

# Michigan Family Connections Newsletter

SPRING 2019

## FAMILY STORIES EDITION

Welcome to the 2019 “Family 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 17 different story or poem submissions. It was incredibly hard to choose which to feature in the newsletter.

Each of the six featured authors will receive a \$50 gift card to say “thank you” for their submission.

Unfortunately, we didn’t have room to publish all of the stories submitted. 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/>



*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

## HONORABLE MENTIONS

The following are some of the individuals who submitted stories to us. While we were unable to publish all of the stories in the newsletter, we appreciate their contribution, and would like to recognize them here.

Tiffany Daniels

Bahiyh Shariff

Lisa Braybrook

Stacey Laho

Caleb Laho

## MISS A THING SUBMITTED BY STEPHANIE BALLARD

Someone said to me one day  
 "I don't know how you do it  
 I don't think I'd be capable  
 Not sure I could get through it.

And some days I'm exhausted  
 (I'm being honest here)  
 At times my motivation  
 Is overwhelmed by fear.

Having a child with special needs  
 Is a rare gift in so many ways  
 But I am only human  
 Sometimes I have bad days.

And then you take my hand in yours  
 In a moment of pure clarity  
 You say, "Hey guess what mama?"  
 Your beautiful to me.

And in a flash, the moment is gone  
 And your singing your own little song  
 Then I realize life's all about "moments"  
 And I realize that you've made me strong.

And you defy convention  
 And you live life out loud  
 And you have overcome so much  
 And you make me so proud.

I can't picture a different life  
 Without these hopes and fears  
 Without all the uncertainty,  
 The questions, joys, and tears.



It's not the life I planned for  
 Sometimes I feel it's sting  
 But one thing remains constant  
 I wouldn't miss a thing.

What a sad thing it would be,  
 If there had been no "You"  
 If I had missed your smiling eyes  
 And all the things you do.

And doubt is our companion  
 What will the future bring?  
 But if I had the choice, I know  
 I wouldn't miss a thing.

Though you have been given  
 A "special needs" label  
 I still see a child who...  
 Is loving, kind, and able.

Life has had it's battles  
 But please remember this,  
 Tomorrow is a precious gift  
 I'd never want to miss.

And you surprise me everyday  
 By what you do to reach me  
 And I am constantly amazed  
 By all the ways you teach me.

As every long cold winter  
 Will melt into a spring  
 I cherish every moment  
 I wouldn't miss a thing.

## WE'RE NOT SO SPECIAL SUBMITTED BY BETHANN ROBINS



Twenty six years ago, my youngest son, Kaegan, was born very prematurely. He wasn't expected to live. The list of disabilities lengthened, as did his stay in NICU and PICU. Of course I took it personally. I must have done something atrociously wrong to have this visited on my baby, on myself.

Hospice helped bring him home. It was the Hospice nurse who told me: "This is not a punishment. Death is a natural part of life."

It was an incredible relief, this notion that we were simply in the flow of life, that we had done nothing wrong to deserve this. That death is as natural as birth, regardless of the circumstances of either.

Kaegan was not supposed to see his first birthday. He did, and more. Throughout our life together, I had opportunities to learn many things I don't believe I would have without him. That there is something larger than each of us, and that it connects us. That we each have disabilities, and challenges- our own customized opportunities to learn how to be our better selves. That what we label as tragic, and devastating, are not punishments

but silver lining lessons waiting to be seen.

One of my favorite authors, Anne Lamott, put it pithily: "We're not so special. That's the good and bad news."

In 1975, IDEA was first signed into law. Within, it states:

*"Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational main stream of American society."*

Just as I had learned death was not a punishment, over the years of watching Kaegan, learning from his joy to simply be, I also began to learn what Anne Lamott, and the DD Assistance and Bill of Rights Act meant.

Kaegan passed- or Graduated, as I like to call it - March of last year. He is no longer obligated to struggle with the lessons of this life. But he continues to teach, myself and others who remember him. We are continuing to learn that disabilities, and death, are natural. And happen to everyone.

When we stop seeing ourselves as special in these, we can begin to see, and enjoy, the gifts that life, and disability, offer.





## POEM SUBMITTED BY MACKENZIE ARMSTRONG

Sickness once overcame me  
 To a level I could not bear  
 But now I'm living fine  
 Sure a pill once a day has kept  
 me from being completely  
 normal  
 But now I am a "normal" teen  
 other than my sickness  
 With all the hardships included  
 I have crushes  
 I have friends  
 Slumber parties too

But two pills each day have kept  
 me from being a "normal" kid  
 But normal is not new  
 It is not what I need  
 Not because it is overrated  
 Or because it isn't cool  
 But because I love to be the  
 weird kid at school  
 Not because I yell or interrupt  
 class or anything like that  
 But because I accept my quirks  
 And love me just like that



## YOUR CHILD HAS MADE AN IMPACT

Special-needs is a difficult term because, in reality, all children have special and unique needs. That being said, my cousin was born extra special 18 years ago. She was premature and had a full head of jet black hair. I was 10 years old, the oldest sibling of 6 girls and still fell in love with her and couldn't get enough of her amazing self.

It would be hard to describe the full extent of the disabilities Chloe is considered to have. She has CMV which presents as cerebral palsy. Over the years she has had numerous surgeries, treatments etc.

As a young teen I remember babysitting and learning how to use a feeding tube. It was terrifying and also exciting to be trusted with such care for her. She hadn't been able to keep anything down for so long that I was happy to feed her in a way that I thought would leave me mess-free, rather than being vomited on. That backfired when I was holding her following a tube feeding and I forgot to close the g-tube and ended up a mess anyway. That was a mistake that I only made once!

I decided to pursue a career in special education and Chloe had a large hand in my decision. Throughout high school and college I worked with special needs students in varying settings. I loved the challenge and the exciting moments the children experienced that may be ordinary to others.

## SUBMITTED BY NOEL STRIETER



You never know the impact that your child will have on the life of others. I speak of the glorious moments of learning and developing that I was able to experience. I know there were also challenges, rough moments (or longer) and times of grief over what could never be for Chloe's family. I respect that and understand that everyone's experience with their special needs child is entirely different and unique.

Chloe and her family could never have known the impact that she would make upon me at a young age. Similarly, you will never know who your child is impacting at any given moment. Your child is here and the way they are for a reason that may never truly be understood.

## CARSON'S RIDE SUBMITTED BY MELISSA GALLAGHER



This story involves our son, Carson, who is almost 14-years old and was diagnosed with Smith-Lemli-Opitz syndrome at birth. He has multiple physical and developmental delays, but he is also one of the happiest, cheeriest, friendliest kids you will ever meet. Carson is a very social little boy and has a way of bringing people together in the most unexpected ways.

Carson has loved motorcycles for several years. We have entertained this passion by taking him to motorcycle shows, following motorcycles for long distances just because, buying motorcycle books and toys, and watching videos of people riding motorcycles. The one thing that we wished for, but seemed unattainable, was to get him a ride in a motorcycle sidecar. This was something we discussed for years but we knew no one who had the means of making this happen.

In August, 2018, an acquaintance, Bill, who had met Carson and knew of his love for motorcycles (and was a Harley owner himself), mentioned that he had a friend with a sidecar and he would organize a ride for him. By a miracle of miracles, Carson was able to get his sidecar ride! It was a short ride through town and lasted about 15 minutes. There was an instant connection between Dan, the bike owner, and Carson, and he offered to take him on another ride that would last longer.

Bill and Dan had an idea of making this a true event in Carson's honor, and with the help of social media and some very generous, compassionate people, we were able to bring together nearly 40 motorcycles and a police escort for the ride of Carson's life.

On the morning of October 7, we all met in the parking lot of the Harley Davidson dealership in Tecumseh and Carson was able to walk around and meet the bikers and admire all of the beautiful motorcycles! He was given a goodie bag with lots of Harley swag (including many patches) and had his picture taken with his new friends.

When everyone was ready, the police escort led the way from Tecumseh to Dundee (nearly a 30-minute ride), where we all ended at an ice cream shop that opened just for this occasion. It was a day to remember and we are planning to make this an annual ride. Our hope is to somehow tie this in with fundraising to raise money for research.

These biker men and women have hearts of gold and exhibit pure love and compassion for Carson and our family. We never expected so much to come out of a sidecar ride. But, again, Carson has shown us in his own, unique way how easy it is to bring people together and form bonds of friendship that are sure to last for many years to come.





## LIVING EVERYDAY LIKE IT'S YOUR LAST

SUBMITTED BY TAMMY KOOISTRA

August 12, 2014 a little boy was born. The youngest of seven we instantly knew something wasn't right from the jumping and jerking to noises and the blank stare in his eyes. Then the body shakes a day later that landed him in the NICU. "What was happening"?? No one could tell us.

Test after test showed nothing. Nothing prepared me for the morning I walked into the NICU to find every nurse and doctor surrounding my child. I was shown a full twenty-four minute video of my newborn baby having a severe seizure. I just began to cry!! No diagnosis, no answers, but we took him home.

This was the beginning of a life I wasn't prepared for. Within a couple of weeks we were in an ambulance. Seizures, seizures, seizures and more seizures. With no answers, no diagnosis, and no medicines working.

Two years passed with no answers. The witnessing of having your child resuscitated, watching them drill a hole in his bone for IV access, and bagged to breathe was becoming a normal. It was hard not to have a panic attack when hearing sirens. Waking at night to alarms that were not going off. The nausea that sets in when entering the hospitals.

Depression, PTSD, and trauma were starting to take a toll on me as a mom.



At the age of two we got our diagnosis. Rare SCN8A epilepsy. To this day there are only three-hundred worldwide. My emotions were denial, anger, and grief. There is no cure or specific treatment.

Just a recently discovered genetic mutation that happened randomly in my child. A disorder that wasn't just epilepsy.



For my son it has taken his abilities to sit, talk, eat, and walk. I ask myself why? I pray for God to let me take his place. I try to barter with God. I would do anything to take his place. My hope was dwindling. My friends and family disappeared and the isolation and depression worsened. I was grieving my child and he was alive.

But with the new diagnosis came resources, a Facebook page with families like my Liam from all over the world. Moms and Dads just like me. Answers to the crazy things my child does that doctors can't figure out. Finally I was starting to feel listened to again.

I met other people who are experiencing what we are experiencing. Learning my child needs to sleep with a pulse ox because our children are dying of Sudden Unexpected Death in Epilepsy (SUDEP). Grieving with the parents who have already lost their child to this horrible disease.

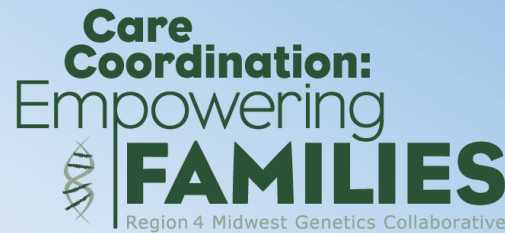
Accepting was the only way I was able to live and enjoy life again. Accepting the diagnosis meant I was going to live every day to its fullest. Never going to bed without a kiss and an "I love you."

I have chosen to not let this take our joy! There are many things in this life that my son has been robbed of. We will not let joy be one of them. His smile can light up anyone's world. I was blind to my blessings because I was focused on the bad.

"SCN8A, you have lost!"

## CARE COORDINATION: EMPOWERING FAMILIES

Michigan Family to Family Health Information Center is pleased to offer a *Care Coordination: Empowering Families* training in Lansing on May 23rd, 2019.



This one-day training opportunity was created for families of children to help them learn new ways to manage care coordination for a child with complex medical needs. The training is open to any parent (bio, step, foster, kinship, adoptive) or legal guardian of a child (age birth to 18) with special health care needs. This includes mental health, behavioral and emotional conditions.

Registration is required, and childcare is not provided, however participants who attend the full day (9 am to 5 pm) training will receive a \$100 gift card.

To register, please use the following link:

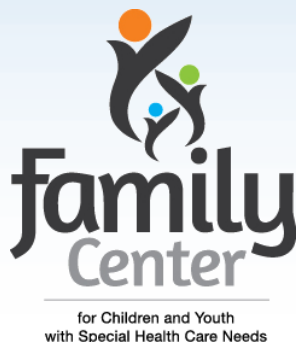
<https://mphf.wufoo.com/forms/lansing-2019-care-coordination/>

For more information, or to register by phone, call Kristen Reese at 517-324-7396.

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](http://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.