cinema Carousel Muskegon

<https://celebrationcinema.com/events/sensory-showtimes/>

Board Message

Jessica Elenbaas-Domingues

As we start into the second month of the school year the Autism Support of West Shore would like to introduce you to the Parent Advisory Committee (PAC). The *Michigan Administrative Rules for Special Education* requires all intermediate school districts (ISD) to establish a PAC, which is made up of parents and guardians of children with disabilities. The role of the PAC is to provide an open meeting where parents and guardians of children with special needs can meet with school administrators. The PAC is able to provide a positive impact on special education programs and services by providing an avenue for advice and feedback directly related to special education topics.

In addition to providing parents of children with special needs advice and feedback related to special education topics, PAC members participate in several additional activities, which may include the following:

- Take part in reviewing the ISD plan. The ISD Plan documents how special education programs and services are provided within an ISD and each of its local school districts.
- Stay knowledgeable about changes and topics in special education and give input on special education issues.
- Serve as a source of information for other families.
- Stress cooperation between parents, school personnel, and other service providers.
- Encourage, advise, and process information for parents and guardians of children with disabilities.

The PAC works to encourage parent leadership and parent-school district partnerships, which directly support research showing student success can be directly linked to parental involvement in schools. By building relationships based on trust, parent leaders and school professionals can team up to make positive change happen. The PAC can assist in increasing knowledge and skills related to special education for families to become more connected with their child's progress. Anyone is able to get involved with their ISD's PAC and attend the PAC meetings throughout the year. To learn more about your PAC or to get involved, you may contact your ISD, your school district's special education department.

The Autism Support of West Shore hopes you take the time to look up your ISD's PAC.

Muskegon Area ISD – www.muskegonisd.org

Ottawa Area ISD – www.oaisd.org

Kent ISD – www.kentisd.org

Allegan Area ESA – www.alleganaesa.org

West Shore ESD – www.wsesd.org

Newaygo County RESA – www.ncresa.org



Presents

CONNOR'S FRIENDS

A special night for children and families affected by autism.

WEDNESDAY, NOVEMBER 20, 2019

FREE EVENT | STARTS AT 6:00 PM | FREE VALET PARKING

Space is limited and reservations are required.

Registration information coming soon!

Visit grcm.org for more information.

22 SHELDON AVENUE NE, GRAND RAPIDS, MI 49503