The Foundation for
FNMS
Nager and Miller Syndromes

Winter 2014–15

All About Us

All About Us is the newsletter of the Foundation for Nager and Miller Syndromes. We took our name from a story submitted by Monica Quinn in our Autumn 1991 issue. Monica captured our entire theme and purpose in three little words.

"Us" is all persons who live with our syndromes, the members of our families, our friends, our neighborhoods, the medical community and everyone we can reach. We offer information and communication for everyone interested in Nager and Miller syndromes.

As you read our newsletter, as you think about getting involved, as you contribute your features, reports, photographs, or your own experiences and poetry, think to yourself — "This is all about us."

FNMS is an international support group dedicated to helping those affected by Nager and Miller syndromes. We serve as a clearinghouse of information and link families seeking support, hope, and advice. FNMS empowers families and guides them through the process of surviving to thriving.

FNMS is a parent-run volunteer organization with a 501 (c) (3) not-for-profit status.

Hey from New Zealand — my name is Erica Perry, I'm a 29-year-old young lady who just so happens to have Miller syndrome!

Earlier this year I started on the most amazing journey I could have ever imagined, given the attitudes of many when it comes to people who look different, resulting in shyness from putting ones self in the spotlight. It's a journey that I think may have surprised some, but delighted others!

In New Zealand there is only one other person that I know of with Miller syndrome, and that's my brother.

I wanted to see if I could find someone else in New Zealand with the same syndrome. It's a lonely world out there when no one else looks like you, but, being the sociable person that I am, I got in contact with a television company here in New Zealand called Attitude TV. I left them a message on Facebook saying that I was searching for people like me, I have tried all avenues, is there anyway you could help? They messaged me back and asked me to contact one of their researchers. I phoned a lovely young girl called Robbie, and, after an initial half-hour interview, said "I think we can help and we would really love to film your story".

This once shy young woman, who, often bullied in her young life, was now being followed around town for two and a half days, talking in interviews and showing the world just what goes on in the life of Erica Perry!

Anyone all over the world can watch, click "Like", and share my half-hour TV program by typing out this link: http://attitudelive.com/documentary/erica-takes-control. The response from the community after this program aired, was, in one word, amazing! Months and months later, I still have people coming up to me, hugging me, and telling me how good, positive and awesome it was, and how amazing it is that I can do just what everyone else in the world can do!

Before my episode aired, I met a young man at the park. He was writing a story for our daily paper and I struck up a conversation with him about how I was going to be on TV, and he was keen to write a story and try get as many people in town to watch as possible. Of course I said yes. He also did a follow-up story and I mentioned how it would be nice to go into schools and inspire young people. This started off another chain I never imagined happening so soon. The local Sacred Heart Girl's College got in contact with

All About Us

www.fnms.net

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me, and one teacher in particular asked if I would come speak to his class of 11–12 year olds about how to cope with bullying and how I coped when I was younger. Each child had a list of questions and no one wanted to leave!

After I visited the school and they found out I was raising money to get to a conference on my syndrome, they went away and came up with ideas on how they could help fundraise for me. They each did jobs over a 2-week period and earned pocket money to donate to my cause. I was extremely thankful for their generosity.

Huw and Helen Griffith presenting a fundraising check from their indoor playground, the Rumpus Room.

As well as all this going on, I had a friend who started up a fundraising page for me to raise funds so I can go to the next conference. If I raise enough, I would like to visit a few families around the world I have never met before who also have Miller syndrome. I would like to run a workshop for your kids at the conference and give them a chance to talk to someone if they are struggling, and also show them how they can stand up for themselves and become independent young people in the community. The link to my fundraising page is here if you would like to share it around and maybe I might be visiting you in the very near future! I realize the conference will be somewhere else now in 2015 so excuse the name my page was set as: https://www.givealittle.co.nz/cause/ericatoboston.

I hope to see many of you at the next conference, which has been the most valuable experience I've ever had as a young child — to see and be with people who look just like me!

Photo: Rob Haveswood

FNMS Advisory Board

Blocked

Yes, blocked! I struggled for weeks to write this one simple section of our newsletter and I grew increasingly frustrated.

Frustrated searching for something meaningful to write, as evidenced by the number of drafts only half written and tossed away, and also frustrated by my inability to convey with any import the message I finally settled on as being worthy enough to share. That draft, too, was eventually scrapped due to an epiphany gained through a misunderstanding, which struck me as especially ironic.

I complained to Leslie, our amazing editor, that I had writer's block. Her response was that I should definitely not write about that! However, I misread her response and thought, "this woman is brilliant!" She is, but that is not the point that I'm trying to make. The irony was that I was completely out of sorts over what amounts to an exceedingly minor hurdle in the grand scheme of things. What a horrible example I was setting for my children! Certainly, my eldest, a college freshman, who happens to be legally blind, faces greater problems than mine almost daily. There is no doubt that her brother Jackson, born with Miller syndrome, faces still greater challenges than those she encounters.

While we all struggle with obstacles and encounter adversity at times in our lives, it is absurd that I should allow myself to be so vexed by such a small, conquerable and temporary hindrance. There is no comparison between my writer's block and the chronic health issues, physical complications and disabilities faced by many. Yet I am frequently awed by the remarkable talents and achievements of so many of our affected members. Among our members we have a doctor, an award-winning concert pianist, a few poets, some truly gifted public speakers and several extremely talented artists. The list goes on and on.

They all set the bar pretty high; I hope one day to measure up to the example they set. This issue highlights a number of our members and the challenges they face, from breathing and eating issues to discrimination and more. I hope you will find it both enlightening and thought provoking. Thank you for being a part of the FNMS family!

DeDe Van Quill

"Taste of the World"

Hosted by the Morton Grove Foundation

Come join us as we sample a selection of delicious food from area restaurants. Each year a portion of the proceeds from this event are donated to FNMS.

Thursday, March 5, 2015
5:30 – 9:00 p.m.

White Eagle Banquets & Restaurant
6845 Milwaukee Ave., Niles, Illinois 60714

Contact Margaret Hogan (mepti40@aol.com) for information about tickets for this event. Ticket prices: $30 in advance; $40 at door.

Laissez les bons temps rouler!

(Let the good times roll!)

FNMS Family Conference

June 25-28, 2015

New Orleans, Louisiana, USA

We have a room block at the Country Inn & Suites in New Orleans' famous French Quarter district

Our direct online booking link is:
www.countryinns.com/FNMS

phone: +1 (504) 342-2307
fax: +1 (504) 342-2313
Toll free phone: 1-866-460-7456
315 Magazine Street
New Orleans, LA 70130, USA

More information will be available soon at
www.FNMS.net

In the pages of the FNMS newsletter we always like to publish the accomplishments of our kids and tell you how they are making their way in the world even though they may only have four fingers, poor hearing, or a trach to help them breathe. Among those who have grown up affected by Miller or Nager syndrome are painters, poets, doctors, nurses, musicians and caregivers. We hold them up to be admired and to encourage families with young children affected by one of these syndromes to not give up and to never underestimate what your child can do.

But that doesn't mean there aren't many difficult moments to be endured and that the numerous surgeries often undertaken are a walk in the park. Far from it. This goes for the affected child along with their families in many cases.

There is the pain that goes along with the surgeries; the sadness from being bullied or having people think you somehow have lower intelligence because you have atypical facial features or a hearing aid or feeding tube; the loneliness, because it can be hard to make friends when your speech isn't always intelligible; and the anger that, for seemingly no reason at all, you had to be the one born that way.

Every human being has their share of challenges, but for the child or adult born with Nager or Miller syndrome, those challenges might look like something you couldn't imagine as anyone else's reality. But they are.

We asked a few of our members or their parents to share some of these challenges:

Alyson Donofrio (Pennsylvania, USA) is 15 years old and in the 9th grade. She was born with Nager syndrome and has a trach, g-tube and bone-anchored hearing aid (BAHA). She is very shy and rarely speaks to others. She is not interested in sign language or assistive technology or even writing on paper. We're in the process to have her tested for autism as we have seen some signs to signal this.

A big worry right now is jaw distraction. Alyson has had three distractions at an early age, but she has grown out of them. Her temporomandibular joint (TMJ) is fused. We've been to our craniofacial team at Children's Hospital of Pittsburgh and they want to do jaw distractions and release her TMJ utilizing a rib graft, free fibula, TMJ replacement, or other methods. There are a couple of other physicians I would like to interview in other states and will need to find out if they accept our insurance. Once we decide, we'd like to have the surgery done in June when she's out of school.

On a positive note, Alyson rarely gets sick except for the occasional cold. She used to get sick with respiratory infections all the time and would have to spend time in the hospital.

I would love to hear from other families their thoughts on craniofacial surgeons and whether or not jaw distraction surgery was worth it to them. Also any thoughts on types of hearing aids used and methods of communication. Please email me at donofriobj@verizon.net or friend me on Facebook.

Barbara Donofrio, Alyson's mom

David González (Mexico): Life sometimes is very challenging, especially if you don´t have all the strength in your hands, but I have learned to focus on what is possible for me. My father taught me how to play the piano with my four fingers. I don´t play it like other people but I found the way to play it with my possibilities and I have won several prizes and acknowledgments, thanks to the support and acceptance of the people.

Redefining Normal

Keira Robinson (Oklahoma, USA): When I was pregnant with Keira I was asked by my former boss how I could willingly have a child knowing she would be special needs and have deformities. My husband's answer said it best: "She is my daughter and I am not going to love her any less."

In July of 2006, Keira was born three weeks early and, despite her "deformities", she was a healthy and feisty little girl. In that tiny little baby you could instantly see her personality of a fighter with a zest for life. Words, such as "quality of life" or "normal life", were thrown around, meaning many believed she would not lead a normal life.

But what is normal? What may be normal for one person or family may not fit the ideal of normal for another person or family. We are all human and therefore we are all normal, however, we all have our differences, some just a bit more noticeable than others.

Keira was born with some variation of most of the anomalies associated with Nager Syndrome, such as shortened forearms, missing thumb, underdeveloped thumb, fused elbow, moderate hearing loss — and the biggest anomaly — a severely recessed lower jaw, which was fused due to a condition called bony ankylosis. Just after birth, Keira had to have a tracheotomy to manage her airway, as well as a feeding tube placed for feeding. To date Keira has had 15 surgeries to help correct her thumbs and her jaw. She is now eating by mouth, vocalizing, and her trach has been removed.

Because children who are born "abnormal" in the eyes of most people, stares and whispers always seem to follow, and as much as you wish you could shield your child from this the reality is that you can't. Keira has known she is "different" from others for many years and this has led to her having difficulties in social settings.

In the spring of 2013 we enrolled Keira in a special needs cheer/tumbling group. I didn't know what my hopes were with this other than to show Keira she could do everything any other little girl could. It proved to be exactly what she needed. As Keira grew in her cheer abilities, her confidence grew too. Slowly we, as well as her teachers, started noticing her opening up and bonding with other little girls in her class. The real breakthrough would come in the spring of 2014.

Keira cheers with Empire Elite-Heart of the Empire and they are a special needs cheer squad. Over the weekend of Feb. 28 – Mar. 2, 2014, Heart of the Empire competed for their fifth National Cheerleaders Association All-Star National Cheer title — and they won. The amazing thing wasn't the win or watching them perform (although it was pretty awesome) but the overall acceptance of these special athletes in the world of cheer. It didn't matter that these kids were special needs, they were deemed "normal" because they were cheerleaders just like all the other young men and women there to compete.

Keira had found the world she belonged in. I watched with pride as she mingled, smiled, and took pictures with other champions. They saw her for who she was and not what she looked like. As we left the convention center we had a multitude of strangers approach us asking for pictures with her. She was a little celebrity, smiling and posing with anyone who asked. I had never seen her so free.

The weeks and months that followed proved just how much cheer had changed her. Her confidence in school grew, of course it probably helped as she strutted around school showing off her jacket. Kids came up to congratulate her, and the school went one step further, honoring her accomplishment during a school assembly. She beamed with pride. And I beamed with pride knowing she was showing the world she could do anything she put her mind to, just like a "normal" little girl.

Keira still has some social issues from time to time but when she enters the world of cheer, all of it fades away. The difference barrier has been broken and making friends has now become easier, not just in the world of cheer but in school as well. Before she started cheer, making friends didn't come easy, now she is forging friendships. From the moment Keira was born, she has faced the world head on. She keeps fighting, trying, and doing things until she has overcome any challenge in front of her. Little by little and in her own way, Keira is redefining what normal really means.

Natalie Robinson, Keira's mom

Eli Hammond (Illinois, USA) is 15 months old and was born with Nager Syndrome. He continues to amaze me with his progress and his ability to learn. We feel so blessed to have him with us. When he was born he developed pulmonary hypertension, which almost took his life. The first week of his life was touch and go, but he recovered thanks to an ECMO machine, which did the work of his heart and lungs so his body could recover. It really was a miracle.

With that being said he has four therapies each week and has had many doctors appointments and surgeries in his young life. My main concern right now is his right arm. It does not fully extend and is very weak. He can barely hold himself up on it in a crawling position, thus preventing him from crawling. He gets around by scooting along on his bottom. That may seem like a small concern but the bigger obstacles can be fixed through surgery or therapy and he already has had some of those. The doctors have not addressed or given any options for his arm.

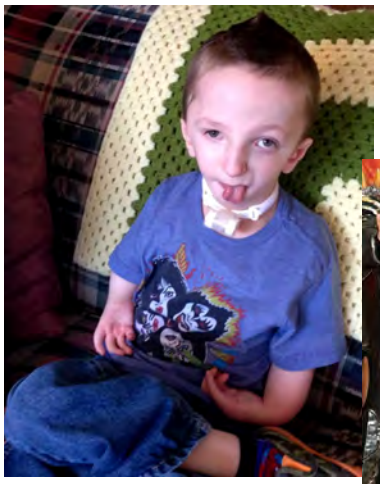
Eli is mainly affected on the right arm. His thumbs are present but are underdeveloped. He has pollicization surgery coming up on January 28th to take off his right thumb and move his pointer finger into the position of the thumb — 6 months after that they will do the same thing to his left hand.

Annie Hammond, Eli's mom

Isaac Barnett (Kentucky, USA): It started with an article in their hometown newspaper with the headline: "Social media helps sick Johnson County boy's dream come true" and ended with a little boy meeting his musical heroes and his family connecting with others with Nager syndrome when previously they knew none. After social media caught Isaac's story, the Miller's soon had enough money to travel to Cincinnati to go to a KISS concert and there they were treated like royalty.

Meeting KISS was by far the best day of our lives! I often avoid situations that involve a lot of kids, like birthday parties of people I'm not close too, parks, kid-friendly attractions, etc. It's mostly because I just get overwhelmed at the stares and looks. But this night ... this night ALL eyes were on Isaac! This time I felt like, 'Go ahead and stare because you are looking at a KISS VIP!' Not only did we get VIP tickets, we also got 'All Access' passes to the backstage!.

Natasha Miller, Isaac's mom



To find Isaac's story and video put the above title in Google or click on the hyperlinked title above.

Theo de Heer (New Zealand): It's hard to see your child struggle with something, knowing that it will never be something they are good at, and will always have to work extra hard to do. There are many things like this for Theo; eating, writing, doing up buttons, tying shoe laces, opening containers, chewing, playing tennis … the list goes on.

But the one thing that breaks my heart every single time, is seeing Theo with his peers. The ones that just stand and stare at him making him turn away from them rather than stand tall under their glares. And how shy and almost embarrassed he gets when other kids ask, "Why does he talk like that? I can't understand him." He completely withdraws. I have physically seen him shrink into my side and hold my hand, silently looking for comfort and strength, while also trying to become invisible.

How do you teach your Nager child to be proud of who they are? How do you give them the self-confidence to stand up and answer these other children themselves? How do you teach them to initiate interactions with others when they are staring, showing them you are just like them, while being comfortable with your physical differences?

It's the hardest thing for Theo, and the hardest thing for me as his mother. He is accepted for who he is among his family, deaf classmates, FNMS families, and family friends. We know him, and how wonderful he is and the challenges he overcomes everyday of his life. We understand the way he speaks, and love him unconditionally.

But at some point in his young life, he is going to have to find a way to 'be' with his peers. He will need to do the explaining. He will need to have the confidence to initiate conversations. He will have to find a way to make himself heard as an individual.

I won't ever stop shouting from the rooftops how amazing my boy is — I just hope that he hears me, accepts it, and knows it himself one day, developing the confidence to be proud to be Theo.

Saul Beranek (Wisconsin, USA): We really struggled with Saul's hearing as we were told his hearing was on the lower side of the normal range. He had been followed regularly by an ENT, getting two sets of ear tubes placed and battling what we were told were ear infections.

In kindergarten, his behavior was not good. We had a behavior specialist from the county come to observe him in the classroom, and what she saw was indicative of a kid with hearing loss. A hearing specialist was consulted, and she agreed that many of Saul's "behavior problems" were actually because he wasn't hearing well. She recommended an ENT who is very good with complicated cases, and life has improved immensely for Saul.

First, we found that his ears had been so over-treated with antibiotic drops that he had a major build-up of probable fungal infection in his ear canals (which explains his constantly itching ears). It required going under anesthesia to clean out his ear canals and remove his ear tubes. Shortly after that, he was fitted with a BAHA aid that he wore on a soft headband. It made an incredible difference! His hearing with the BAHA was well within the normal range upon testing. He still wears his BAHA, but now on a metal band. The use of the BAHA, along with an FM system in the school, has improved his school experience immensely.

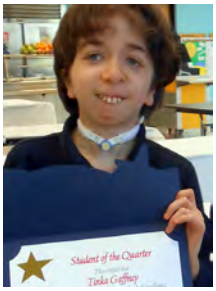
I do think that his troubles and constant punishments his kindergarten year have had a lasting effect on him. He became labeled as a naughty kid, and that has stuck with him to this day. He is in 4th grade now, and has wonderful support of special education teachers and county staff.

Lara Beranek, Saul's mom

Monica Quinn (California, USA): We all have challenges in our lives, but I think the biggest issue relates to our teeth. I do everything to keep my teeth clean and healthy: brushing them twice a day, flossing, drinking water, etc. However, no matter what I do I always have trouble with my teeth. Although my front upper teeth have been cavity free, I had them cleaned this past week and the dental hygienist noticed that two new cavities are starting to form.

My dentist wants me to get veneers. At this time I have decided to get a second opinion. I will keep you updated on my progress with my dental concerns.

Tinka Gaffney (Massachusetts, USA): When I'm at school there are three things I can say that really bother me about having Nager syndrome. First, when my hearing aid battery is about to die, sudden loud noises make it turn off temporarily. Second, is seeing the other kids get excited about what's for lunch, like hamburgers or pizza, but I can't really chew food so I've never eaten it and don't know what's the big deal. And third is my independence. I can't even walk home alone like the other kids my age, I have to go everywhere with the nurse who takes care of me.



Mel LeBaron (Illinois, USA): Growing up with a craniofacial anomaly, mine being Nager Syndrome, has been a beautiful, tumultuous, painful, and intriguing time for me. I still can keenly recall all of the heartache, moments of assertion, and challenges that I experienced over my 31 years of life. Whilst I would never want to be born with any other face, there have been a multitude of times where I was misunderstood, ridiculed, or in pain (related to surgeries), which is a lot for anyone to undergo.

A number of my childhood memories involve the hospital: its hallways, intensive care unit rooms, and being rolled into operating rooms under bright lights when THE TIME came. It kind of felt like I was in an alien movie, staring up at faces floating above me, their voices barely audible (my hearing aid was always off at this juncture) as they asked me to count backward from 100.

100, 99, 98 … I often would wake up in a recovery room before being transported to my hospital room to meet with my worried parents — this same, typical (for me) experience happened repeatedly, as if I were in a time loop — surgery after surgery, the only difference being the procedure and my age.

Outside of the medical realm, I learned that, in order to survive the world, I needed to become my own advocate. I tried to not allow myself to feel let down by people who didn't know what to say to me, or to feel hurt by those who stared at me, or conversely, ignored me.

I cannot "hide" my syndrome on the phone due to my mild speech impediment. I cannot count the times people would loudly ask me to repeat myself, or impatiently ask me to SPEAK CLEARLY, or pass me onto another person to decipher my foreign tongue. I try to not let this bother me either. I know I can be hard to understand, but scolding or losing patience with me never helps.

I am not ashamed to look the way I do, but I am frustrated with some of the unintentional ignorance that I encounter from time to time. However, I taught myself (and learned from many who were also born with a craniofacial anomaly), to be positive. It sure isn't always easy, but I cannot change my outward appearance.

Despite all of the medical procedures and emotional roller coasters that I've lived through, I've grown as a more sympathetic person. It has also prepared me to remain calm as I face my recent diagnosis with breast cancer — my body does not define who I am, but I embrace it anyway.

Logan Madsen (Utah, USA): Logan is 34 years old, a gifted artist, self-employed, and selling his original paintings as well as prints and greeting cards made from his art. Logan enjoys making a positive difference by speaking publically. He has spoken to over 2000 medical students, 200 caseworkers at the Department of Workforce Services, local libraries with Heather and myself, and to classes of elementary school age children.

In 2013, Art Access Gallery, located in Salt Lake City, asked Logan to have an exhibit in May 2014. Logan describes his exhibit: "'Syndrome Psychology' invites you to stare at my deformities caused by Miller syndrome through staring at my oil paintings. The unknown is scary. With this exhibit I am baring my reality for everyone to see. This includes the psychological effects of looking different alongside autism and a chronic lung condition. My autism locks onto the subtle details in life as exhibited in my paintings. There is beauty and magic that exists in even a small patch of skin. We all have skin. Share my rare experience and celebrate how much we all have in common."

As many of you know, an exciting project is underway — a documentary called "Logan's Syndrome." Logan's life's journey having Miller syndrome, and many other seen and unseen disabilities, is being told through the lens of his childhood friend and filmmaker Nathan Meier. Through a Kickstarter campaign, $25,168 was raised to fund the film. FNMS as well as many of you donated to this project. We say a big THANK YOU to all of you!

Recently, Logan was one of 22 artists included in an exhibit titled, "Differences and Dialogue," which was followed by an important panel discussion about how differences as human beings are what make humans so fascinating. But differences can create distance and keep us separate. The panel discussed differences, identity, perspective and power.

Logan struggled through four surgeries over the past year. He had reconstructive surgeries on both his lower eyelids and eye muscle correction surgery on both eyes. He is disappointed that the surgeries haven't solved as many of the problems he has had with eye tearing and dryness. He takes one day at a time and tries to focus on the positive in life. His faithful companion, Charlie, his dog, helps him find happiness every day.

Logan's "Syndrome Psychology" paintings are an outlet for him to face the realities that come from looking different and having the limitations caused by his disabilities. Logan has come a long way on his journey toward accepting his challenges. He says he hasn't fully accepted the difficulties he faces, but he is closer than ever. Acceptance is what opens the door to creating peace and joy.

Link to youTube video of some of Logan's "Syndrome Psychology" artwork:
https://www.youtube.com/watch?v=Cy3VDBNsLzY

Logan's website: http://www.loganmadsenfineart.com/

Heather Madsen (Utah, USA): Heather is now 37 years old. She is a talented writer and many of you have read some of her writings in our book "Eight Fingers and Eight Toes: Accepting Life's Challenges."

Writing talks is a strong point of her writing skills because Heather is a natural born teacher. She has spoken to over 2000 medical students, given a talk for Autism Speaks kick off, spoken at The Inner Light Center, at the University of Utah at a Spiritual Healing and Medicine (SHIM) presentation, to caseworkers at the Department of Workforce Services, and with Logan and myself at local libraries.

Heather uses her teaching skills when meeting with Logan every Sunday to teach him about autism so he can better understand himself and live a happier life having autism. Heather is a goldmine of knowledge about autism and helps friends and acquaintances who seek her out for advice.

Reading is a favorite activity of Heathers. She loves the written language. She said she loves seeing how writers put their words in a sentence and how the sentences flow. Heather said sometimes it's like watching a beautiful movie when she is reading. Currently Heather enjoys reading books about animal communication. This topic moves her close to her spirit and opens her mind to all the beautiful possibilities in life.

Heather's new companion, her cat Thomas, brings her great joy. She has trained Thomas to do many tricks. Thomas "picked" Heather when we met him at the Humane Society. He quickly crawled off of my lap and right onto Heather's lap and couldn't seem to get close enough to her. He is exactly the right companion for her.

Heather finds happiness in life by focusing on the positive. In her talk, "Seeing Beyond Appearances: Is What You See What You Get?", Heather relates her struggles and challenges and how she transforms them into deliberate creations of joy, through appreciating the simple beauties of living: https://www.youtube.com/watch?v=28Q5hFIQ8TY&list=PLA478A1293BFA02D9.

Debbie Jorde, Logan's and Heather's mom
https://www.youtube.com/user/debbiejorde

Logan won first place in a contest between artists at Artist Connect in December 2013. The painting is titled, "Grab".

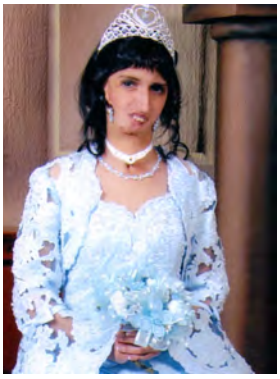
Anna Franklin (Virginia, USA): Having a child with Nager syndrome is having a life filled with the greatest joy with each of their accomplishments and the greatest sadness at watching their struggles. Life has presented many challenges for them to overcome and we stand back in admiration as they do just that. Our daughter Anna is an amazing little girl who has many more accomplishments in her 7 years than I will ever be able to boast in mine. However, she, unfortunately, has to face these challenges every day.

Since Anna was born, she, like many children with Nager, has struggled with her ability and desire to eat. Something most people take for granted and thoroughly enjoy has been the source of much stress and heartache in our home. When Anna was born, she spent 3 weeks in the NICU learning to drink from a Haberman Feeder, a special bottle designed for babies with impaired sucking ability. She was discharged from the hospital after successfully learning to drink 20 cc at each feeding. After bringing her home from the hospital, however, the amount she was able to drink did not increase and she was not gaining weight. She had an NG tube for about 1 month, until we ultimately decided that a g-tube was the necessary solution to help her thrive. The g-tube saved her life, allowing her to grow and develop, but her oral feedings quickly began to decrease as she became less interested and more fatigued with the effort it required from her.

Shortly before Anna turned 2 years old we began an intensive feeding program, where, after 8 weeks, she went from being about 90% fed through a g-tube to eating 100% orally. We were overjoyed! At first the food she ate was all soft or pureed, until one day she tried a French fry and loved it. From there we started experimenting with different textures in food, hoping to introduce Anna to all of the wonderful tastes she was yet to behold. However, this is not how things have unfolded. As Anna has had surgeries along the way and her oral structures have changed, her ability and desire to eat has waxed and waned. We have shed many tears together and had hours of stand-offs trying to outlast the other in our battles over food; but eating is a physical, sensory, and emotional experience for Anna. We have to remember that all of her experiences are not as we have experienced them. Every bite she takes uses 100 times more effort than it does for us. Just the act of chewing and swallowing is a challenge. We are thankful for her g-tube, it has allowed her to thrive as she has and we still use it for the better part of her nutrition. However, we continue to celebrate every new taste and are hopeful that one day, with continued faith and the right interventions, Anna will learn to eat to sustain her health and enjoy a well-balanced meal at the family table.

Ashley Franklin, Anna's mom

Tiffany Castillo (California, USA): Tiffany has battled through to get to 21 years of age, and, like the majority of children affected by Nager syndrome, she requires the use of a trach and g-tube to sustain herself. She has endured multiple operations and transplants in an effort to correct abnormalities in her mandible among many other, serious, surgeries, but none have worked. Besides operations, Tiffany has gone through a large amount of therapies — everything from eating and speech to occupational and behavioral.



She is now a young woman, but in spite of all the surgery and therapy she is still completely non-verbal, still relies on a trach and g-tube, and wrestles with her autism. While all these years have been difficult, Tiffany and her family have always counted and relied on her beloved nurse, Cynthia, who has been with Tiffany since she was 5 months old. Cynthia has become such a large part of Tiffany's life that 6 years ago a health magazine wrote an article on both of them that I would like to share (see below).

Lourdes Castillo, Tiffany's mom

CALIFORNIA ASSOCIATION FOR HEALTH SERVICES AT HOME

FEATURE STORY

"Ms. Joseph ... continues to provide care for Tiffany today, despite having to drive 25 miles each way"

A Life MATTERS

AN ONGOING SERIES HIGHLIGHTING *The* PEOPLE *And* STORIES *In* HOME CARE

It was 1993 when **Cynthia Joseph** LVN first arrived at **Oxford HealthCare** in Southern California. Ms. Joseph's first case was unfortunately very brief and, because of the limited availability, Oxford offered her a new case that only included respite care. Ms. Joseph was unsure about the new case with limited hours but agreed to accept it on a trial basis. Her new patient would be a five-month-old baby girl named **Tiffany Castillo**.

Tiffany Castillo was born with abnormal facial anomalies and respiratory problems, along with numerous other challenges including deafness in both ears. It only took one visit for Ms. Joseph to become instantly fond of little Tiffany, and fifteen years later the two are still by each other's side.

In the first few years of their relationship Ms. Joseph and Tiffany had to conquer the challenge of communication, prompting them to take sign language classes together; and today they have both mastered this form of communication. As the years of service and friendship continued a very tight bond developed between Ms. Joseph and all members of the Castillo family.

In 2007 Ms. Joseph fell gravely ill and was unable to provide care for Tiffany for a year. This was a very difficult transition period for both Tiffany and Ms. Joseph, but despite the challenges Tiffany and her mother visited Ms. Joseph in the hospital every day. Tiffany would often lie next to Ms. Joseph in the hospital bed and assist her in getting up out of bed when needed.

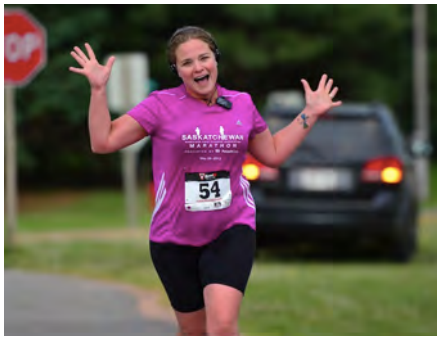
Thankfully, Ms. Joseph has fully recuperated and continues to provide care for Tiffany today, despite having to drive 25 miles each way. Although state cuts have greatly affected Ms. Joseph's finances, she has commented that she would never leave Tiffany without her daily care. **Not only is Ms. Joseph Tiffany's LVN, she is also her friend and advocate.**

Submitted by Oxford HealthCare

If you would like to submit a story for this series please contact Jordan Lindsey at jlindsey@cahsah.org

THE CALIFORNIA ASSOCIATION FOR HEALTH SERVICES AT HOME IS DEDICATED TO PROMOTING QUALITY HOME CARE AND ENHANCING THE EFFECTIVENESS OF ITS MEMBERS.

Another TRI for FNMS: the Beranek Family Fundraiser



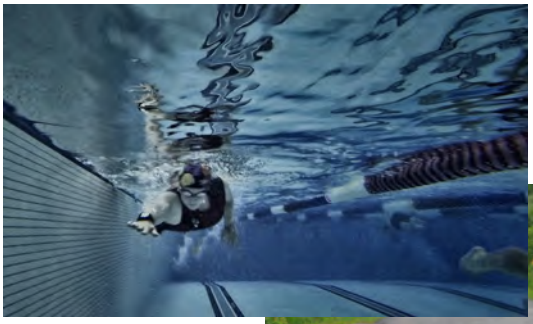
Beautiful Marathon, Wisconsin, was the site of another successful fundraiser for FNMS. In June our family hosted the 9th Annual Marathon Ultra-Mini Triathlon benefitting the foundation. We started this fundraiser as a way to give back to an organization that had been so incredibly helpful and supportive to us when our son, Saul, was born with Nager syndrome.

When Saul was born in a small hospital in central Wisconsin, no one knew what his diagnosis was. After being transferred to a larger hospital, we were introduced to a geneticist who found Nager syndrome in a big book she had. She had seen one case of Nager in 1980 and could tell us no more than what the two paragraphs in her book said. I know many of the parents of children with Nager or Miller syndromes felt the same way we did in those first weeks after birth: alone, uninformed, lost. For us, finding FNMS was exactly what we needed. We received two large packets of information on Nager sydrome, including many previous issues of this newsletter. Having all of that information, as well as contact information for other families affected by Nager, was such a relief. We were comforted by the stories of older kids doing well, educated by the scientific articles, and connected to a whole network of families and medical professionals who would support us in that first, difficult year. When Saul was nearing his second birthday, we were feeling a lot less overwhelmed and like we had the energy and time to give back to FNMS to show our gratitude. We also were very passionate about keeping FNMS funded so that new families hearing a diagnosis of Nager or Miller syndrome would find information and support like we did. We started a small fundraiser that year, and have added and changed it to be what it is today.

Our event includes two triathlon divisions, a mini-tri and a sprint-length tri. We also had a 5K run for those who aren't up for the swimming and biking before they run (that would be me!). Many families and first-time triathletes came out to participate in the mini triathlon. This short triathlon consisted of a 1/8 mile swim, a 5K bike, and a 1/2 mile run. There were a lot of smiles as families crossed the finish line together, or better yet, when a kid sprinted at the end to beat mom or dad. In the sprint triathlon, which we call our Athlete Division, we saw amazing athletes pushing themselves to their limits. This division is open to individuals and teams, where one person does each leg of the triathlon. **All together, we had over 100 people participate in the events, and we raised nearly $5000 for FNMS.**

Special thanks to the following individuals and businesses for donating needed items:

Chippewa Valley Digital Design (web svc.)
Dave Kallaway (photography)
Marathon Area Swim Association (prizes)
RoadID (bib #s, prizes)
Sun Country Tees (t-shirts)
Ready Rental Center (dunk tank)
Trig's (food, beverages, misc. supplies)



Special thanks to Marathon Elementary School for donating the proceeds from the dunk tank to FNMS.

A large portion of the money we raised comes from business and individual sponsors who donate money to the event. We feel absolutely blessed to have the continuing support of so many. We also receive donations of t-shirts, refreshments, and prizes from local businesses, which makes the event better and keeps our expenses to a minimum. We do pay for trophies and medals, timing services, and insurance for the day. Many volunteers make the event run smoothly. Overall, this is a fairly simple and really fun way to raise a decent donation for FNMS.

FNMS uses its funds for things like this newsletter, but their big expense is the family conference held every 2 years. First off, if you haven't been to one, you really need to come! We have attended three conferences and they are just about the best thing ever. You will meet other people who have faced similar challenges, hear from experts on the syndromes, and get to sight-see in amazing places (last one was Seattle, WA). People say attending one of these conferences can be life-changing. For Saul, who was 9 at the last one, it was a place where he could fit in and not feel different. He was just looking at his hands the other day, looked up at me and said, "I want to go back to Seattle."

The FNMS family conference is like a learning experience combined with a mini-vacation. I hope to see you at the next one!

As a mother of four kids, one with Nager syndrome, I understand how busy life is. I know how hard it is to find the time to do anything "extra". I also am aware that there are a hundred different fundraisers going on at any given time in every little town. I just want to encourage you to try doing a fundraiser for FNMS. You might be as surprised as we were that first year. We didn't do much, and yet we raised about $2500. Every year as we tally our donations, we are overcome by the generosity of people. And these folks in Marathon just have continued to give and support, year after year. It makes us feel so good, I can't even describe it! I challenge you to get something started where you live. It doesn't have to be big. **If many of us pitch in, the result could be amazing!**

To find out more about our event visit **www.ultraminitri.org** or "Like" us on Facebook

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in honor of Tinka Gaffney

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Essie & Rick Streicher donated in loving memory of Joseph Rago

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FNMS
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Auburn, WA 98092
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fax 253-288-7679
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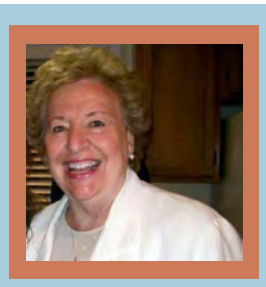
Donations in memory of FNMS volunteer

Joan S. Troka

May 10, 1930 – March 1, 2014



Mother to FNMS founder, Margaret Hogan, and grandmother to FNMS member, Bridget Ieronimo. The Troka family is most grateful to all who made donations, had masses said, prayed, visited, sent sympathy cards and whose kindness and consideration supported all of us during Joan's brave fight against cancer.

She will forever be loved and missed.

Mary Pat Adams
Mary Adler-Steiger
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Kelly DeMarino on behalf of the Russell & DeMarino families
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