

# Autism Support of West Shore

*A place where everyone fits*



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## The Run

Susan Judd

The track is wide, and four times around equals one mile.

It is a hot, sunny morning in June as my son and I make our way down the bleachers and toward our friends who have gathered on the track. He is smiling and calling out the names of the people he sees. He gravitates toward his running partner, a kind and understanding man who not only talks the talk, he walks the walk of Jesus. Or, in this case, he runs. He has made the commitment to be not only a running partner but also a trusted friend.

After a round of introductions, a heartfelt prayer and a few stretches, the runners are off. One of our friends is halfway around the track before I have time to catch my breath on the sidelines. Then I see my son, the runner who goes from zero to 180 in a matter of seconds. He is flying around the track, arms pumping, legs striding wide, a smile on his beautiful face.

He is free.

These are the moments that I treasure. Watching him, it seems like time stands still. There is only one thing to focus on, and that's his enjoyment. There are so few times in his life that he is completely carefree. My son has an autism spectrum disorder and it significantly challenges him in the areas of behavior, communication and social skills. He has sensory issues and the world is often too bright and too loud for him. Without careful preparation, new situations can be bewildering, causing him to become upset or even shut down. The speech that starts in his brain becomes tangled as he tries his best to keep up in a conversation or answer simple questions.

Yet on the track he is fearless. Even when he slows down to walk, I can see a determination in his eyes to push forward. He is awarded a brightly colored bracelet for each lap around the track. I'm not surprised when he chooses yellow first. Yellow is his color of choice this summer for golf balls at the miniature golf course we frequent.

I like to think that he likes yellow because it's the color of the sun, of having a light heart. There is a lot weighing on him, to be sure. He is a young man now, crossing the threshold to adulthood. He faces what every other young man faces only magnified a thousand times. Where will he live? Where will he work? Will he work? What can we do to make sure that he has a meaningful life?

But on this sunny morning, those questions seem far away. The only thing that I'm thinking about is how happy he looks.

The track is wide, and four times around equals one mile. When the runners are finished, we count his bracelets. He has eight of them. He has met his goal of completing two miles. It is a good day.

We bid our friends goodbye. We are separate, but we remain together, bound by the shared experience of running. My son has an appointment with a beloved speech therapist. Upon seeing her, he extends his arm. He isn't one to call attention to himself. Never once in his childhood did I hear: "Look at this, Mommy!" or "Watch me!" His tutor understands the significance of his gesture. She admires his outstretched arm and asks him how many bracelets he has and then suggests that they count them. Together. I watch the two of them enter the school. I drive away.

The track is wide, and four times around equals one mile. On this day, it is the distance of one heart connecting with another.

## Save the Date

### **August 7-8, 2019 Introduction to PODD Communication Books**

This two-day course will demonstrate the use of a Pragmatic Organization Dynamic Display (PODD) approach developed by Gayle Porter (Melbourne, Australia). Generic templates for multi-page "light tech" communication books have been carefully designed to support genuine communication for a variety of functions throughout the day. These templates may be customized for a range of access methods and other individual needs.

Come learn strategies for creating multi-modal language learning environments that provide receptive models and expressive opportunities for language development. Learn strategies for teaching and using PODD with children and their communication partners. Videos and case examples will be shared.

<https://www.altshift.education/event/introduction-podd-communication-books-0>

### **August 10, 2019 Autism Awareness Walk**

11:00a.m. dz6

Grand River Park

9473 28<sup>th</sup> Ave, Jenison

Join families and friends for a one-mile walk and cookout. Paths are barrier free. There is no cost to attend, however pledges are welcome to support autism initiatives. This is a free event please register name and number attending by August 7<sup>th</sup> at [contact@asws.org](mailto:contact@asws.org)

### **August 15, 2019 Disability Pride**

10:00 – 12:00

Herrick District Library

300 South River, Holland

Learn tools to help your family member's self – esteem and advocacy skills. This is a free seminar but registration is required. To register online visit <https://es.surveymonkey.com/r/DZ6KWXL> or call (800)292-7851 extension 472. See flier for complete information.

### **August 17, 2019 EFFECT**

10:00 – 2:00

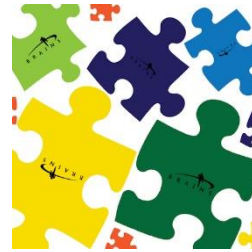
This program is appropriate for children 12 – 16 years of age, have and ASD diagnosis. Would benefit from the opportunity to interact socially with like – minded peers. <https://brainspotential.com/effect/>

## September 18, 2019 Autism 101

6:00 – 7:00pm

This presentation is appropriate for: parents or caregivers of children and young adults who have been newly diagnosed with an Autism Spectrum Disorder (ASD).

Register <https://brainspotential.com/autism101registration/>



## September 21, 2019 ASWS Annual Golf Outing and 19<sup>th</sup> Hole Party

8:00 am registration

Oakridge Golf Course

<https://www.asws.org/events-1/asws-golf-outing>

## 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>

## Looking Back to the Future

McKenna Coyne

In the movie *The Help*, the opening scene begins with one of the African American maids, Maybelline, talking to the little girl she watches over. She proceeds to tell her “Now, repeat after me, you is kind, you is smart, and you is important.” The little girl smiled and repeated the sentence word for word as if she had it memorized. “That’s right baby girl, and don’t you ever forget it,” Maybelline added. Looking deeper into this scene, I realize that Maybelline not only said this for the little girl but more so for herself because she too needed a reminder of just how valuable she was, especially living in a society that told her she would never amount to anything, which is how my story begins.

In third grade, my parents took me on a trip to Chicago where I thought I was going to have a fun-filled day in the city. Instead, I found myself in a doctor’s office where I was informed I have Fragile X Syndrome. The doctor told my parents that I would struggle immensely with school as a whole and have an overabundance of anxiety for the rest of my life. Being only in third grade, this all went in one ear and out the other. I left that office just as clueless as I was when I walked in. However, when I entered middle school, all of the symptoms the doctor had warned my parents about finally caught up to me. My self-confidence plummeted, and I convinced myself that I was a failure. I began to put my hope in earthly things because I thought that if I had the right clothes and the right friends, I could bury the truth of who I was, but that just did not happen.

Eighth grade was when the symptoms were at their worst. I worked hard, but my grades did not reflect it. I still remember a day where I was sitting in science class and had just been handed back my test. I slowly turned it over only to see a sixty-nine percent right in the center of the page. I felt my face getting warmer as I tried to hold back the tears. No amount of name brand clothes could have saved me at that moment. The things I obtained on Earth, I had turned into a counterfeit God and tried to make them do something that they were never intended to do, fix the hole in my heart. However, I do not remember that day because of how

terrible my test score was. I remember that day because just when I was about to give fear its victory, God gave me a miracle.

My teacher could see I was on the brink of tears, so he decided to pull me aside after class when he told me something that I had never seen in myself. "You are exceptional. I need you to start seeing all of the astonishing things that everyone else sees in you. That test does not define your worth, always remember this."

From that moment on, the way I lived my life changed forever. Through my teacher's words, I fully believe that God was speaking to me. He came to me in my darkest state and called me home. Fragile X will always be a part of me, but something that the doctors did not predict was against all odds I rose victorious. My junior year of high school, not only did I end with all A's but I also completed my first year of dual enrollment at a community college with a 4.0 GPA. For so long I had let the doctor's words define my worth, but if you have come to know Jesus as your rescuer, you are most defined not by what you own but who owns you.

When I was diagnosed with Fragile X in 2009, I couldn't quite comprehend what that meant. However, I look back at the little nine-year old girl I was ten years ago and cannot help but think of how proud she would be of nineteen-year old me. After all of the struggles that Fragile X has put me through, I was brave anyway. I can just picture little Kenna now. I see the worry in her eyes and the frustration in her heart, but I also see her strength. This is the same strength she used to cover herself in truth when the doctors said that college would never be an option. I can't travel back in time to show little Kenna the success she would have in the future, but there is a part of me that thinks she already knows. Every time I look at my acceptance letter to Saint Mary's College, my heart is filled with an indescribable joy that comes from the part of me that still holds onto little nine-year old Kenna as reminder of how far I have come. This dream is for her.

## Resources

### Meet Up and Eat Up

The Summer Food Service Program (SFSP) was created to ensure that children in lower-income areas could continue to receive nutritious meals during long school vacations, when they do not have access to the National School Lunch or School Breakfast Programs. The SFSP, also known as Meet Up and Eat Up, is operated at the local level by program Sponsors and is administered in Michigan by the Michigan Department of Education (MDE), Office of Health and Nutrition Services.

[https://www.michigan.gov/mde/0,4615,7-140-66254\\_34491---,00.html](https://www.michigan.gov/mde/0,4615,7-140-66254_34491---,00.html)

Program Office: 517-241-5374

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/>

# Time to Sign Up!

## Autism Support of West Shore Presents 2019 Annual Autism Awareness Walk

In coordination with Ottawa County Parks Association

AT GRAND RIVER PARK



### Details:

- We will meet rain or shine under the pavillion.
- Barrier-free walk trail.
- The walk will take place at 11:00 AM with lunch following.
- There is no cost to attend, however pledges and donations are welcome to support initiatives in autism support.

**Register:** Please register by **August 7** with family name and number attending (head count for food) to: [contact@asws.org](mailto:contact@asws.org)

## ***Message from the Board,***

*This edition of the HOPE newsletter was a true pleasure to put together. Our featured stories **The Run** and **Looking Back to the Future** are inspirational in finding your own path even when facing incredible challenges. They are good reminders that sometimes the greatest predictor of success is our own belief in ourselves. Thank you, Sue and McKenna, for sharing your stories with us.*

*Our Autism Awareness Walk is quickly approaching. All are welcome and we encourage you to invite friends and family members to join us in supporting our children. This is a free event though we are asking for a head count for the lunch after the walk.*

*As we countdown the days before school resumes, we encourage you to get out there with your family and enjoy all West Michigan has to offer. The beach has been hazardous lately with the winds but boy is its great kite flying weather. The free summer concerts that most towns have been offering provide great music in a casual outdoor setting, bring your lawn chairs. Our parks, splash pads and waterfronts can all be enjoyed for nothing more than some planning and bringing your own blanket, chair or towels. Have fun!*

*Linda Elenbaas and the ASWS board*