

Michigan Family Connections Newsletter

Spring 2018

SHARING OUR STORIES EDITION

Welcome to the 2018 “Sharing Our Stories” edition of the Michigan Family Connections Newsletter. This edition is dedicated to the families of children and youth with special health care needs across Michigan who have opened their hearts and shared their stories of joy, heartache, courage, and challenges.

We would like to thank all of the families who took the time to submit their stories to us. We received 23 different submissions. It was incredibly hard to choose which stories to feature in the newsletter.

We hope you enjoy our selections. Each of the six featured authors will receive a \$50 gift card to say “thank you” for their contribution to our newsletter.

Unfortunately, we didn’t have room to publish all 23 of the stories. We wanted to be sure to share them with you so they are available for you to read on the MI Family to Family website at the following link:

<https://f2fmichigan.org/family-stories/>

HONORABLE MENTIONS

In addition to the stories featured in this newsletter, we would like to recognize and thank the following individuals for submitting stories:

Vernonica D.	Kelly Rogers	Jamie Bowman
Annie Coyne	Nicole Ewers	MacKenzie Armstrong
Heather Mason	Cherrie C.	Bambi Burnham
Alicia Genia	Lette Huisman	Jacqueline P.
Stacey Laho	Jessica Turk	Deborah Brewbaker
Cindy Figures		



*A newsletter
for families of
children and youth
with special health
care needs, and
professionals who
help them.
Connecting you
with information
and news you
can use!*



**A quarterly publication
brought to you by the
Family Center for Children
and Youth with Special
Health Care Needs and
Michigan Family to Family
Health Information Center**

DEFINING GRACE

SUBMITTED BY LAURA MILLER

My sister, Sarah was talking to someone about my daughter with Asperger's some years ago. The person hadn't heard of it before and asked what it was. Sarah was at a loss in how to describe it. She didn't want to get it wrong, so she called me and asked, "Laura, how do you describe Grace & her Asperger's?"

That rendered me speechless. Every once in a while you have these moments. The kind that hit you in heart. You want to get it right. You want to educate people on a condition that is a part of your child's life. Yet, you don't want to. You don't want to define your child by medical terms.

You want to answer "My daughter is beautiful inside and out. She has this AMAZING personality that brings me smiles." I want to tell them about her unique bond she has her dog, Kindy. How I let her paint her own bedroom walls and what amazing butterflies and rainbow she made. I want to tell them of her passion for Superman.

I know I should be prepared with a "my child's has" speech, but I'm not. A text book would tell you she has to have so many characteristics to qualify for the Asperger's diagnosis. But my child changes by the month, week, day and sometimes moment.

MY WARRIOR PRINCE

SUBMITTED BY MONIQUE RANDOLPH

I remember looking forward to your arrival in this world with such excitement and some anxiety. Never did I imagine I'd ever hear from the mouths of doctors that "your son doesn't have a normal life expectancy."

Michael, I remember praying to God to heal you my son. Because every time I heard you cry, and with each diagnosis, it made me question the purpose of my existence. I recall being anguished to my soul. Because, I couldn't discern if you were crying out of pain & discomfort, or pleading with God to take you back home.

All the moments when you were inconsolable and seemingly a seasoned insomniac. Hoping, praying as I watch you struggling, that each breath wouldn't be your last. Life has not afforded me the opportunities of seeing you take your first step, or



She is a whirling tornado of unpredictable that can bring me from tears of laughter to those of frustration in seconds. She is loveable and untouchable. She struggles with everyday things and she missed many milestones. She may never tell time from an analog clock or multiply without a calculator. I have learned to stop looking at the might nots. They aren't as important as the amazing things she has accomplished already that we never thought she would.

hearing you call me "mama". Serving you and walking with you through this life has been nothing less than a true privilege and a great honor.

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MY WARRIOR PRINCE CONTINUED

Michael, my "warrior prince" through all of your pain and suffering, you always remained joyful, relentless and a true definition of tenacity. Aside from your big beautiful glistening brown eyes and enviable eyelashes, and your heart-warming smile, your life is a ministry. Through every setback, loss of faith, and flood of tears. I am so thankful to God that you're still here.

Although the war, for most of us, pertaining to justice, adequate support, resources, community faith, family, and everything that would ensure a great quality of life for our special loves rages on. There is no doubt in my mind that like so many

triumphant warriors whether in this life, or the next, that you will emerge and be remembered as nothing less than victorious.

For anyone who says you're lucky to have me as your mom, I'd strongly disagree and tell them why they're wrong. I'm blessed and fortunate to have you as my son, because through it all you've been the one that never loss hope, determination, faith, joy or love, you've been the one who's truly always been strong. You are a conduit of pure love, kindness and wisdom, reminding me that God always gives us His best. For you, my dear Michael, are one of life's Purposed Expressions!!!

SAGAN'S NAME

SUBMITTED BY WILLIAM JONES

For a long time, while pregnant with our son, we had no idea what to name him. We talked about family names and browsed through multiple baby name books for ideas, but we couldn't find a name that made us happy. At times the baby name books seemed to just confound us more, and we'd find ourselves saying things like, "Who would ever name their kid 'Bacon'?"

One day, after dinner, we took a walk. After talking about our day, my wife said to me, "So, have you thought of a baby name?", and I could tell from her tone that she was expecting me to just say, "No.", and follow it with something like, "...but not 'Bacon'!". However, I actually had thought a little about it, and I said, "Well, it may seem strange to use a last name as a first name, but I think I like the name Sagan, after Carl Sagan."

My wife looked thoughtful, but seemed to quickly adjust to the new idea. She knew that I became interested in astronomy as a boy, and that Carl Sagan's "Cosmos" series especially filled my mind with wonder, and that he and his show were a source of inspiration for me through adulthood. She then said, "If we name him Sagan, can his middle name be Muir?", and we stopped walking for a moment.

I knew how inspired my wife was by John Muir's advocacy for preserving American wilderness, but I was dumbfounded for a moment at how easily and quickly we had suddenly come up with two names

that we liked, and I said, "That sounds great!" We were both clearly excited about the idea, and we tried to give the idea some time and see how we felt later as it was an unusual name, but we only became happier about it.

We actively work to get Sagan interested in a variety of things, and he genuinely likes reading, and trains, and bouncing on balls or trampolines, but there's nothing that excites him like outer space, which still feels curiously appropriate considering he was named after an astronomer. It will be interesting to see what other things he becomes interested in, but his first word was "moon", and we've been talking about moons ever since.



HOW I GOT STARTED AS AN ENTREPRENEUR

SUBMITTED BY ANNA SCHUCK

I'm going to tell you about how I got started as a retailer. It all started when I was about three years old. My mom had gotten some plastic animals for me. I played with those animals a lot, and since I'm blind, the animals helped me to understand what real animals looked like. And since I have autism, my collection of plastic animals has become my passion.

Now jump forward to the year 2015. At this time I was standing in a little toy store in Jackson Mi. I was looking at some plastic animals they had displayed there on the shelf. In previous years, I had seen these figures advertised at Michaels, and other craft stores. Yet, as I stood there, looking at them then, I started thinking "I wonder where these toy store people get these figures from? I wonder if I could carry these things too?"

And so, my business began. I started selling and ordering in 2016, but for a while before my first order, I had to scrape together \$100 in order to make my very first order. Now, my dream has



always been to work in a storefront, but that will probably be delayed for a time, perhaps forever, because my autism gets in the way. But in spite of all this, my business has really been the best part of my life.

"The level of our success is limited only by our imagination and no act of kindness, however small, is ever wasted." - Aesop



I LOVE HIM LIKE NO OTHER

SUBMITTED BY MARY PARTAIN

I believe in what he can do.
Who will stop him? No one, that's who!

He is in the ultimate race,
He will definitely win first place.

The warrior in him will fight,
He will try to do what is right.

He will live his dreams and not stop,
He will climb to the very top.

The strength he has everyone will see,
He will be the best he can be.

Every person's heart he will touch,
Everyone loves him very much.

His smile is as bright as the sun,
Cerebral Palsy has not won.

I love him like no other,
He is My Little Brother.

LEARNING TO ADJUST THE SAILS

SUBMITTED BY MATTIE BOOK

Five years ago, I entered motherhood. I jumped in with thoughts, expectations, and plans for how my children would grow up. They would be bilingual, great at sports, top of their class and surrounded by a group of friends to grow up with. I was going to be the mom that never missed a game, booked yearly family vacations to show them the world and of course be there every step of the way. I had no idea that as I held my newborn that I was months away from the waves of a lifetime. I would be learning to sail.

A year later I began noticing my daughter having abnormal eye movements that the doctor referred to as Ocular Motor Apraxia. Some developmental delays were also noticed and the doctor ordered an MRI of Hannah's brain. That same week we found out we were expecting baby number two. The MRI was performed and the doctor told us that we would need to follow up with a local neurologist.

We went in for the appointment and the neurologist told us our daughter had Macrocephallum. Unfortunately, this neurologist was unfamiliar with this condition, however, stated that we needed to enjoy our time with our daughter because the only article she had read was of children who did not live past two. This was the first storm that came raging in and I was forced to use the wind to my advantage.

For about a week I was severely depressed. I couldn't think straight about anything. I was up all hours of the night filled with fear that I would be burying my sweet Hannah as I welcomed our next child. How could this happen to our family? For some reason, I thought I would be above this, as if this was a story I would read about or pray for someone else about, but not experience first-hand.

The storm began to rage around me that week. I had no idea how to deal with a diagnosis that nobody knew anything about. My husband and I had been married for almost three years, yet we were miles away from each other. I was stuck in a place where I was obsessing over the future of what was to come and he was in a place of denial. I would start talking about the "what ifs" and he would tell me that none of this was true. He could not believe that a doctor could diagnose a condition that they knew nothing about.

I was pregnant, exhausted and full of fear when my mom walked through the door and gave me the advice I desperately needed. She told me to stop crying and start working. She told me that right now Hannah needed me to show up for her and use my fear to make things happen. She reminded me of my nursing degree, insurance and support systems. She then took Hannah home with her for the night and told me to start researching until I had a plan.

Little did I know that this would be the moment I would look back on as life-changing. This was the moment I learned to use my fear to drive me, not make me sink. I immediately began working. I spent the night desperate for information on Macrocephallum. I couldn't find anything. I then decided I would start calling hospitals. None of the hospitals I called thought they were "equipped."

The next morning, I started searching again. After hours, I came across a study written about children with this condition. I looked up the doctor who was a part of this study and found him listed at Johns Hopkins Hospital. His email was listed on the site, so I emailed him right away.

I wasn't expecting a reply because it was a Sunday afternoon, but within ten minutes I received one. He said he needed a copy of her MRI overnighted to him and then he would call. Two days later he called me and told me that it was indeed Macrocephallum and if we could travel to Johns Hopkins Hospital, in Baltimore, he would have a team of doctors ready to see us.

Read more of Mattie's story on our website:

<https://f2fmichigan.org/family-voice/learning-to-adjust-the-sails-by-mattie-book/>



UPCOMING DATES FOR PARENT MENTOR TRAININGS

The Family Center for Children and Youth with Special Health Care Needs is proud to offer trainings to parents/caregivers of children with special health care needs who would like to make a difference in the lives of others.

This training is open to all families who have a child with a medical, physical, developmental, behavioral, or emotional condition. As a trained Parent Mentor, you will become a part of a statewide network of volunteer parents supporting one another, sharing resources, and helping to navigate various systems.

PLEASE NOTE: registration will open about 6 weeks prior to the date of the training.

To be placed on our email list, please call the Family Phone Line at 800-359-3722.



Dates and Locations

April 28, 2018—Grand Traverse County

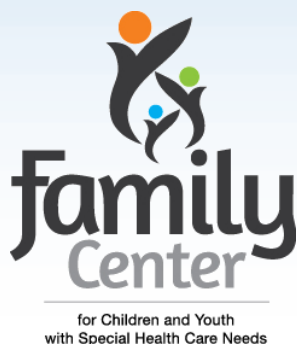
July 13, 2018—Dickinson County

July 14, 2018—Cheboygan County

Michigan Family to Family Health Information Center (MI F2F) is a federally funded project. They share information and resources on disability and health issues with families of children and youth with special health care needs. MI F2F also works with health and other professionals. MI F2F helps families make educated decisions and supports families to partner with professionals. They work to make services for children and youth with special health care needs better.



www.f2fmichigan.org



The Family Center for Children and Youth with Special Health Care Needs (Family Center) is the statewide parent-directed center within Children's Special Health Care Services (CSHCS) and the Michigan Department of Health and Human Services (MDHHS). The primary role of the Family Center is to offer emotional support, information and connections to community-based resources to families of children and youth with special health care needs, including all children who have, or are at an increased risk for: physical, developmental, behavioral or emotional conditions.

Family Phone Line 800-359-3722

Disclaimer: The Family Connections newsletter includes information and links to internet and other resources. These resources are for your consideration only and are not endorsed by the Family Center for Children and Youth with Special Health Care Needs, Michigan Family to Family Health Information Center, or our funders. The Michigan Family to Family Health Information Center is a project of the Michigan Public Health Institute. It is funded by Health Resources Services Administration Maternal and Child Health Bureau under Grant H84MC26214. The information or content and conclusions of the author should not be construed as the official policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government. Furthermore, the information provided should not be used for diagnosing or treating a health problem or disease, and is not a substitute for professional care. Please direct any questions through the Family Phone Line or MI F2F website listed above.