

The Foundation for

# FNMS

Nager and Miller Syndromes

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.

# All About Us

“**WHAT COUNTS IN LIFE IS NOT THE MERE FACT THAT WE HAVE LIVED. IT IS WHAT DIFFERENCE WE HAVE MADE IN THE LIVES OF OTHERS THAT WILL DETERMINE THE SIGNIFICANCE OF THE LIFE WE LEAD.**” — Nelson Mandela



Margaret Hogan (1959–2015) posing with Jackson Van Quill on the ferry ride to Blake Island during the 2013 FNMS conference in Seattle, WA.

# All About Us

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This foundation does not endorse hospitals, teams, products, or treatments. The information in this newsletter is provided to keep you informed of activities and progress internationally regarding Nager and Miller syndromes. Views expressed in this newsletter are not necessarily those of the Foundation for Nager and Miller Syndromes.

## The Margaret Issue

As intended, the phrase can be interpreted two ways. In this edition we celebrate the life of our beloved Founder, Margaret Hogan. The goals of this issue of "All About Us" are two-fold: 1) to allow those who did not know Margaret (or know her well) to learn about her incredible efforts and courage in creating, building and sustaining FNMS, and 2) to remind those of us who did know Margaret that her mission must be carried on and that the foundation must continue to be nurtured in order for Margaret's vision to be fulfilled.

However, the phrase, "the Margaret issue," also can be interpreted to mean that we must address the issue of depression. As caregivers for our affected family members, we often spend the majority of our time focused on their health and well being, sometimes to the detriment of our own. Margaret was always there for anyone struggling with the extreme stress and anxiety that comes with having a medically involved family member. She responded readily and gladly to all who reached out to her. The key is the reaching out. As a support group I want you all to know that we are here for that very thing! Not just for sharing our experiences with medical procedures and treatments, but sharing in our daily emotional struggles. No one could have predicted Margaret's untimely death. She did not reach out to anyone to let them know that she was struggling. Depression too often goes untreated, undiagnosed and even unnoticed. There are times when we operate in survival mode when our child or self is undergoing a medical procedure or a complication from our syndromes or other unrelated health concerns. When not in survival mode we then are frequently forced to face the financial, social and societal issues that come with having physical differences, expensive medical treatments and complications. It is important that we take time to evaluate not only our children's mental health status but our own as well. There are untold contributing factors to depression — the signs and symptoms must not be ignored. Listed below are the most common symptoms. If you or someone you know is experiencing more than two of these, please ask for and get help. We are here for you, please reach out.

### Emotional symptoms:

- Constant sadness
- Irritability
- Hopelessness
- Feeling worthless or guilty for no reason
- Loss of interest in favorite activities

### Physical symptoms:

- Trouble sleeping
- Low energy or fatigue
- Significant weight change
- Difficulty concentrating

Remember that it will get better and as Margaret used to remind me, "this too shall pass."

*DeDe Van Quill*

**National Suicide Prevention Lifeline (in U.S.):** 1-800-273-8255;  
[www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org); English, Spanish; available 24/7

**International Suicide Prevention Info (outside U.S.):**  
<http://www.suicide.org/international-suicide-hotlines.html>

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# 2015 FNMS Conference



in  
New Orleans

**N**ew Orleans is a destination city full of history, unique culture, food and music. And this summer it was the destination of the FNMS biennial conference.

FNMS faced a difficult decision a mere month before our conference was to take place — how could we come together so soon after the loss of our leading light? Members struggled with what would be the painful absence of our dear Margaret — the hugs, the laughs, the energy Margaret brought to everything she did. But there were ultimately more reasons to continue with the conference as planned than not to. First, there were a number of families who would be attending the conference for the first time, traveling long distances, and fundraising to get themselves there. They were looking to connect with others like themselves as we all had before; to gain and share knowledge of therapies and surgeries, and to have their children finally meet and make friends with another child who was the same. We couldn't let these families down. Second, FNMS is a family — one that has endured tragedy and loss — but still a family. There was an overriding sense that carrying on is exactly what Margaret would want us to do, this year and into the future. Finally, it was simply too late to cancel all of the arrangements that DeDe had made with vendors throughout the city, so we needed to pack up our grief at the end of the June and head to New Orleans.

The reunion began on Thursday even before our traditional evening ice cream social. As folks were checking into the hotel throughout the day, there were many old friends milling about greeting newcomers, and there were plenty of hugs to go around. A few families arrived a day or two earlier to make sure they had time to see the sights, and in New Orleans there is little shortage of interesting things to do. Jake Roberts had a magnificent trip over from the U.K., making friends with the flight crew, and arriving early and spending time with the Perry family from New Zealand. The bonding was instantaneous. Jake's mom organized a fundraising campaign in their hometown and raised enough money to give them both a great experience. Everyone loved meeting Jake, who was always smiling and so excited to meet the other members of his "team."

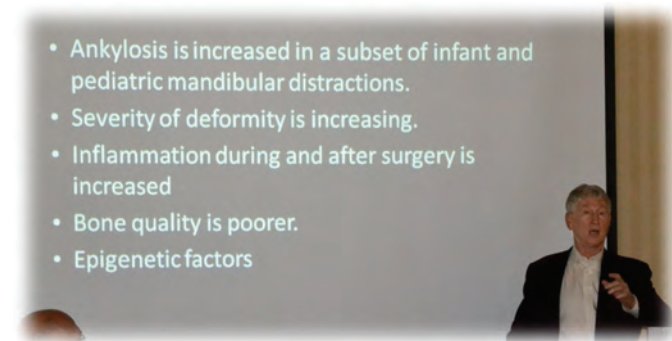
At the ice cream social that evening there was more time to make new friends and meet new families. It never gets old to hear a child say, "Wow, they look like me." Little Eli Hammond, who was there with his parents and older brother and sister, reminded parents what their affected children were like at that young of an age. It was fantastic seeing the immediate bonding the children had, and parents there for the first time had many questions for others who were more than happy to share what they could. This is why we come together.

Friday we had a planned group outing to the National World War II museum. The museum is vast and spread out over several buildings — there was much to see and learn. The highlight was an interactive exhibit that recreated one crew's experience on a doomed submarine mission, but there were many other exhibits to explore. After lunch together, families took off alone or in groups to explore more of what the city had to offer.

The hotel had a nice area between the pool and the breakfast room with comfortable seating to have conversations. When Dr. David Matthews, our guest speaker that weekend, arrived Friday night, it was nice to be able to sit in the lobby area and for him to get to know the families on an informal basis. Dr. Matthews is a plastic surgeon located in Charlotte, North Carolina, who has done jaw distraction and other surgeries on several FNMS children. A particular area that can be problematic for those with craniofacial anomalies is the temporomandibular joint, or the TMJ. This is an area where Dr. Matthews has particular expertise and he shared his knowledge on the subject Friday evening as well as during Saturday's presentation.

There were some technical difficulties on Saturday morning and we were unable to get our speaker started on time, but thankfully Dr. Matthews is quite relaxed and had no problem flipping his intended presentation and having the discussion portion first and showing his slides when the technical issues were resolved. He discussed at length the importance of diet on the quality of bone. Essentially a typical western diet is acidic, which creates chronic inflammation in the body and adversely affects the quality of our bones. Our children need to have strong bones for the surgeries they undergo or those surgeries will fail. The Bueno family were impressed with how knowledgeable Dr. Matthews was on the subjects he discussed and said it was refreshing to talk to a doctor who thinks holistically.

- Ankylosis is increased in a subset of infant and pediatric mandibular distractions.
- Severity of deformity is increasing.
- Inflammation during and after surgery is increased
- Bone quality is poorer.
- Epigenetic factors



We closed out the weekend with dinner and a party at a nearby hotel. One thing that can certainly be said about our group is that they love to dance!

*It was great for all of us to attend. We can't wait for the next one. I think Eli was too young to really understand what was going on but I know he had a good time. We had a lot of questions answered. I liked seeing all the kids with each other and I was especially amazed how far they all had come. It was great to see the support all of the kids had from their families. I was pleased to see how Will and Ellie got on with the other kids. My hope has always been that Eli's siblings would be his biggest supporters and best friends.*

Hammond family (Annie, Wade, Will, Ellie and Eli)



The Robinson's from Oklahoma City.



Erica and Saul practice their duck lips.



Aunt Cathy helping out Theo and Jake.



Beth, Lucas, Loretta, Janusz, Julia and Ursula share smiles and stories in the breakfast room.



Long-time friends Bridget, Jackson, David and Julia take in the exhibits at the WWII museum.

*Portions of Logan Madsen's documentary-in-the-making were filmed during the conference. "Logan's Syndrome" focuses on Logan, his life, and the incredible paintings he continues to create despite the pain he must endure due to his physical limitations.*

*One special moment, that most of us will have to wait for the final movie to see, occurred on the last night when a piano was located at a nearby hotel and David González delivered a moving performance for a small but attentive audience. Look for the "Logan's Syndrome" page on Facebook for updates.*





Castillo family with Cynthia Joseph



Derrico/  
Winns  
family



Ryba  
family



Bridget

Sherman

Jackson



Kehler/Mokrey family

Williamson  
family



Steph  
Roberts

Brittany

Harlena

*It was an absolute privilege to spend time with the FNMS Family in New Orleans. Despite our initial sadness, we hugged, cried and eventually laughed and danced our way to a fabulous retreat in a phenomenal city! Kudos to all of the families who worked hard to present an awesome experience and keep the FNMS organization alive and relevant.*

Harlena Morton, Brittany Stevens and family



Hammond family  
arrives ready to  
party



González  
family

Mike  
Hogan

**M**argaret Ieronimo Hogan created the Foundation for Nager and Miller Syndromes after her daughter Bridget was born so that other parents would not have to face such a difficult, uphill battle in order to learn more about the condition their child, or children, were born with and to learn what could be done to help these children lead healthy, successful lives.

In 2009 FNMS celebrated 20 years of existence. At the time, Margaret wrote in this newsletter about the fear and helplessness she felt when Bridget was born with Miller syndrome and in need of immediate life-saving interventions, then of her strong desire and need to connect with other families who were going through the same things she was. Through determination and a lot of letter writing (the Internet barely existed for consumers in 1989), she found others to share information with, and the network of families grew and grew and included parents with children affected by Nager syndrome as well. One of the doctors Margaret wrote to and kept in contact with was Dr. Marvin E. Miller, a pediatric specialist in genetic disorders and birth defects who authored the paper that gave Miller syndrome its name. Dr. Miller spoke at FNMS's first fundraising event hosted in Chicago in September 1993 with an incredible crew of 500 local supporters, and the event raised a whopping \$80,000 for FNMS. Dr. Miller commented on this event in an obituary article for Margaret published in the *Chicago-Sun Times*: "I had the great privilege of attending her first fundraiser for her foundation," Miller said. "A picture of Margaret and her sister at that event sits in my office to constantly remind me of the goodness that committed people do in a troubled world." Dr. Miller told me in a separate conversation that he thought Margaret was a wonderful human being, and that she didn't want others to have to reinvent the wheel.



**Left:** Dr. Miller pictured with sisters Beth Atkins and Margaret.  
**Right:** Margaret speaking at another FNMS-sponsored event.



The 1993 event at Stephani's restaurant was just one of the fundraising efforts Margaret embarked on over the years, but on its own it is an example of the many that came after it and showed: 1) Margaret's ability to rally others to come together for a common cause, 2) the vast network of friends and supporters who loved Margaret and her family and wanted to support their cause over the years, and 3) the enormous amount of compassion Margaret had and her desire to reduce others' suffering.

Margaret started FNMS and the accompanying newsletter in 1991 with another mom. Pam LeBaron's daughter, Melissa, has Nager syndrome, and the two mom's met at Childrens Memorial Hospital when each of their children were there for similar procedures. After launching the foundation, they started fundraising for the benefit of other families: to start a newsletter to spread the word and reach more families who might need support as well as find other people and resources who could help them better provide support; to set up an 800# to give and receive calls from affected families; and to attend conferences to learn more about available resources and share any knew knowledge. They were also working toward holding the first FNMS conference in Chicago, which they were finally able to coordinate in 1996.

Margaret's family and network of friends have been major supporters of FNMS over the years. They have participated in the fundraising efforts and contribute to FNMS on a regular basis. It has been Margaret's singular determination and drive that has kept FNMS going for 26 years. Even after she handed over the directorship more than a decade ago to DeDe Van Quill to take a less strenuous role in the foundation, she was needed for her wisdom, compassion, creativeness, and continued efforts to bring in funds — the majority of funds — to FNMS.

from Dr. Marvin Miller, Pediatrics specialist in genetics disorders and birth defects and FNMS Advisory Committee Member:

No seat in life could be more lonely or isolated than the one a parent sits in when they are told their child has a rare disease or disorder and the



Dr. Marvin Miller

prognosis is uncertain because of limited experience with this condition. While physicians and other health care professionals are usually well-intentioned in their dealings with such parents, no individual can provide any greater comfort of insight into such an event

than someone who has previously had to face the birth of a baby with the same type of problem. No greater sense of communion exists than that between parents who have had to face the same situation of their children with a rare disorder in which the prognosis is uncertain, and information scant.

As a pediatrician who has spent much of his professional career in the management of children with genetic disorders and birth defects and their families, I can attest to the need and immense benefit of support groups such as the Foundation for Nager and Miller Syndromes.

Children see the world through the eyes of their parents, and thus the attitude of a child who has a special need such as a birth defect will be greatly determined by the attitude of the parents. A child who has a special need can see that special need as a challenge which will allow him or her to grow up to be a contributing member of society.

There are rare, very special people who see the need to try to make sure every parent who has been through what they have comes through the experiences with a positive and optimistic outlook toward their child and toward life. These special people are the angels who take the time and spend the energy and resources to form support groups. We have two such angels here tonight—Mrs. Ieronimo and Mrs. LeBaron.

Margaret and Pam, you have earned my heartfelt admiration for the work you have done so far in establishing this organization and I wish you every bit of success in your worthy mission.

In Margaret's family, celebrations as well as personal losses spurred new campaigns to bring in more money for the foundation. In 2004 Margaret's father, James Troka, passed away, and her extended circle donated funds to FNMS. Since 2007, the year I started to help produce this newsletter, I have compiled names from many personal campaigns printed in thanks for their donations to FNMS. The first time was when Margaret married Judge Mike Hogan in 2007. They included a card with their wedding invitations stating: "Please, no gifts. But if

you must, please send a donation to our favorite charity." They raised \$20,000. Since that time there have been acknowledgments for donations when Margaret's Uncle George Strickland, brother Jim Troka, cousin Trish Strickland, and mother Joan Troka passed away. And not just one time ... additional donations came in as dedications on the anniversary of some of those deaths. For these events they would regularly write "in lieu of flowers, please send a donation to FNMS."

Margaret has touched the hearts and changed the lives of most families who have had the chance to meet her in person. I know she has certainly done that for our family. But the foundation has grown so much over the years, particularly with the Internet, that there are many FNMS members who have never had the privilege of meeting Margaret because they have not yet participated in a conference. Margaret always did her best to make the conferences accessible by hosting them in various locations across the United States and Canada, so that it would give as many members as possible the chance to attend. FNMS always provided travel scholarships, paid for nights at the conference hotel, and never charged fees for the conference itself while always providing inspiring and informative guest speakers, ample food at the event, and hosting a group excursion so that everyone felt safe and comfortable enough to take in public attractions surrounded by our loving FNMS family.

During the time I've been part of FNMS and volunteered to work on the newsletter, my communication with Margaret only averaged a few times during the year, typically around the time the newsletter was being produced. But when we did speak she would always ask what amazing thing our daughter Tinka was up to and how our family was doing. In recent years we had another connection: our mothers were probably close to the same age and both moms were given a cancer diagnosis around the same time, so we shared conversations and empathy around that. Her mother was determined to triumph over her cancer and sought aggressive treatment. My mother had the opposite reaction to her diagnosis, basically stating, "Now I know how I'm going to die," and she refused treatment. Margaret's emails during this time were touching. I remember once she was glad for the task I gave her of proofreading the mailing list while she kept vigil at her mother's hospital bedside. She wrote: "Thanks for the prayers, Leslie. Mom was cat napping as she did not have a restful prior night's sleep here. The mailing list gives me something productive to do while sitting around the hospital."

Margaret's mother's cancer was in remission for a short time before it came back and she passed away. My mother stubbornly kept going. I wrote to Margaret about how

hard it was for me to not be there to help my siblings care for my mom and getting those last few moments in person with her. She wrote me a note, which I treasure, and want to share here. I think the last line is more true for her than for myself, but it was a beautiful sentiment for her to give to me at the time. She wrote: "I'm sorry your mom has lost the energy to do her usual activities around the house. I was amazed to hear she pushed on and was reading, doing laundry, etc. It's so important that she is doing this her way. She sounds like a practical person, as she does not want to disrupt her loved one's lives. That is so considerate. I understand how you wish you could be closer to her at this time. The fact is, the morphine, which is so necessary now, would most likely not allow her to be aware. Thank God for morphine. In the end, all I wanted was for my mom to be pain free and worry free. I keep you in my daily prayers for strength and acceptance. In your capacity to work hard for your own family, in your career, and to pursue your other interests with such devotion and determination, I surely see your mother's reflection in all you do. You have inherited great heart and smarts. *A mother's legacy is often passed on through the successful lives their children live. You have, and always will, make her forever proud in all the good you do.*"

The foundation, and especially the individual families and those affected with either Miller or Nager, were so important to Margaret. She sacrificed her time, her energy, and in some cases her own health, to push for more information relevant to the families to help them navigate difficult social situations, such as bullying, or learn about new medical advances or advances in the genetic understanding of the syndromes. If she discovered a product that helped Bridget adapt with the limited range of movement in her limbs she wanted to share it with everyone else so they, too, could have an easier time.

Margaret's life was all about giving, and now it is our turn to give back. Each of us. So that we can continue what she started, for the well being of our own as well as for those who are still to come along.

If you have ideas for things you can do to fundraise or volunteer with FNMS please share them with myself or DeDe. Our contact information is on page 2.

My mother passed away in May 2014. Margaret wrote to express her condolences and said, "I'm sure my mom has already introduced herself to your mom!"

By now my mom has likely met Margaret, and I know she must love and admire her as much as I always have.

**Leslie Gaffney**



**The story of FNMS starts before Margaret. It starts when we had Erica in 1985 and I was desperate to meet or talk to someone who had a child like mine. I wrote to Dr. Fineman, the lead author on the small article about Miller Syndrome found in a large genetic paediatric text book. Dr. Fineman put me in contact with Debbie Jorde, mom to Heather and Logan, and we went to visit them when Erica was 2 years old. The joy and encouragement of meeting two such wonderful young people, and to see how well they were doing, was indescribable.**

Margaret made contact with Debbie after Bridget was born and we were in the States on a visit at about the same time. Debbie made contact with me and let me know about Bridget and this new family in Chicago. I first met Margaret when Bridget was 7 months old, Sherman was 18 months old and Erica had just turned 5. Being with others who could connect on such a personal level, who knew what the journey was like, was like a drink of water in the desert. Margaret welcomed us into her home, strangers yet family. From that time on, we three mums kept in contact, sent photos of our children to each other, talked on the phone, and encouraged one another — we were a pretty exclusive club! There were only five children with Miller's syndrome that we knew of at that time. We treasured the letters and photos that Debbie and Margaret sent, and we could all see how much it benefitted us to share our experiences and our knowledge, our highs and lows.

We were so excited when Margaret co-founded FNMS with Melissa LeBaron's mom and suggested we have a conference. To meet others walking a similar journey had been such an encouragement to us, and we hoped to be an encouragement to others. Margaret seemed to have an unlimited amount of energy and drive and a desire to make it happen. She worked tirelessly, as did her family, to raise funds and write to knowledgeable people, experts in their fields, to get information and advice, so that our children would have the best opportunities possible. The first conference was extra special, with so many people giving of their time and expertise, pediatricians, neurodevelopmental therapists, plastic surgeons and, of course, the wisest, most experienced experts, the parents.

There is so much done behind the scenes to keep FNMS going and Margaret was tireless in her efforts to keep us all in touch so we could be a supportive family. She will be greatly missed.

**Carla Perry**



Heather's geneticist contacted me and asked if it would be okay for them to give Margaret my phone number as she just had a baby with Miller syndrome, had questions, and wanted to connect with me as a mother to two children with Miller syndrome.

Margaret called me shortly after and introduced herself. She wanted to know how Heather and Logan were doing. I gave her descriptions of when they were born, surgeries they had, and how well they were doing. Margaret was so grateful for our connection and always expressed sentiments of appreciation every time she saw me or talked with me through the years. Talking with Margaret didn't feel to me like I was doing a big service, but Margaret communicated what a huge difference our conversation had for her. Margaret always made me feel special and treated Heather and Logan as if they were too. She showed so much love to Heather and Logan whenever she saw them.

When Margaret started FNMS I was amazed that she could do this because I knew what life having a child with Miller syndrome was like. I was impressed with her vision and ability to carry out the tasks needed to make her vision a reality.

Even though I didn't talk with Margaret socially a lot, when we did talk we connected heart to heart. I felt like we were so much alike. I knew we could call each other anytime and we would be there for each other.

Margaret was supportive and a light at times of darkness. Knowing she was handling the challenges of raising two children, one with Miller syndrome, as well as running FNMS, gave me strength during difficult times. I believe she felt the same about me. We spoke of our personal challenges through email and occasionally on the phone, empathized and supported each other, and gained strength from each other.

Margaret was an amazing, loving, kind, generous, supportive woman. She was a light in this world. I miss her greatly.

**Debbie Jorde**



Spring 1991, I sat down to write what would prove to be the first of many articles for the FNMS newsletter. We originally called the newsletter "All About Me," but it was later changed to "All About Us." By we, I'm talking about my cofounder



Margaret Ieronimo Hogan, who had a little girl with Miller named Bridget and, of course, my little girl, all of 7 years old by then, was Melissa LeBaron (above right with Bridget), who was born with Nager syndrome.

Before we started the foundation we had few places to turn to for information and advice regarding the many and varied questions we had about what to expect for our girls. Melissa and Bridget both went to doctors at Children's Memorial in Chicago, and after meeting Margaret and talking about our frustrations, we decided to join forces and try to form a network for other parents with children just like ours.

After several years and great success in finding and helping other families around the world who faced similar challenges, Margaret went on to make FNMS the great success it has become. My life took a different turn, and I eventually had seven children to raise and little time to devote to our cause. But, I am proud to say that I was there

when it all started and am pleased to see what FNMS has become.

**Pamela Siemens (nee LeBaron)**

When we first met Margaret, we were overwhelmed by her gracious personality, vivacious spirit, unique style and wonderful smile. This was more than 20 years ago as she welcomed us into the "exclusive club called FNMS."

She took charge and we felt empowered by her example. The family conferences were so well planned, allowing for fun, sharing of medical "best practices," and getting to make friendships with so many families all drawn together by the vision of Margaret. She almost single-handedly raised the funds to provide the financial resources to put on the conferences, the cost of airfares and other associated amenities.

Margaret built an organization that represented not only a venue for camaraderie, but a formula for hope as we all shared medical stories of what worked and what did not. Throughout the years, medical advancements for the treatment of our children spawned new techniques and it is amazing to think how far this process will take us in the years to come...all because one energetic, thoughtful and dynamic person followed her intuition!

**Claudia and Greg Myall**



Dear Friends,

FNMS Director DeDe Van Quill and we, Margaret's family, want to extend our deepest gratitude for honoring Margaret's memory through your generous donations to the foundation she started. Your selflessness will enable the work she began and nurtured. Volunteer parents run our foundation, compose our newsletters and plan our conferences from their homes. Your donations provide for the material and mailing of our newsletters, for distributing educational information, and, most importantly, costs for our family retreats. Our conferences have become our FNMS family reunions. They bring acceptance, comfort, counseling, educational seminars, fun and friendship to our special members. As young Jake from England said at his very first conference this year, "I'm not alone anymore. I have a team."

Your sympathy, kind words, prayers, Masses and hugs meant more to us than we can express here on paper. Your donations give hope to the future of Margaret's beloved FNMS.

With admiration and sincere thankfulness,  
Mike, Mick, Bridget, Beth and Cathy

Mary Eileen Aamodt  
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\* We regret any inadvertent omissions to this list. Please know that we are overwhelmed by your generosity and love for Margaret. We would appreciate if you could let us know if your donation was not properly acknowledged.



The Beranek family at the 2015 FNMS conference: Mira, Lara, Dave, Saul, Satchel and Silas. Thanks for all you do for FNMS!

I can hardly believe it, but it's been 10 years of fundraising by the Beranek family. Yes, that means our "baby," Saul, is 11 years old! Many of you have heard our story (probably more times than you wish...), but for the benefit of our new members, I'll recap. Saul was born in 2004 in a small hospital in a small city where no one had seen or knew about Nager syndrome. FNMS was a huge support to us, providing us and our doctors with information we needed as well as emotional support. I remember getting these huge envelopes of information and old newsletters from FNMS founder, Margaret Hogan. I remember being surprised to receive a handwritten note in the package from Margaret. I was thinking "how does the founder of a worldwide foundation take time

to hand write a personal note?" That was my first clue as to how special a woman we were about to know was. I got to know Margaret through email conversations and was utterly impressed. She had no foundation to help her when her daughter was born with a syndrome even more rare than Nager (Miller syndrome). She had no network of parents or medical professionals to call upon, no one who could truly relate to her situation. There was a void that needed filling, and she filled it. Here she was, this mom of two little ones, one with an unbelievably rare syndrome, who found a way to start a foundation. This foundation would eventually bring people together from across the world. Margaret was really something special, and she was there for

my family as we went through a really hard and scary time.

After things settled down with Saul and we had found our new normal, we wanted to give back to FNMS. We wanted to help those families in the future who faced a rare diagnosis like we had. We began raising money for FNMS with an event that coincided with Saul's birthday. We have been organizing a small triathlon, and now also a 5K race, each summer. We have raised \$4000-6000 each year for FNMS with an event that draws around 100 athletes.

The time and work we put in to raise money for FNMS did not go unnoticed by its founder, Margaret. Of all the years we've done this event, the absolute best year was the one that Margaret came to our little town to join in the fun! I cannot even tell you how excited (and nervous!) I was to have the founder of FNMS coming to our event. I wanted to put it in the newspaper and tell everyone to have their flowers planted and grass mowed. I wanted our town to look its best because Margaret was coming to Marathon, WI! She made the trip from Chicago with her daughter, Bridget, husband, Mike, and sister, Beth. She told me that she was so touched by our desire to help out FNMS that she wanted to come and show her support. She and her sister formed a team for the mini triathlon, with Margaret being the swimmer. Oh my goodness, did those ladies have fun!! Mike rode along on the



bike route, if I recall correctly. Bridget captured many moments with her camera. I remember so many smiles that day. Margaret continued to show her support every year with a note or email wishing us luck, and most years she also made a generous donation. At the FNMS conference in Chicago, Margaret presented our family with a wall hanging of the FNMS heart logo that she had made herself. She truly appreciated having someone pitch in to help fund her foundation.

After 10 years of organizing this event, we had had enough. We were going to quit. Yes, this past year was going to be the last year for the triathlon. Even though we hadn't offi-

cially announced it, we had made up our minds that we would get through June, and wrap it up. Then we got the unbelievable news that Margaret was gone. It was, and still is, surreal.

*She did the hard part,  
now we just have to  
keep the good going.*

My first thought was, "What will happen to FNMS without Margaret?" Six months later, I still don't know the answer to that, but I do know that the Beraneks are not quitting. I can't imagine parents of new babies with Nager or Miller syndrome not having FNMS. I just can't. So, next

June, there will again be a triathlon and 5K race to benefit FNMS. In past newsletters I have tried to encourage others to raise some money for the foundation. It has never been more important for us to come together to keep FNMS viable. We all need to do what we can so FNMS is able to continue to do its important work — offer support, information, and opportunity to network with others affected by and educated on these conditions. If you have thought about it but just haven't found quite enough motivation, please use the memory of Margaret as inspiration. She did the hard part; now we just have to keep the good going.

To find out more about our event visit [www.ultraminitri.org](http://www.ultraminitri.org) or "Like" us on Facebook.

## Marathon Ultra-mini Triathlon Donors

### Individual donors:

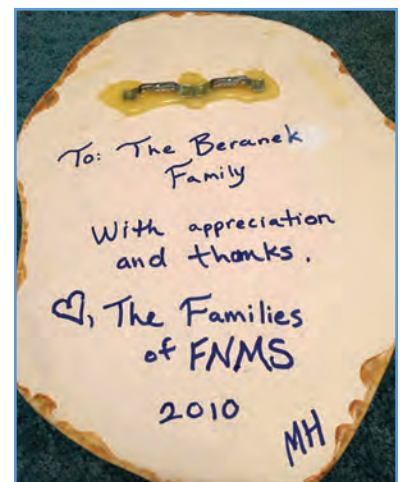
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Wausau Police Benefit Association

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

Chippewa Valley Digital Design (web svc.)  
Marathon Area Swim Association (prizes)  
RoadID (bib #s, prizes)  
Sun Country Tees (t-shirts)  
Trig's (food, beverages, misc. supplies)



Hand-sculpted FNMS heart made by Margaret and presented to the Beranek family at the 2010 FNMS conference for their long-standing commitment to FNMS.

# FNMS Donor Recognition

## General donations (December 2014 – December 2015)

Beth Atkins  
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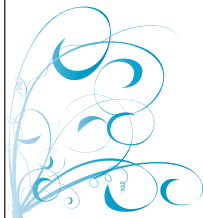


### IN HONOR OF

The Dolan Family Foundation  
donated in honor of Bridget Ieronimo

Jean E. Lubbe  
donated in honor of Saul Beranek

### In loving memory of Carl W. Hodson



Paul Hodson  
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Janelle, Erica & Sherman Perry  
Kristi, Kelly, Kim & Tim Hodson  
Carla & Maurice Perry  
David & Brenda Hodson

### In honor of Beth Atkins' birthday

*Eileen & Dan O'Reilly*



### In honor of David Hodson's 55th birthday

*Carla Perry*

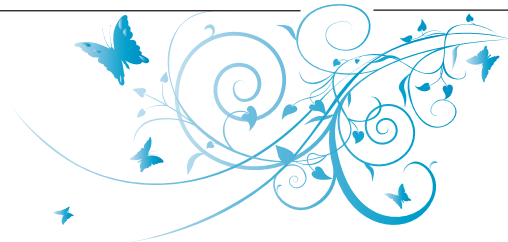
### In honor of Brittany Stevens' 25th birthday

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*Carla Perry  
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### IN MEMORIAM

*Leslie Gaffney donated in memory of Marilyn Gaffney  
Carl W. Hodson donated in memory of Delores M. Hodson  
M. Miller donated in memory of Jack Austin  
Melodie Mowray and Carla Perry donated in memory of Carol E. Franklin  
Carla Perry donated in memory of Betty & Bob Chytraus  
Carla Perry and Bob Hilligoss donated in memory of Billie Lou Hilligoss*





The Morton Grove Foundation held their “Taste the World” event Thursday, March 5, 2015 to benefit local charities.

Bridget and Margaret accept a check on behalf of FNMS from foundation members Tom Schultz (left) and Mike Simkins.

The members of FNMS would like to thank the Morton Grove Foundation for its continued support.



Support FNMS by shopping on Amazon:  
Amazon has made shopping online profitable for FNMS. Go to **smile.amazon.com** and choose FNMS as your charity. Then, everytime you shop via the **smile.amazon.com** link, Amazon will donate a certain percentage of your purchase to FNMS if that purchase qualifies. And many do. Give it a try!

### FNMS welcomes new Board Members

- Beth Atkins, Chicago, IL
- Claudia Myall, San Francisco, CA
- Shari Larsen, Seattle, WA
- Karen Vanderveen, Canada, BC

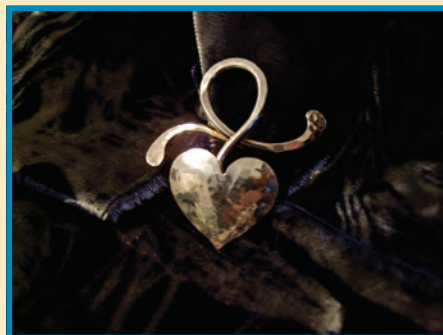
### Honorary Board Member

Mike Hogan, Glenview, IL

Foundation for Nager and Miller Syndromes is on Facebook



Find us and Like us to stay up-to-date with your favorite charity.



*Look stylish while helping FNMS!*

Katy Boldt, longtime FNMS supporter from Glenview, IL, replicates the FNMS heart logo as a sterling silver pin to be worn with pride. A portion of the proceeds from the sale of these pins benefits FNMS. Pins are \$50.

**Katy Boldt Designs is on Facebook or call 847-729-9199.**

## Margaret's Loving Legacy

A noted African proverb states, "It takes a whole village to raise a child." Before 1989 there was no Nager and Miller Syndrome village. Where was the community, the village that would help mothers and fathers, grandparents and families to raise these special and gifted children? Where was the village that would offer familiarity, likeness and acceptance to those children of unique souls? What leader and visionary would emerge forth to show and pave the way? That leader and visionary was Margaret Ieronimo Hogan. If the village does not exist, build it! And that is what she did.

– RBStJ, friend, FNMS village



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Bandera, TX 2004



Bandera, TX 2004



San Francisco 2006



San Francisco 2006



Myrtle Beach, SC 2008

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