Michigan Family Connections

for Families of Children and Youth with Special Health Care Needs

Winter 2016

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!

The Family Stories Edition

Welcome to the Michigan Family Connections Family Stories Edition. Instead of our usual news and information, we asked families to share their original stories, poems and pictures with us. It was difficult to choose from all the great submissions received. We couldn't include them all so we will share additional stories in future editions. While each of our individual stories may differ, there is a common bond we share in raising a child with a disability or special health care need. Novelist Amy Tan once said, "Writing...is a gift. It's a gift to yourself and it's a gift of giving a story to someone." Each one of these stories is a gift and a glimpse into someone's life. We hope you enjoy reading this edition as much as we enjoyed putting it together.

With Hope and Perseverance

My daughter Alexis, 14, has a deletion of Chromosome 22 q11 which progressed to DiGeorge Syndrome. One day a friend said to me, "Alexis looks like she has Down syndrome", but if it was not for her, I would not have ever known. Our local hospital specialists; genetics, neurologists and others told me Alexis would not walk, talk, needed to learn sign language, would have a feeding tube, use a wheelchair and need center-based schooling and there was nothing more they could do.

In August 2005, I took Alexis to U of M Hospital in Ann Arbor to see a geneticist. Alexis was diagnosed with Velo Cardio Facial Syndrome, which progressed into DiGeorge Syndrome. It affects her developmentally, physically, emotionally and cognitively. I learned a lot through support groups, research, and traveling to New York. It hurt and still does at times.

At 1 ½ years old, Alexis took her first step, but didn't walk again for a few years. What hurt the most was she could not communicate with me. Alexis wants to be like children without disabilities; she wants friends her age, but most are younger than she.

In 2012, her Dr. at U of M hospital began performing many surgeries on Alexis to correct her speech and improve her hearing. Alexis's speech and hearing is better. At times she talks too much, I want to say Shhhhh...but than I remember when she couldn't talk. Her self esteem has improved, and she walks with the support of AFO's.

One day at a time, a lot of work, good communication, building relationships, patience, love, and coordination of services with providers make a difference. I thank God, my mom Sadie, my brother Rufus and her teacher from Early On for helping me along the way.

-Submitted by Dorothea Nicholson

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.

Raising a "Twice Exceptional" Child

My daughter is exceptional. She tests at college level for most subjects and can read a 300-page book in hours. She is a gifted 11 year old. But she is so much more than that. Haven is referred to as Twice Exceptional. Simply put; she is both gifted and disabled. Children who have above average abilities while struggling with a physical, mental, or learning disability are not uncommon. My husband and I spent years struggling with frustration and guilt. Once we understood, it was much easier to help her, and more importantly, teach her how to help herself.

When Haven was a toddler we noticed some signs of extreme frustration such as head banging, self-biting and severe tantrums. We were proactive and a hearing problem was discovered. After a simple operation she went from being almost nonverbal to a chatterbox.

Unfortunately the behaviors did not stop and grew progressively worse. At 10 years old she was diagnosed with *Disruptive Mood Dysregulation Disorder,* a fairly new term used to replace a diagnosis of Childhood Bipolar. We were relieved. All the guilt and fear that we were failing as parents was gone.

ME

By Haven age 10

People don't realize
How much I know
Underestimate me
If only they saw
What I'm capable of
And I

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School has been an interesting experience for Haven. We were so focused on trying to help her improve her behavior problems; we didn't take time to help her excel in her gifted areas. She spent her school days bored or frustrated.

One night I typed something like "kids good at reading but not at math" into my laptop. I found websites and articles about Twice Exceptional Children. It was one of the biggest "Ah ha" moments of my life.

What stood out was that Twice Exceptional children are often overlooked because their gifts mask their disability or vice versa. With this information, I was better able to advocate for my daughter. The school evaluated her and we were floored with the results. We learned our 10 year old was gifted. She also struggled with a math learning disability.

We made some hard decisions and huge life changes. Haven began medication for her mood disorder and I homeschooled her so she could attend online classes. It was a rewarding experience but we knew it was imperative that she got back into the world and experience life. Haven now attends a private school that is dedicated to teaching the individual child not the average student.

Raising any child is *far* from easy. But I have learned it takes perseverance, patience and sometimes even detective work to understand how to parent a Twice Exceptional child. Although I am not naive enough to think things will be easy, I am can look to the future with hope and confidence knowing that my exceptional daughter will lead an exceptional life.

-Submitted by Heather Durren

"While we try to teach our children all about life, our children teach us what life is all about."

- Angela Schwindt

Giving Others a Voice

There are so many sorrows in the world, so while getting a diagnosis of autism for my fifth and youngest, late-life baby girl, Jasmynn, rocked my universe, it was only the beginning of choosing to do something "good" rather than wallow in self-pity.

At the age of 3½, at the end of a long examination, my daughter was labeled "severe autism with an I.Q of 31" The doctor said, "Don't mortgage your home trying to fix it; she is what she is. There is no cure, but help her learn to navigate this world."

Brainstorming with the other four older sisters, we came up with the idea of creating a nonprofit, called ***Jasmynn's Voice*** which would "gift" others on the spectrum with an iPad and apps to help them find their voices and show what was locked away academically. Jasmynn had excelled beyond all expectations when given a device. She is a phenomenally smart girl, just one who cannot speak so that the outside world might understand.

So ***Jasmynn's Voice*** began back in 2012. Since then our precious daughter has "gifted" over 130 iPads/ OtterBoxes/and many apps to those on the autism spectrum, like herself. She has met each applicant, had a picture taken alongside them, and is overjoyed to consider them "friends" in her eyes. She inspires those who've just begun this journey and don't have any idea what the outcome may bring.

We have met and shared with "friends" who are in their 30's and 40's, refusing to sell them short that though they are older they will always have something to say and a desire to do so. We hope to bring hope to others through the darkness, that while this journey brings its struggles, it is not without purpose and gifts.

What one little girl has brought to so many, including this family, is the understanding that each of us has a purpose, some wisdom to impart and a mission to make this world a more kind, and compassionate place. Jazz does that in so many ways with a sheer joy for living, that even without words, is visible.

-Submitted by Melissa Archer

The Label

This flesh I created,
A limitless dream covered in the skin of his ancestors,
Has been distilled into a living toe tag,
A label.

Relegated to slavery,
A limited existence covered in the lie of equality,
His stars have been rendered
Inaccessible.
Climbing the mountain,
Covering his face, baring his feet, he stretches.
His star meets him in a bush
Burning.

The label,
A limited word covered by the name of my child,
Becomes ash in the wind
Voiceless.

-Submitted by Amy Helmuth

Our Favorite Hockey Star

David was born severely addicted to drugs. His bio Mom used drugs throughout her pregnancy. David was born full term but had to be sent to Bronson Kalamazoo via helicopter and intubated in flight. We first met him in NICU, on day 60, as his foster parents.

He has been through many surgeries and his neurologist predicted he would never walk or talk. David has a trach and a Mic-Key feeding button. He is in 1st grade and has special education supports. We are the proud adoptive parents of this very active little boy.

Several years ago David went to a K-Wings game. After the game was over he announced that he was going to play hockey. We thought he was just excited about the game and didn't think he really wanted to play. The K-Wings took an interest in David and had him come to a special practice where he was given some free tickets, went out on the ice with the players, and "scored" a goal against the goalie Joel Martin (goal horn included). Again David announced he was going to be a hockey player.

We enrolled David in a floor hockey league through Full Blast in Battle Creek. He loved to play floor hockey, played all the positions during the season, but often stated "I want to play on the ice!" His hockey hero Sam Ftorek #8 with the K-Wings told us he thought David could play.

There are very few special needs hockey teams in Michigan. We discovered the West Michigan Special Hockey Association (WMSHA) in Grand Rapids. The team name is the Patriots and are in their 2nd year of playing Ice Hockey. WMSHA is part of the American Special Hockey Association (ASHA), "Where every player is a star." Our hockey on ice journey began.

David was accepted as a player at age 6. The team wears full hockey gear and takes to the ice at least weekly. David is #8 (he wanted to play wearing his hero's number). Sam Ftorek has gone on to be the Assistant Coach with the K-Wings. WMSHA has players from the Griffins and Davenport University who come out every week and assist the players.

David couldn't skate when he started, now he skates all over the ice unassisted. He has played in several games against much larger players. As parents we have always felt it was partly our job to help our sons achieve their dreams. David is our favorite hockey star.

We know just how much it takes to dress in full gear, tie skates, and dare to go out on the ice against players twice as big. David's favorite position is that of Center, "because I can go anywhere I want." Yes, we have learned that no dream is impossible and special needs make every achievement extra sweet.

- Submitted by Betty Facey

"I've learned the hard way, that some poems don't rhyme and some stories don't have a clear beginning, middle, and end. Life is about not knowing, having to change, taking the movement and making the best of it, without knowing what's going to happen next. Delicious ambiguity."

–Gilda Radner

A Not-So-Ordinary Bucket List

Research: careful study that is done to find and report new knowledge about something. That is as simple as you can get for a definition of research. As the parent of a child with a diagnosis of fragile X and autism, research played an important role in my quest to become an expert on my son. In Michigan in 1997, there were no experts on fragile X. Participating in studies put me in touch with world-renowned experts.

My son, Austin, 23, entered his first research study when he was ten. It involved a plane trip to Wisconsin for a speech and language study. We prepared for the trip by practicing all the steps prior to our flight, to take away as many of the unknowns as possible. I was nervous but reassured when the research staff told me that if I got to the airport and decided he wasn't able to successfully travel, it would be okay to return home.

Austin was successful and we traveled to Wisconsin once a year for five years. That was the beginning of our research adventure. I, as a fragile X carrier, also became involved in research and so did Austin's siblings.

The furthest we've traveled was Sacramento, California. Through the Fragile X Association of Michigan we've even got some researchers to travel to Michigan and visit numerous families at once.

We've done studies that only required a short visit and evaluation. We've done studies on the autism front and the fragile X front. We started our first and only clinical drug trial in 2009 with STX209. We traveled often to Chicago and just like flying, Austin has become accomplished at long car trips.

STX209 was the best medication he was ever on. I was heartbroken in 2013 when the trial ended. I was frustrated when I learned that funding, measurements and the placebo effect had a very negative impact on the success of the study.

Last year when we hit number 40 I decided I had to have a new bucket list item, to complete at least 50 research studies. Last summer we did studies involving an app to measure cognition, an EEG, a blood draw looking at seizures, a speech/language study and a literacy study. Research doesn't just involve drugs, although drugs for possible targeted treatments are very important.

All but one of the studies above are a result of the STX209 study. It was discovered through the research process that existing behavior measurement tools aren't good at measuring changes in behavior. So even though it ended, much was accomplished through that study.

When I quit working in 2001 I continued to update my resume with a list of all our study and volunteer participation. To date we have participated in 44 major studies with only one being a clinical drug trial. We love being involved because it is simply a way to become an active participate in hopes that something they learn from us will one day help others.

Please, if you have the opportunity, get involved in research. Who could ask for anything more than to possibly make a difference in someone else's life?

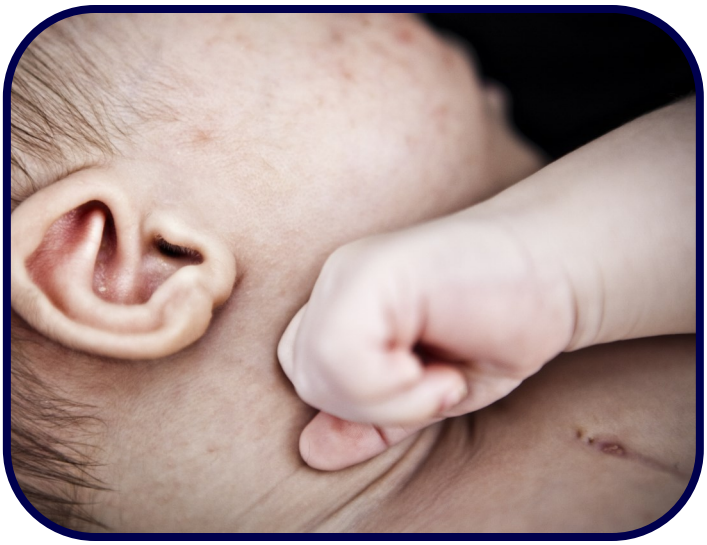
-Submitted by Sally Nantais

"You are never too old to set another goal or to dream a new dream
-C.S. Lewis

"What you do today can improve all your tomorrows"
- Ralph Marston

Stigmata

My hands are gloved with the stench of the NICU:
Swabbing alcohol, iodine, iron, dirty diaper.
I have despair under my nails.
My hair is braided with flashing lights, tubes, needles, bandages,
Tied loosely with the frayed, wet-edged ribbon of hope.
I sometimes smell the silent sounds in my sleep,
Machines beep and suck and drip and breathe,
Whispered words sting my skin,
Wafting worry singes blistered wounds,
And the tributary of tears punctures my tongue.
This all, I know, can be scoured away
By time's pruned hands
Or at least masked by life's living.
But it's your cry
I will always wear
Echoing, rearing, pulsing, singing,
Bleeding into the small tomb buried
Deep in my chest's dark cave.



Poems submitted by Sarah Avink. Her son, now 6, was born with 2 congenital heart defects (dTGA and an ASD - diagnosed by pulse ox at 24 hours old). He also has a sacral dimple, congenital scoliosis due to a hemivertibrae, and some external ear abnormalities, some executive function delays, severe food allergies, and a zest for life like none other!

Mutation

Only a few shifts in the double-helix turn "perfect" to "defect."
Baby boy, born into welcoming arms.
Ten fingers, ten toes.
Clutched to his mother's chest, as she
peeks at his avalanching eyelashes,
strokes his velvety crown,
searches his face for her own features.
She is consumed by the love embodied in the embrace,
but is also gnawed by the tiny, harsh teeth
of aversion, as her fingers find his anomalous ears.
Small physical differences that shouldn't matter,
but bother her that they do.

Only one difference in letters turns "vain" to "vein."
Days later, her blood pulses, pushes shallowness
out of the way to make place for worry.
Sitting at his bedside, his infant body draped with wires,
she peeks at his swollen fingers,
strokes an imaginary line down his chest,
following the scar made by a surgeon's steady hand.
Imagines the wired sternum, the scarred heart
as small as his fist,
searches his face for signs of recovery,
of forgiveness. Both healing hearts are on display:
his on the monitors, hers on her face.

Only a few shifts in language turn "defect" to "perfect."
A toddler now, runs into welcoming arms.
Ten fingers, ten toes.
Clutched to his mother's chest, as she
peeks at his avalanching eyelashes,
strokes his velvety crown,
recognizes in his face her own features.
She is consumed by the love embodied in the embrace,
and draws a line down his chest,
cups her hand over his heart just to feel it beating,
outlines the irregular contour of one ear, and kisses
the three clustered bumps on the other: her past, present, and future.

"The depth of the love of parents for their children cannot be measured. It is like no other relationship."

- James E. Faust

A Song From the Heart

My son, Michael has Autism. He is a seventh grader and his only general education class is Choir. He loves music. He is very well accepted in class and the teacher encourages Michael to join in at his comfort level.

At the end of the semester, the final was to pick a song and sing it in front of his peers in choir. Michael watched as each of his friends went up and gave the name of their song to the choir teacher to put on the music. When they were all finished Michael wanted to know when it was his turn. The choir teacher, not wanting to put any pressure n Michael, was going to excuse him from the final.

But Michael wanted his turn on stage. Michael picked the song "Love Story" by Taylor Swift. Michael went up to the microphone and began to sing but his voice was barely audible. Then a student in the audience stood up and joined in with Michael, then another and another until the whole room of choir students, his friends, were standing and finished that song with him. They all applauded him. He walked off stage so proud of himself and so was everyone else.

He passed his general education class, Choir.

-Submitted by Sue Mulder

MICHIGAN FAMILY TO FAMILY HEALTH INFORMATION CENTER

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

Family Center for Children and Youth with Special Health Care Needs

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

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.