

Michigan Family Connections

for Families of Children and Youth with Special Health Care Needs

Winter 2017

*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!*

“Sharing Our Stories” Edition

Welcome to the 2017 “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 26 different submissions. It was incredibly hard to choose which stories to feature in the newsletter.

In fact, it was so difficult, seven submissions were chosen instead of just six! Each of the seven featured authors will receive a \$50 gift card to say “thank you” for their submission.

Unfortunately, we didn’t have room to publish all 26 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/>



Thank You For Your Stories!

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

Stacey L.	Matt Jachalke	Kellie Carpentri	Anne Ryan
Morgan Burgard	Healthier Cole	Kathryn Prout	Amy H.
Alethea Mshar	LaTashia Webb	Bob Huisman	Christina Gajewski
Cherrie Chandler	Susan Eidson	Jacqueline Dalzell	Debra Bosch
Kristi Meyers	Dawn S.	AbebaMali Cunningham	

**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.**

The Courage To Go First by Kasey Hilton

"So, you're the first..." Not exactly the words you anticipate hearing at an appointment when it comes to your unborn child, are they?

I was 19 weeks pregnant with my first child when we found out he was diagnosed with Spina Bifida, myelomeningocele, the most severe type. After listening to our options we decided to pursue fetal surgery. After weeks of tests I was a confirmed candidate. I asked, "Is there someone I can talk to who has been through this so I know what to expect?" And then we heard it... "So, you're the first."

There are times where you, or your child, may be the first of their kind. It's scary to think that there is no one to compare or talk to about the things that you are going through and at times you may feel very alone.



However, I realized that it's not just the doctors, nurses, and staff paving the way, you are too. Taking the chance to be the first, or for your child to be the first, will help to pave the way to help those who come after. You're the reason programs will become better, you're the person who has real feedback that can be heard and appreciated, you're the reason that people want to come to this hospital because you had the courage to trust the team to watch over your child.

After going through fetal surgery, Carter was born at 34 weeks and spent time in the NICU. He was incredibly well taken care of, watched over, and to top it all off, I had the chance to teach people on that floor all about my son! How amazing to take what could have been a terrifying experience, and turn it into something others could learn from.

Since our fetal surgery in 2014, Mott has successfully completed this surgery six more times for other children. I am thankful that we were the first because when I hear about these new moms learning what I learned about my own child and the surgery that might take place, instead of them hearing, "So, you're the first," they can hear "We have successfully had seven fetal surgeries."

How amazing is it to be one of those numbers?

Finding the Warrior Within by Latrieva Boston

As I sat with Chloe on my lap and listened to the geneticist give the diagnosis of Angelman Syndrome, I was numb. She had not gotten all of the 15th chromosome from me that she needed, it was my fault she was this way. The doctor listed all the things that my daughter would never be able to do and all my dreams died at that moment.

I was excited to be a mom again, I had all of these things I wanted to do. To really enjoy motherhood and now they were gone. Tears streamed down my face and I gathered her up and cried all the way to the car. She was my beautiful and perfect little girl and I felt like she had been cursed. I asked God, "What had I done to deserve this"? I went from numb to mad to everything in between but the warrior in me knew I had to fight and push because if I didn't I would be doing my daughter a disservice.

So with each accomplishment from holding her cup, walking by herself, and saying "mom" it was everything

the doctor had said she wouldn't do. Now if you ever met Miss Chloe, you would see she has a very strong will and sometimes it can be difficult to deal with but I believe without it she would not be where she is today, a 6 year old who loves to run, play with her hamster, and watch Mickey Mouse Clubhouse over and over again.

I won't say that I don't have my bad days but they are fewer and far between and when she smiles at me, everything seems right with the world!



Learning to Ride The Waves by Sara Voth

With the birth our second child, a daughter, I have become much aware of the synonymic presence and importance of opposites: the ebb and flow that is the keeper of balance. Our journey began with a routine 20 week ultrasound and the idea proposed of a heart complication. We were referred to a pediatric cardiologist who specialized in fetal echocardiograms.

After much anticipation, the cardiologist told us that we were dealing with a possible Hypo-Plastic (small-sized) Left Heart (atrium/ventricle) Syndrome. This was very serious. A box of thin tissues and a thick pamphlet were candidly slid across the table. To say the least, we left with many questions and heavy hearts.

I would be remiss if I said we weren't desperate, depleted and desolate for weeks to come. Our minds and hearts dealt with the idea of her in vastly different ways, but one thing was consistent: we both desired and sought to be informed.

Much of the following weeks and months were filled with the gathering of information about our special girl through serial echoes, ultrasounds, blood draws and genetic tests to help us and her medical team prepare for her arrival. Many other congenital anomalies were discovered, but still no real answers came. Her genetic profiling all came back perfectly normal.

There were days where I would lie, swollen with fluttering child, and know nothing other than the comfort of stroking the slick black fur of my pup. He would curl close to me, solemnly lick the salty tears from my cheek, and confirm that there was at least the blessing of a sympathetic



creature-comfort to lend some ease. I would find my husband, the sole breadwinner, late-night awake at his computer, trying to create busyness to distract himself. I often prayed for a miscarriage; to be spared her pain and suffering, and ours.

After experiencing the first few stages of grief, I knew I needed to keep myself busy and distracted so I could carry her with a loving heart and open mind. Eventually, I wanted to at least offer her the chance of birth, to hold her to my breast, sing in her tiny newborn ears, and let her know earthly love for at least an instant.

Somewhere, along the ticking time line before her birth, we resigned. I remember likening our situation to a tsunami. We waited for her, blessed, but flooded with so much overwhelming information and speculation about her complicated anatomy. The moment occurred thereafter where we knew to do nothing else but allow the wave to consume us.

Read more of this story at:

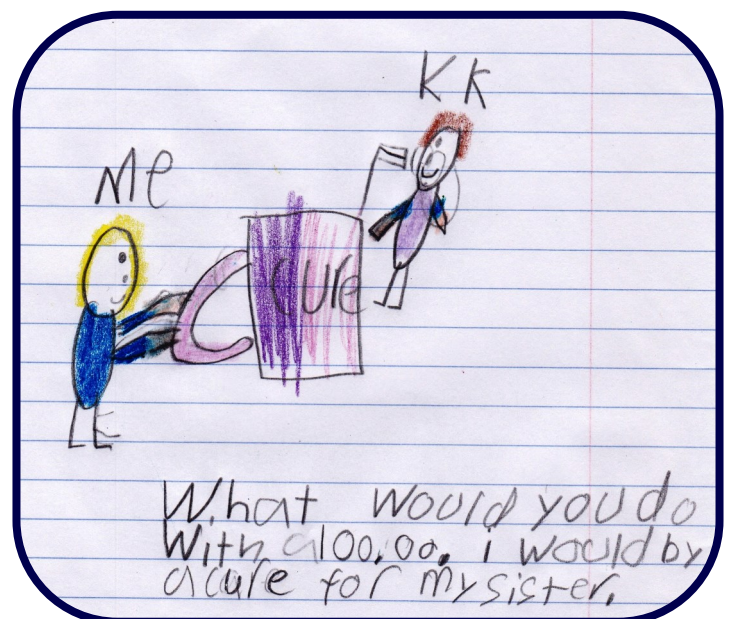
[Learning to Ride the Waves](#)

Picturing A Cure

by Madison Mast



This picture was drawn by 9 year old Madison (right) for her sister, Makayla, or 'KK', as she calls her. When asked how she would spend \$100, she said she would buy a cure for her sister, who has Rett Syndrome.



Breathe In, Breathe Out by Emily D

At night, I sit in Max's dimly lit room, watching his chest go up and down as I count his breaths. I count once, but I'm still worried. So I count again. And again. As he sleeps, I check his oxygen level with a cheap monitor I bought at Walgreens. Sometimes, I even listen to his lungs with a stethoscope. But I'm not a doctor, so I don't know what I'm listening for. Then I go to sleep for a few hours before I wake up and do it all over again.

In the morning, I run through the plan in my head. Two puffs of this medicine and four puffs of that one. Give him the steroid. I remember trying to explain to his grandma that the steroids make him crazy. I also think about how I'm going to explain to him that he can't go to the arcade with his brother because he can't be exposed to any germs right now.

Because Max has asthma which makes him just a little bit different.

Asthma is not uncommon. Anyone reading this has heard of it. Yet, I wonder if people without asthma in their lives know what it actually means for a child to face asthma every day.

For Max, it's been a life-or-death experience. Asthma has landed him in the hospital a few times. Once it was so bad he was on life support. Something called an ECMO machine. It's a lung bypass machine. Or, in hospital terms, "The Last Option".

So, yeah. Asthma is scary.



Since Max was born I've had to learn the difference between rescue inhalers and maintenance inhalers. I have learned what pulmonology means. I've learned how long it takes to get to the emergency room from my house. And, if you tell the doctors your kid can't breathe, they'll see him right away.

Most importantly, I've learned that asthma is not going away any time soon. Max will have to spend a lifetime worrying about catching his breath.

Through all of it I admire his strength. Max is only 6 years old. So little to have suffered so much. My hope is he will be all the tougher for it.

Asthma is a frightening, debilitating disease. It is our reality. I just pray some day we will be able to change that.

A Poem For My Sister by Jacob Powers



This poem was written by Jacob when he was 10 years old. He wrote it in his little sister, Kaycie's, voice, who happens to have Down syndrome. They are not just siblings, but best friends. He wrote the poem so others could understand the struggles she faces every day.

"My Life"

I have Down syndrome and I have a high profile.
Don't make fun of me, I'll have it a while.

I know it's weird but yes, I do like lime
Don't move the mountains, teach me to climb.

Attention is good for me and my friends.
Oh I hate it, when friendship ends.

No, I don't want to stay away
I like to go outside to run and play

Yes, I have things to say.
Try holding your tongue and talking all day.

That is how hard it is for me to say....
Will you be my friend? Let's go and play!

Every Day Is A Privilege by Jeffrey Brown

"I don't know if I can do this."

"Yes you can, son."

"How can you be this strong?"

"Well, because I have to be."

These words were between my father and I while I laid in a hospital bed getting my first dosage of chemotherapy, and they have impacted my personal character forever.

The summer before my high school freshman year, I was diagnosed with Primary CNS large B-cell lymphoma, a type of brain cancer. I spent the entire season in the trenches on the Oncology Floor of C.S. Mott Children's Hospital, with IV pumps ready to fire and pain relievers prepared to support.

When I was diagnosed, I didn't fully understand what it was (I was still recovering from a craniotomy) but I had started experiencing its effects months before. It all started with my stomach. I threw up nearly everything I ate. In two months, I lost 25 pounds. My pediatrician considered me anorexic and prescribed me a gastrointestinal medicine.

My stomach started to recover, but then the uncontrollable "eye twitching" started. When I tried to read sheet music while playing the saxophone in band class, the notes would dance all over the page. While playing soccer at recess, the ball would suddenly change directions when coming towards me on the field. When trying to solve quadratic equations in Algebra, the variables would hop from positive to negative infinity.

This unusual activity resulted from nystagmus, an involuntary rapid movement of the eyes, caused by the tumors in my brain putting pressure on my optic nerves. Eventually, I lost control of the muscles of my eye lids. Even when I worked hard to open them, I had double vision. My visual field was reduced to the size of a paper towel roll.

The pediatric oncologists gave my family and me an 8-month chemotherapy schedule with a 50:50 success prognosis, and a list of the possible side effects of each chemotherapy drug. The chemo was supposed to destroy both me and the tumors, but the tumors definitely had the larger portion of the destruction. While the tumors were getting their daily dose of chemo, I was eating my



favorite cereal watching "Duck Dynasty." While the tumors were being eaten away by cytotoxins, I was playing board games with friends in the hospital room. While the tumors were writhing in pain, I was screaming in delight on the Millennium Force roller coaster at Cedar Point.

Of course there were agonizing moments, but nothing could break my spirit. Every pain was remedied with laughter, every cry with prayers, and every discomfort with get-well cards. While the tumors disappeared from the MRI scans, I grew stronger and stronger, more alive and well.

It has been two and a half years since my last round of chemo, and I have not wasted a minute of it. I am fortunate for surviving cancer and my life is purposefully lived, out of respect for those who were not as fortunate.

Every day is a privilege to connect with others on this earth, to share the pleasure of existence. Every sight, sound, taste, touch, and smell I experience is unique, irreplaceable and invaluable.

Although there are days when it is hard to keep going, I consider the blessings I have had in my life and use them as inspiration to persevere. Every day I strive to learn more about this life, to learn of its laws, to learn from its ancestors, so that by knowing more of the gift of life, I may be even more grateful for it.

Through the grace of God, I worked very hard to maintain a 4.0 GPA throughout this journey and have been accepted at the University of Michigan this fall to begin as a freshman - possibly someday, I will be a pediatric oncologist to encourage other cancer patients.

"Although there are days when it is hard to keep going, I consider the blessings I have had in my life and use them as inspiration to persevere."

New Opportunity—Camp Scholarships!

The Family Center For Children and Youth with Special Health Care Needs (Family Center) is excited to share their Summer Camp Scholarship opportunity!

Effective immediately, families are invited to apply to receive a summer camp scholarship up to \$250. The Summer Camp Scholarship is designed to assist families with sending their child with special health care needs to a summer camp of their choosing.

Applications are being accepted through the end of March 2017. Families will be required to submit a completed application along with the Attendance Confirmation Form, which will need to be filled out by the Camp Director.

Families may request the forms through the Family Phone Line at 800-359-3722. Funding is limited, so families are encouraged to apply as soon as possible.



Her Power! Her Pride! Her Voice! camper **Kylie Hawkins** enjoying a day of fun with friends at Camp Fish Tales in Pinconning, MI.



Michigan Family to Family Health Information Center (MI F2F) is part of 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.

For more information and helpful resources, look for them on Facebook or go to their website at:



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.

Children do not have to be enrolled in CSHCS to receive services from the Family Center.

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.

If you have something you would like to share in a future newsletter, please contact us for information on how to submit articles, events, etc. We welcome contributions from families, caregivers, youth, healthcare and other professionals, as well as agencies and organizations. Thank you.