



Family to Family Michigan Update

VOLUME 2, ISSUE 1

WINTER 2015

F2F Michigan provides: "Resources, information and education for children and youth with special health care needs; the families who love them and the professionals who help them."

Join our email list!
Click on the tab on our website and fill out the form to be notified of upcoming news, resources and educational opportunities.

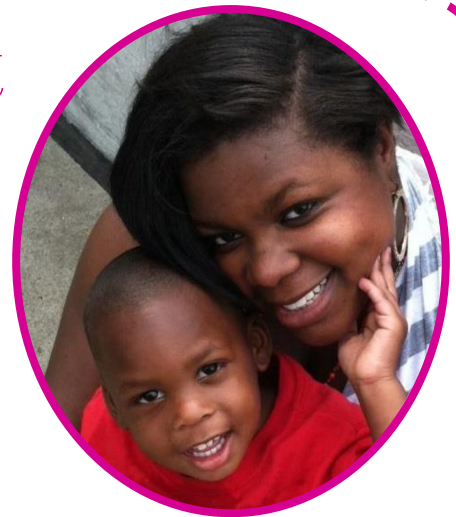
Stories From the Heart

Welcome to the Family to Family (F2F) Michigan Update! We provide this newsletter quarterly to families and community partners. This month we are offering a special edition. Since Valentine's Day is in February, we thought we would highlight some stories from the heart.

Sharing your story with others can be a powerful tool. When you share your personal experiences, people connect with you. Having a family member with special health care needs can be a challenging and often isolating experience. Sharing your story with other families may give them hope and support, and let them know they are not alone.

Sometimes families share their story with policy makers. This helps people in government know what is important to the families they represent, and is a way to affect change.

We hope you enjoy reading these stories. If you are interested in sharing your story, please visit our website www.f2fmichigan.org. We will feature these stories in the *Family Stories* section of our website.



Tips for Sharing Your Story

Have you ever been asked to share your story? It isn't always easy to do. It is helpful to think about who asked you, and what you want to achieve. Ask yourself "What do I want people to do, or feel, after hearing my story?" Below are some guidelines that are helpful if you are asked to share your personal experiences:

- ◇ Plan ahead what you are going to write or say.
- ◇ Identify your topic. It is good to have no more than 2 or 3 main points.
- ◇ Describe why this is important to you. Talk about what has been helpful to you.
- ◇ Be respectful of others. Avoid negativity or blaming.
- ◇ If you want people to take action or do something, make sure you ask them to do it.
- ◇ If writing your story, ask a friend to read it. If speaking your story, practice with an audience.

Find us on
facebook

*Run, leap
and celebrate
for you are
alive today!*

*~Bryant
McGill*

Beth's Birthday Bash

Celebrations are an integral part of family life, but sometimes we are saddened that our children with special needs may miss out on the celebrations of college graduation, starting a career, becoming a bride or groom or having children of their own.

Our Elizabeth was born with a genetic disorder called Galactosemia. It is a rare disease that since 1987 is detected through newborn screening, but in 1977 little was known about it. We were fortunate to have a neonatologist who knew of the disease and essentially saved Elizabeth's life. She has both physical and intellectual disabilities. Despite the many doctors' appointments, therapies of all sorts, endless blood tests and many setbacks, Elizabeth is a girl who lives to socialize.

After many family weddings and graduations, we decided to throw a big surprise 30th birthday party for Elizabeth to give her a chance to celebrate a milestone in her life.

Pulling it off was a challenge since she has an amazing ability to hear even the faintest whisper, but Beth's Birthday Bash came together. Because Dalmatians are her favorite, the theme was set. We rented a room at the local senior center, hired a DJ, decorated with black and white Mylar balloons (the non poppers to keep the fear of sudden loud noises to a minimum), black and white tablecloths, chocolate and vanilla frosted cupcakes, paw print favor boxes and all of her favorite foods.

Family from Seattle to New York, friends and their families from school and camp, guests ranging from one to 83 arrived ready to party. The delight on Elizabeth's face as each guest came through the door was priceless. Everyone was dancing, laughing, and visiting. Neither age or ability made a difference to anyone there, just a Sunday afternoon of pure joy and celebrating Elizabeth.

Seven years later, we still talk about it, look at the pictures and remember how much this celebration meant to Elizabeth.

We are looking forward to celebrating her Fabulous Forty in 2017!

~Submitted by Mary Lanigan



Beth and her sister Karen

*"There is nothing more
beautiful in life than
celebrating the talents,
dreams, joys and
accomplishments of another
being, to see-and call
attention to-the best in
someone else."*

~Kate Mullane Robertson

Discovering Hidden Talents

My daughter Sarah is a 16 year old who I have raised since birth. Like many teenagers, she is a bit brooding and likes to keep to herself. Needless to say she is usually a bit of an introvert. She would rather sit in a corner with her art books drawing than be at some big party. Her idea of a really big outing would be to be turned loose in a Barnes and Nobles or a library. I don't get it. I am the total opposite.

So, when my other kids came home and asked to be part of a Young Americans week-long performing arts camp that ended with performances at a packed auditorium, I didn't think there was any way I could convince Sarah to go along with them. I was wrong. With very little coercing, she agreed to participate. As a dad, I was so proud of her willingness to get out of her comfort zone and give it a try.

For a week she learned songs and dance steps. She made friends and worked hard to prepare for the three Saturday performances. I got there early and got seats in the front row. Watching quiet, shy, Sarah come out and perform with all the others kids really made my father's heart soar.

The biggest surprise was seeing Sarah perform in an acting solo. It was a fun little routine where she came up front and pretended to be playing the flute in a band. I was so proud watching her grow and stretch herself to the limits. I laughed and cheered and learned to never count her out without letting her give something new a try. Sarah's hidden talents and abilities just may surprise me, and her!

~Submitted by Randy Hitts



Sarah performing



My silent angel - Isenia

My Daughter

My daughter, she's strong but silent;
 She will grow, but will not grow a voice;
 She needs help, but helps others more;
 She is poetic, but can not make a rhyme;
 She hears, but can not be heard;
 On the inside she screams for help, but no one ever hears her;
 She's full of responses but saves them for the right time to respond;
 She is looking for a voice but can not find the right one to use;
 She is a fighter but can not give a command;

This is the life without being heard.

~Submitted by Lorena Brady

*It is what we make out of what we have,
 not what we are given,
 that separates one person from another.*

- Nelson Mandela

What About the Siblings?

As the single parent of three children, one of whom has significant special needs, I often worried how our unique family dynamics impacted my other two children. My youngest, Kylie, was diagnosed with a neuro-developmental disorder at age 3. At that time her siblings, Kelsey and Cedric, were 7 and 10 years old. Despite some rough early years with their sister, the older two seemed to accept that our life was the way it was, and have grown up into great young adults. I am very proud of them, especially their natural ease when it comes to interacting with people of all abilities.

Their relationship with their sister gave them both understanding and kindness, and this was brought home to me by an experience my son had a few years ago at work. He was working for a cell phone company at the local mall. He was alone in the kiosk and was approached by a man who had some questions about a cell phone. They ended up talking for a while. Traffic at the mall was slow, and my son loves to share his knowledge about electronics. He said the man was nice, and they had a good conversation. When they were done, the man thanked him and left.

My son said the man got a little ways away from the kiosk when he abruptly turned around and came back. He walked up to my son and said he wanted to thank him again. My son said "You're welcome...but what are you thanking me for?" He said the man paused...and then said..."For treating me just like everyone else." He explained that he had a diagnosis of Asperger syndrome, a form of autism. He said often people don't talk to him, or worse yet, treat him differently. He shook my son's hand and walked away.

I'm not sure what touched me more, my son's kindness, or his genuine confusion about why it was a big deal to this man. It showed me that my son doesn't see what makes someone appear different, but instead focuses on the person inside. It also made me sad that this man had obviously experienced a lot of pain in his life, enough that he felt compelled to thank my son for something anyone else would have taken for granted.

I know that my older children's experience and relationship with their sister has given them something they wouldn't have had otherwise. It reassured me that the painful, chaotic, difficult early years after their sister's diagnosis hadn't damaged or scarred them. We made it through, and I think we are a better family...not despite it...but because of it.

~Submitted by Kristen Hawkins

"Sometimes being a brother is even better than being a superhero."

~Marc Brown



Kylie and her big brother, Cedric

Live-Breathe-Inspire!

I would not wish a chronic disease on anyone, but it certainly does give a person perspective and appreciation for life. Joe and I have two girls with cystic fibrosis (CF). Molly is 20 years old and a sophomore in college in New York. Emily is 17 years old and will be heading to college in the Fall (probably out of state too).

Our life isn't picture perfect. Our girls are best friends, but do fight. The laundry gets backed up, and the house is certainly not always clean. But one thing we do on a daily basis is LIVE. I want our girls to live life, dream big and don't let CF hold them back. They are **living** life with CF.

I have always told the girls: Everyone has something we just have CF. No excuses; we're not suffering anymore than someone else. Of course there are many times over the years we have broken down, frustrated and sad by the challenges of cystic fibrosis. Usually once a year we pretend they don't have CF. It's freeing for them, and great therapy. Molly and Emily are mentally strong, "We do what we have to do and move on," they say.

I promised myself when they were babies I would not hold the girls back because of my fears. Both of my girls have been involved in one sport or another. One particular year Molly had a picc line (I.V.) so she could do her intravenous drugs from home and fight off the pneumonia. It would be in her arm for three weeks. She had ski club, was in middle school and wasn't going to be stopped from zooming down the hill. I was worried about her skiing with a picc line, but she was not. So off she went in the bus to the snow hill. I immediately got on the phone to the ski hills health clinic and told them my daughter had a picc line in her right arm—should anything happen! She was fine that day and has gone on several ski trips to Utah and Colorado with her sister.

Emily is the sicker of the two girls. When she was in 7th grade I thought she might die after a high fever and new bacteria in her lungs. Emily has suffered eleven cases of pneumonia, a bronchoscopy, and numerous other challenges over the years. She's missed school dances, school trips and family gatherings. So when she said she wanted to go on a mission trip to Nicaragua with her religion class I was shaking inside. I called her CF doctor and she said if her health was good she could go and that she'd send along some medication incase she got sick. Of course she could get some strange "bug" there and get deathly ill but I could not keep her from going because I was worried about what might happen. It's a hard place to get to, to let them go. Emily had a fabulous trip and came home with story after story about how she was so touched by the Nicaraguan people. She wanted to save the world.

My girls are glad they both have cystic fibrosis (as opposed to one having it). They can relate to each other's struggles, do treatments together and support one another when they're hospitalized. The key for us is to talk about CF. Molly and Emily joke with one another that they're going to die together like the couple in the movie, *The Notebook*; holding hands. They laugh, act silly, and sing together all the time, even via Skype. They live!

~Submitted by Laura Bonnell (www.thebonnellfoundation.org)



Sisters Emily and Molly

Never Give Up



The Gritter family

We are the Gritters. Dad...Don Gritter, mom...Holly Gritter, and big brother Easton...3 years old. Little sister Lylah June was born August 15th, 2013. She was the daughter we had been praying for. She was born perfect, with a perfect apgar score of 10. Perfect family of four.

When Lylah was around 4 months old we started noticing a decrease in her muscle strength. Within weeks she could no longer hold up her head or put any weight on her legs. After a month of visiting specialists and tests we were told Lylah has Spinal Muscular Atrophy (SMA), the number one genetic killer in children under the age of two. Why had we never heard of this? We were told to call hospice, and love our daughter as much as possible for as long as we had her. Our lives turned upside down.

SMA affects approximately 1 in 6,000 births. It is a recessive genetic disorder that affects both infants and children. Infants with SMA suffer from severe muscle weakness and atrophy of voluntary skeletal muscles. Muscle weakness in SMA is due to the death of the nerve cells (called the motor neurons) that connect the brain to muscle. SMA is progressive. Infants with SMA become weaker and weaker over time, eventually losing the ability to walk, sit, stand, eat, swallow, and even breathe. The mind is not affected. One in 35 people, or nearly 8 million Americans, unknowingly carry the gene mutation responsible for SMA. Few have any known family history. There is no cure for SMA.

Today, Lylah is 16 months old. She is **NOT** in hospice and is a happy, bright, little spitfire. She has the strength of a four week old infant, but can talk, smile, eat on her own, and sing her ABC's! She is a busy girl, and participates in physical therapy, occupational therapy, water therapy, speech therapy, and visits a chiropractor on a weekly basis. She is defying the odds. We are not giving up on her. We have high hopes for our girl! We pray every day for a cure. Never give up. #Lylahstrong.

You can follow Lylah's story at www.facebook.com/Prayersforlylah.

~Submitted by Holly Gritter



Lylah

*"And though she be but little,
she is fierce!"*

- Shakespeare



For the Quarter That Make It

My husband and I recently celebrated our 25th wedding anniversary. I feel like this is a huge accomplishment because there were definitely times I wasn't sure we would make it. Raising a child with special healthcare needs is a tremendous strain on the entire family, and put an incredible amount of stress on our relationship. Instead of supporting each other, we were taking our anger and frustration out on each other. I was very unhappy, and contemplated whether or not we would be better off apart.

Our son Michael was chronically ill as an infant, and the doctors didn't expect him to live past his second birthday. I had read a book about couples who lose a child, and it said that 75% of them end up divorcing. I was convinced that in addition to all of the changes and disruptions in life that we had already experienced with the birth of our son, a divorce was looking more and more inevitable.

I tend to be a worrier; and the sleep deprivation and emotional roller coaster we were on had taken its toll. My husband is an optimist. I started noticing that every morning he was leaving change on my dresser. In addition to being an optimist, he is a bit disorganized, and is always leaving his things lying around the bedroom. At first I didn't think anything of it, but finally I realized that he was putting a single quarter on my dresser every morning. Finally I said, "What's with the quarters?"

He said, "It's for the quarter that make it." Instead of assuming we would be in the 75% that divorce, he knew we would be in the 25% that make it.

I now know that marital strain is a **normal** part of raising a child with special needs. It is only natural to take some of your frustration out on the only other person who knows exactly what you are going through. We learned different ways to cope with our stress, and tried to give each other room to deal with the situation in our own ways. I also learned that when you are in the midst of a crisis, it is no time to make life-changing decisions. I am so grateful that we stuck with it. Michael is a happy, thriving 22 year old, and our marriage is stronger and better than ever because of the challenges we overcame. I am looking forward to the next 25 years!

~Submitted by Jane Pilditch



"Motherhood is about raising and celebrating the child you have, not the child you thought you'd have. It's about understanding he is exactly the person he's supposed to be. And, if you're lucky, he might be the teacher who turns you into the person you're supposed to be."

The Water Giver



Michigan Family to Family Health Information Center has a **Facebook** page! **LIKE** us to learn about resources, events, and to connect with other families.



For more information, contact:

F2Fmichigan@mphi.org.



Michigan Family to Family Health Information Center

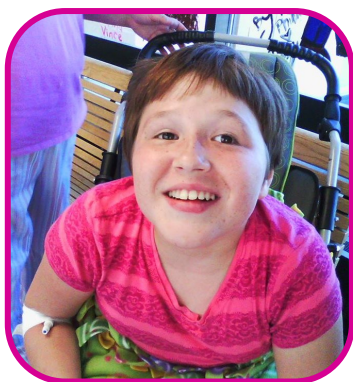
assures that families of children and youth with special health care needs (CYSHCN) are able to participate in decision-making at all levels and be satisfied with the services they receive.

How Can Family to Family Help?

Family to Family can help families with CYSHCN because they are staffed by family members who have experience. They know firsthand how to navigate the maze of health care services and programs for CYSHCN. F2F staff understand the issues families face. They help families make informed decisions.

The Michigan Family to Family Health Information Center is a project of the Michigan Public Health Institute. It is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Grant H84MC26214. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

“Providing information, resources and education on health issues to help families navigate systems, become more confident and partner with professionals in decision-making.”



Disclaimer: The Michigan Family to Family newsletter includes information and links to internet and other resources. These resources are for your consideration only and are not endorsed by Michigan Family to Family Health Information Center, Michigan Public Health Institute or our funders. The information provided should not be used for diagnosing or treating a health problem or disease, and is not a substitute for professional care.

How to contribute to upcoming newsletters:

Michigan F2F is interested in sharing on topics of interest to families of children and youth with special health care needs across Michigan, and the professionals who work with them. If you have an upcoming event, learning opportunity, educational resource or other items you would like to share, please contact us via email at:

F2Fmichigan@mphi.org.