The Foundation for
FNMS
Nager and Miller Syndromes

Winter 2009

FNMS Worldwide News

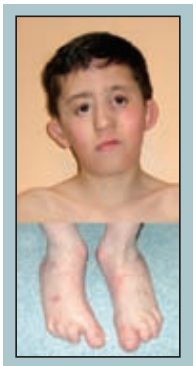
EXTRA! EXTRA!

Scientists Discover Miller Syndrome Gene

Seattle: Scientists from Seattle Children's Hospital Research Center and the University of Washington have done it. They have identified the gene mutation that causes Miller syndrome. Using a newer gene sequencing method, known as exome sequencing, and donations of FNMS member families' DNA, the researchers methodically worked their way through a multitude of possible gene candidates until they found a single candidate gene, *DHODH*.

This discovery is important and ground breaking on several levels. First, one of the most meaningful indications for our member families and others affected by Miller syndrome is that this study confirms the syndrome is of autosomal recessive inheritance. Meaning each parent must carry one copy of the mutation in this gene to have a child affected by the syndrome, who then inherits both mutations from the parents. Second, the location of the gene mutation itself gives rise to new information contrary to what was previously thought about the function of this particular gene, and perhaps what it and other genes do or do not do during embryonic development. Third, this study may help researchers contract the length of time it takes to locate genes or gene mutations that lead to other rare genetic disorders by virtue of this new methodology. Furthermore, this study has given rise to a renewed investigation of the cause of Nager syndrome. The research team is currently seeking volunteers from families affected by Nager syndrome to contribute DNA to the study. Our hope is that at some point in the future this discovery will lead to increased accuracy and timeliness of diagnosis as well as the development of potential gene therapies and effective treatments.

"This study confirms the syndrome is of autosomal recessive inheritance"



Facial features and feet of affected individual in study.

The Foundation for Nager and Miller Syndromes would like to thank Maggie McMillin for her guidance, support and diligence in working with us. FNMS would also like to thank the authors involved in this study: University of Washington and Seattle Children's Hospital, Michael Bamshad, Jay Shendure, Sarah Ng, Deborah Nickerson, Kati Buckingham, Abigail Bigham, Cho Lee and Holly Tabor. Also, Karin Dent and Chad Huff from the University of Utah, Paul Shannon from the Institute of Systems Biology, Seattle, and Ethylin Wang Jabs from Mount Sinai School of Medicine and Johns Hopkins University.

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.

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Big news, big changes, big thanks and big fun — that is what this issue is all about! This year has flown by. Looking back at where we started the year and sitting here writing this now, it seems like we packed much more than 365 days worth of happenings into 2009.

The year 2009 marks the 20th anniversary of the Foundation for Nager & Miller syndromes! That alone is **big news**, and leads to the **big thanks** that need to be given to our founder, Margaret Hogan, and her beautiful daughter, Bridget Ieronimo — the very reasons the Foundation came into being. Margaret tells more about the evolution of the Foundation in her article on page 6. Thank you Margaret and Bridget.

This year also marks a major achievement in the world of science, one that means an enormous amount to the members of our Foundation. The **big news**? The discovery of the recessive gene mutation that causes Miller syndrome! Another **big thanks** to the entire research team at Seattle Children's Hospital Research Center, the University of Washington Research Center, and each of the families who once again donated their time and genetic materials to aid in this accomplishment. The research teams are now working on finding the gene or gene mutation that causes Nager syndrome. The article on the cover of our newsletter goes into much more detail about the discovery of the Miller syndrome gene.

In addition, 2009 is the year that we ushered in a **big change** and a new look for the Foundation and our website. I hope you will visit the website and make use of the new tools that it has to offer. I trust that our members will be encouraged to share their experiences and photos with all of those who come to our site seeking information, confirmation, support and connections. A **big thanks** to the team at Efelle Media for their diligence, humor and tremendous work on our site, as well as to the families who have so generously offered their personal photos for use on the site so far.

I would also like to offer **big thanks** to all of our financial supporters. Obviously we would not be where we are today without their giving hearts. Their generosity is the only thing that allows us to continue to serve our member families as well as the medical community that serves us in turn.

Finally, I would like to encourage all of our member families to participate in the **big fun** this summer at our FNMS Family Conference. Margaret Hogan stepped up to host a wonderful and informative weekend in Chicago, the birthplace of FNMS, in honor and celebration of our 20th anniversary! Another **big thanks** to Margaret. See the events calendar on our website for more information, or call me on the FNMS hotline at 1-800-507-3667.

I wish you all the best in 2010!

DeDe Van Quill
FNMS Director

FNMS welcomes new members

Brenda Ford and Kenri Holder

Kenneth Richard (Kenri) Holder
Harriman, Tennessee

New Baby's Motto

My face may be different, but my feelings the same.
I laugh and I cry and take pride in my gains.
I was sent here among you to teach and to love
as God in the heavens looks down from above.
To Him I'm no different, His love knows no bounds;
It's those here among you, in cities and towns
that judge me by standards that man has imparted,
but this family I've chosen will help me get started.
For I'm one of the children, so special and few,
that come here to learn the same lessons as you.
That love is acceptance, it must come from the heart;
we all have the same purpose, though not the same start.
The Lord gave me life to live and embrace,
and I'll do it as you do, but at my own pace.

LOOK! FNMS has a new website!

We are pleased to announce the launch of our totally redesigned website, **www.fnms.net**! After many months of planning, designing, development and content screening, the new and improved FNMS site has gone live. It is our hope that the new site will be a useful resource not only for our member families, but for the medical and educational professionals that serve them as well as our many supporters and the friends and families of affected individuals everywhere.

A few of the improvements you will notice as you peruse the new site include: a new and more responsive donation system utilizing PayPal, an interactive events calendar, user blogs, a translation link through Yahoo's Babel Fish and updated photo galleries separated by category. There are currently five photo galleries, including: Family Conference Gallery, As We Grow, Before and After Surgery Gallery, Events & Fundraisers Gallery and a general member's gallery. If you have submissions for any of these, please contact DeDe at **dede@fnms.net**.

Stop on by, check it out and let us know what you think!

*The new site includes several new photo galleries. We hope our member families will consider sending in pictures to populate the different galleries. Please send all photos to DeDe by e-mail at **dede@fnms.net** or to the FNMS mail address: 13210 SE 342nd Street, Auburn, WA 98092 U.S.A.*

FNMS Donor Recognition (December 2008 through November 2009)

GENERAL DONATIONS

Mario Adamo
Lourdes & Lawrence Cairo
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Brac & Sharon Carr
Ian & Sheila Chin
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Patrick Tyrrell
Mary Schramm
Henry & Sandra Schuster
U.S. Bancorp (matching gift)
Gerald & Virginia Waldron
Mary & Robert Winter
Patricia Wolf

IN HONOR OF

Margaret & Michael Hogan, Jay Ieronimo and Lois Schaefer donated in honor of Bridget Ieronimo

Michael Quinn donated in honor of Monica Quinn

Dot & John Rohan and Ryan & DeDe Van Quill donated in honor of Jackson Van Quill

Walter Kucharski and the Wolf Family donated in honor of Derrick Wolf

IN HONOR OF RACHEL EGGERT'S BIRTHDAY

Bryan Dudley
JoAnn Eggert
Ann Riegert

IN HONOR OF MARY SCHRAMM'S BIRTHDAY

Howard & Nancy Bultinck
Geoffrey & Catherine Lutz
Thomas & Maureen Lux

IN MEMORY OF JIM TROKA'S BIRTHDAY

Beth Atkins

In lieu of giving presents, Rachel Dudley-Eggert's loving and thoughtful family in Milwaukee, Wisconsin, made donations to FNMS instead.

Happy 30th Rachel!
(third from left)

IN MEMORIAM

Beth Atkins donated in memory of Jim & James Troka and in memory of William & Lillian Streicher

Robert & Catherine Cerone donated in memory of Bill Streicher

Jere A. Troka Edel donated in memory of Fred C. Edel

Michael Moyer donated in memory of John Murray

Northbrook Police Department in memory of George D. Strickland

DONATIONS IN MEMORY OF ANGELINE RYBA

(beloved great grandmother of Kolton Ryba)

L.D. & P.A. Ball
Suzanne Bartlett
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Brian & Lisa Ryba
J.L. & Marilyn Sievers
E. Lance & Joan Stearns
Mr. & Mrs. James Tice
Brian & Nancy Zitek

OUR KIND OF TOWN ... CHICAGO IS!

The Olympic Committee may not have chosen Chicago, but FNMS has chosen this dynamic city for the backdrop of its international family conference June 25–27, 2010. The very city where it all started 20 years ago!

The majority of FNMS's budget is wisely spent on hosting our biannual, international family conference. The fact that we represent extremely rare conditions has always presented us with a far greater challenge in securing donations from the larger population. Now, the economy has further impacted the inflow of donations so we are being extra selective how funds are spent. We ask you to please donate to the very best of your ability. Keep in mind that your dollars go much further with FNMS than any other charity. This is because we pay no office rents or salaries to anyone to do this important work. We remain a committed and parent-run volunteer organization.

To ensure high conference attendance, FNMS grants families with stipends toward their travel and hotel expenses. By doing so, more are able to attend and benefit from this unique gathering. Insurmountable medical expenses for the affected individual's care prohibit them from otherwise affording the trip. Meeting others with Nager and Miller syndromes is an invaluable experience and rare opportunity — not to be missed.

Other conference expenses include guest lecturer fees, group meals, interpreter fees, group transportation to outside activities and entertainment. Conference costs for our 2007 meeting in San Francisco were $45,000. ***We desperately need your sponsorship to underwrite our Chicago conference.*** Let's show our Chicago spirit!

The goal at these conferences is to share ideas, information and practical solutions that dramatically improve the quality of many deserving lives. One example is the time I brought special scissors to a conference to show families how our children with missing fingers could successfully cut with them. They were amazed how well their children could now cut with precision. Prior to this, children were left out of class projects because they could not cut with ordinary scissors. The happiness on the kid's faces at being able to simply cut proved they were capable and gave them a feeling of accomplishment. A real self esteem builder.

Another idea shared at a conference was the laser lock. Since turning locks on school lockers proved so difficult and time consuming for my daughter, we tried a new remote controlled laser lock. It worked so well that we had to bring it to the conference to show others. This little device took the sweat out of the daily task of opening a locker and made their lives easier. There is no other source like FNMS that provides families with help for the numerous daily medical, physical, social and emotional challenges.

Families who have attended FNMS conferences have described them as "life altering" and like a "family reunion". Children do not want to leave because they are so comfortable, and for the first time feel they belong and are part of a group that accepts them.

It's not just our affected kids thrilled to meet others just like themselves with trachs and/or feeding tubes, but also their brothers and sisters. They meet other siblings who worry and care for their affected brothers and sisters.

There is no other source like FNMS that provides families with help for the numerous daily medical, physical, social and emotional challenges.

In this environment they don't need to explain anything and stop feeling self conscious about their siblings looking, eating, walking and breathing differently. I'm always in awe of the unconditional love shown by brothers and sisters toward their special needs siblings who have Nager and Miller syndromes. My life is especially enriched when I witness brothers and sisters helping with their own sibling's care, yet do extra by going to help with the care of another family's affected child. That's just one example how the conferences give me joy and fulfillment — still, even after 20 years.

Please join up with FNMS to put joy into your own heart and into the hearts of others by making a donation that will ensure our services continue and that our upcoming conference is a memorable success — Chicago style!

Donate at **www.fnms.net**, or send your check in this newsletter's donation envelope.

Thankfully,

Margaret Hogan

FNMS Founder

Wishing you a joyful and fulfilling New Year!

Dr. Michael Cunningham named to FNMS Medical Advisory Board

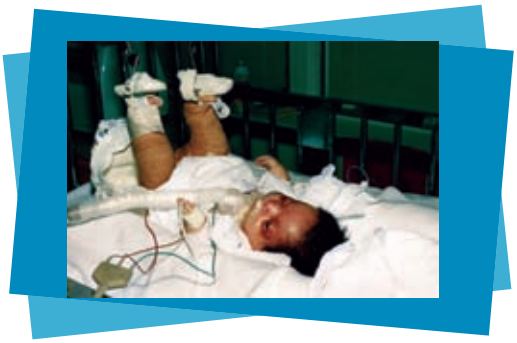
FNMS is privileged to announce the additon of Dr. Michael L. Cunningham, MD, PhD, to our Advisory Board. He joins Drs. Polley, Sawyer, Stevenson and Wulfsberg as contacts for families and professionals regarding medical information and second opinions.

Dr. Cunningham currently serves as the Division Chief, Craniofacial Medicine Chief and Medical Director of Seattle Children's Hospital Craniofacial Center. He is a Professor at the University of Washington Medical School as well and is Board Certified in Pediatrics. He is the medical team leader for numerous children, including one of our own members.

Dr. Cunningham has received numerous awards and honors throughout his career and is a valuable addition to our Medical Advisory Board. FNMS is fortunate to have him aboard!

FNMS Celebrates 20 Years

. . . of hope, tears, fears, joys and triumphs!



Wow … 20 years! Never in my wildest dreams would I have guessed that I'd start a charity after my second child's birth and celebrate 20 years of service helping others with Nager and Miller syndromes. Here's how it all began:

It was immediately obvious at Bridget's birth that she had severe craniofacial and limb differences. The situation was alarming and tense for everyone in that delivery room on May 24th, 1989. This was unexpected and no one was prepared since the previous 9 months of ultrasounds assured us that everything was "normal."

The most critical of Bridget's physical problems immediately at birth was her inability to breathe. Doctors and nurses quickly whisked her away and were rushing around as I lay helpless watching this pandemonium. I wondered what was going on and if she was going to live or die. I felt myself surrealistically floating away from the familiar world I knew and entering into a new state of stress-producing concern for Bridget's survival. In just a matter of seconds everything turned upside down and there was no going back — ever.

Doctors and nurses were busy doing their urgent examinations on her. I heard Bridget's cry become angrier as they huddled over her. I could not see her and felt totally powerless to answer her cries as she was poked and prodded. It seemed an eternity that I lay waiting for someone to tell me what was happening to my baby.

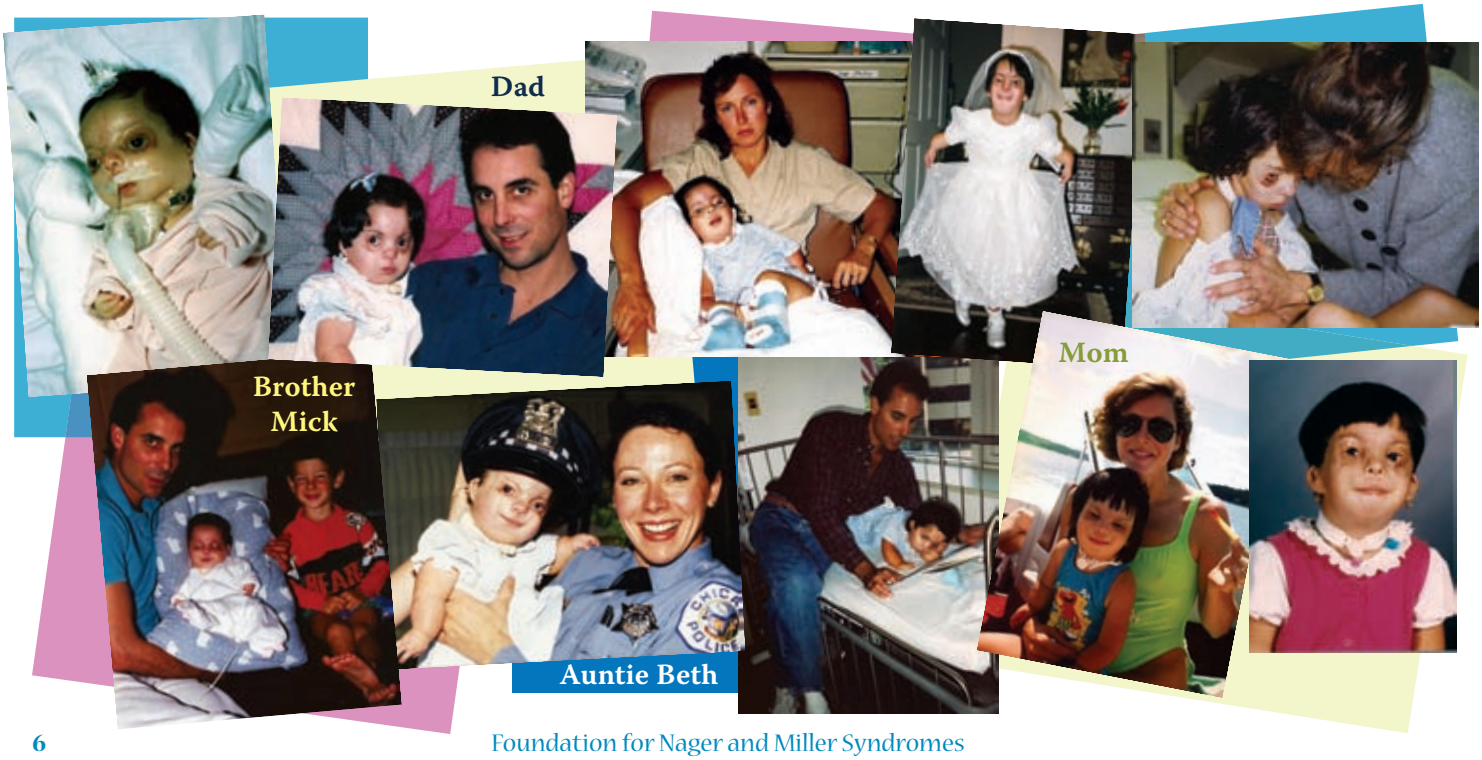
I was scared for her life and thought that if she was going to die I wanted to at least hold her. Maternal instincts kicked in and I managed to find my voice and said, "I want to hold my baby." They soon brought Bridget to me. I could finally see her up close now and saw her dark curly hair and big brown eyes. Our gaze met and that is when my tears began flowing uncontrollably.

We at least were finally able to make our connection with each other and bonded instantly. Through my tears I managed to force the words out and said, "Bridget, we love you," and I kissed her head. I felt her calming and she soon stopped crying. She was responding to being soothed and comforted. Her response gave me what I needed most at that moment … the mightiest gift of wondrous *hope*.

When I had to give Bridget back to the nurse I was able to do so with a bit of hope now for her survival. Perhaps our embrace also gave Bridget just enough hope to help her get through. Her future would depend on her receiving life-saving medical care and for us to provide her with an abundance of love. It was that love and hope that would carry us all through Bridget's 20-plus surgeries.

What I really needed was to be put in touch with another parent who had experienced the same feelings of confusion, loss, fear, despair, isolation, uncertainty and heartache.

An hour or two later that day, the neonatologist brought a weighty genetics journal to my bedside. Upon opening it to a certain page she enthusiastically remarked, "This is what we think it is!" This doctor had just



found the needle in the genetic haystack. I looked over the side of my bed at this book and saw medical terminology as foreign to me as hieroglyphics. The page was filled with unpronounceable words, like "postaxial acrofacial dysostosis", "micrognathia", "colobomas", "malar hypoplasia" … and the list went on. What I really needed was to be put in touch with another parent who had experienced the same feelings of confusion, loss, fear, despair, isolation, uncertainty and heartache. I would have clung to any words of encouragement. I had so many questions about the quality of life if Bridget survived. Receiving support would have spared me lots of worry and made the greatest emotional difference to me. At one point I wished to escape with Bridget to a deserted island to protect her from a lifetime of pain and cruel ridicule.

Bridget was finally discharged from the hospital after 3 months and three surgeries. We were overjoyed to get her home. She had 24-hour nursing care there, life-saving medical equipment, a tracheotomy for a secure airway to breathe through and a stomach feeding tube to receive nutrition. Bridget's bedroom looked like a hospital room, but we adjusted as well as possible to our next phase of life.

During this time we had been searching for others with Miller syndrome. This was not an easy search since we were told Bridget was one of twelve in the world with Miller syndrome. Computers were not common then, so there was no quick Internet search either.

It was exhilarating seeing something so positive happening around this syndrome, all while filling a huge void for us struggling parents.

We wrote to geneticists who authored articles in journals about their patients with Miller syndrome. We asked these geneticists to put us in touch with their patients, and, when permission was granted, we were able to contact our very first family with Miller syndrome.

Debbie Madsen lived in Utah and had two children with Miller syndrome. Today she is still my hero. Finding her felt like the greatest discovery in all of history and I did not want to get off the phone with her. And Debbie knew of a family in New Zealand, who knew of a family in England, also with Miller syndrome. We were not alone! I was thrilled to learn of others and eagerly started writing and exchanging photos with them. These communications proved invaluable and their benefits immeasurable. I couldn't get enough letters or photos! It was exhilarating seeing something so positive happening around this syndrome, all while filling a huge void for us struggling parents.

Families with Nager syndrome joined up in our correspondence, too, since the characteristics and challenges of Nager are so like Miller syndrome. Our collection of shared information and experiences improved the quality of our lives. We gained strength and knowledge as we navigated together this uncharted territory.

This is basically the evolution how this humble, parent-run volunteer group began. Caring parents are still the backbone of FNMS. Like the movie title, we "Pay It Forward". No employee salaries are paid to anyone to do all this wonderful work — it comes from our true blue (hence, the FNMS logo) hearts.

Hope, love and perseverance brought Bridget and FNMS their successes thus far. Through a series of sweet little victories, both have gone from *surviving to thriving*!

The credit for FNMS's current success goes to Jackson's mom, DeDe Van Quill, our dynamic director, and Tinka's mom, Leslie Gaffney, who works tirelessly on our newsletter and has made it a professional-quality publication.

Many of you reading this — including our families, concerned health professionals, research staff , and our caring communities made up of businesses, schools, neighbors, friends, generous supporters and dedicated volunteers — also deserve much credit and thanks for bringing FNMS to its 20-year anniversary. *Congratulations — we did it!*

Margaret Hogan
FNMS Founder

20 Years of Making Memories

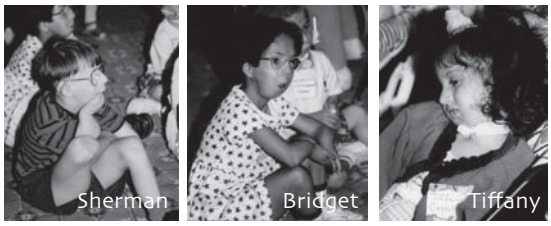
FNMS

Having the Foundation for Nager and Miller Syndromes has added great value to our lives through the years. Meeting parents and children affected with these challenging syndromes connects us with other people facing some of the same problems we face. We know we're not alone in this big world. Having the avenues to stay connected through meeting in a new city and having fun together, reading the newsletters, visiting the website and having contact information to make calls when support is needed is invaluable. Heather, Logan and I always look forward to attending the conferences when the funds in the foundation make it possible. Seeing Heather and Logan enjoy the connection of being with other people like them, a commonly enjoyed reality for typical people, brings joy to my soul. Thank you for starting the foundation Margaret. Thank you for stepping in when Margaret needed to give her attention to other areas DeDe. Thank you to everyone who has donated money, items, time, activities and ideas to make and keep FNMS a reality in our lives.

Happy 20th anniversary FNMS!
Debbie Jorde, Heather Madsen and Logan Madsen
Salt Lake City, Utah

Our very first ever FNMS fundraiser only happened and was a success because of the generosity and love of Karen and Phil Stefani. They closed their popular Chicago restaurant and donated all the food and booze that night. We raised $80,000. Not bad for rookies!

1996



Kids at the very first FNMS conference in Chicago.

1998

The Konowalchuk family graciously hosted the 1998 FNMS conference in Vancouver, Canada.

Former Chicago Bear and Chicago Sportscaster Johnny Morris and wife Kery chose FNMS as their favorite charity at the WBBM-TV Celebrity Golf Shoot Out at Kemper Lakes. FNMS received a "big check" for $7500!

Congratulations FNMS on your 20th anniversary! Thank you for many years of invaluable support and for creating a network of so many wonderful people that have encouraged, strengthened and touched our lives in many wonderful ways.

Our son Kelson is now 15 years old with Nager syndrome and has undergone over 22 surgeries, lengthy hospital stays, periods of isolation and long-term recoveries as well as a variety of therapies to help him speak, eat, listen and develop his gross and fine motor skills. The list goes on and on.

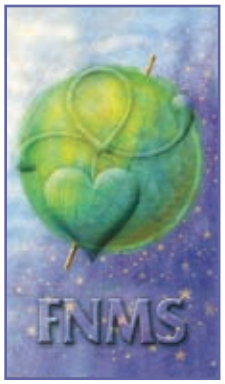
Through all of this we have never been alone and we always had a friend or family member from FMNS to lean on. This organization may be small — as our syndromes are so rare — but the scope and magnitude of the families and children that have been supported is so big in that it has reached out to families and united us across the globe.

Thank you for believing in all of us! We have definitely been riding the road less traveled since giving birth to Kelson, but it has been the most interesting journey traveling it with each and every one of you.

With special thanks to Margaret and Bridget, for without them FNMS would not be what it is today.

Karen, Alex, Kaedin and Kelson Konowalchuk
Vancouver, BC, Canada

Bridget and I pictured with Cher at the CCA conference in Denver. Cher was so generous with her time, allowing for these photos to be taken. She danced with all the kids, and it was such fun seeing everyone forget their troubles and differences out there on the dance floor that night.

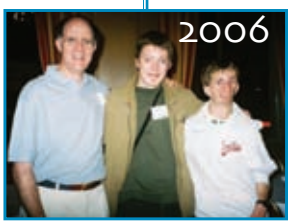


2002

Fundraiser invitation cover and business card design.

Thank you Margaret for your vision, labor of love and leadership which became FNMS. You have provided a forum for communication and support for both the children and their families, giving hope and encouragement to all. We have been blessed to be part of this wonderful organization

The Myall Family
Redwood City, California



Top, Nathaniel Myall with his sister Meredith at the 1994 FNMS conference. Below, the Myall family hosted the spectacular 2006 FNMS conference in San Francisco. Logan Madsen (center) catches up with Greg and Nathaniel Myall.

David, Jackson and Julia at the 2004 FNMS conference at the Flying L Ranch in Bandera, Texas.

Bridget and Margaret visiting new FNMS member family Ireland and Amy Reed in 2004. A recent photo of Ireland, below.

Ireland is 6 years old now, started kindergarten a few weeks ago, loving each new day with her new friends and teachers. It took many weeks negotiating with the school district and their part in meeting Ireland's needs academically and medically was a struggle, but with much perseverance we finally got everything settled. Ireland has totally amazed the teachers and therapists with how smart she is. We have learned over the years that people have attendence to judge Ireland by how she looks. Since the day she was born, however, she has written her own book and will continue to amaze many people of what she holds inside, revealing each day a new surprise and accomplishment as so many of the other Miller syndrome kids have done.

This past year has been the first year where Ireland did not have any surgeries. As her orthopedic surgeon worded it, it was time for a year off for Ireland to "just be a kid" — to grow and develop. What wonderful news that was to our ears as you all well know.

This year has been an amazing year for Ireland, she has been pretty healthy, less hospitalizations for respiratory bugs. She loves being outside, helping mommy plant the flowers in the summertime and pushing her little lawn mower while she scoots on her scooter board following behind daddy with the big lawn mower. Each year, Ireland has seem to have one BIG accomplishment, although probably more little ones throughout the year, but usually one BIG one that brings tears of joy and happiness to mommy and daddy's eyes. This year Ireland learned how to pedal her tricycle all by herself! Yes, it is amazing! After her reconstruction surgeries on her legs in Baltimore, Maryland, in November 2007 and February 2008, this is an awesome accomplishment. For those of you who do not know Ireland, she was born without fibulas in her lower legs, so she has been unable to bear weight on her legs to walk until after these surgeries. She has always scooted around on her bottom. With the surgeries her right leg is pretty straight and bearing great weight. As far as the left leg (for Ireland her left side of her body has seemed to have been affected more by the syndrome with more deformity), it had to have more extensive surgery on her left knee and lower leg. There were some complications and some setbacks, but with intense therapy that leg is getting stronger. For now, Ireland is trying to bear weight on both legs with the help of a walker. But she is a determined little girl with no doubt in her mind she will walk one day. Hopefully one day sooner than later.

Ireland along with the other kids with Miller syndrome continue to amaze each one of us whose lives are touched by some special kids who have more determination and courage that allow us to see that believing in the impossible is what life is all about.

Amy, Bryan and Ireland Reed
Cincinnati, Ohio

Passing the torch to a new director in 2003

by Margaret Hogan

Our heartfelt thanks to DeDe Van Quill, who courageously stepped forward to volunteer to take over the directorship of FNMS in 2003. Friends asked me during that time if it was hard to let go after so many years and allow someone else control over FNMS. In answer, it was not hard at all, because I had complete faith in DeDe. I observed her strong leadership quality, delightful sense of humor, a great business ethic, was very organized, and had much more computer knowledge than I ever did. She came along like a guardian angel who breathed new life and ideas into FNMS when I could no longer sustain the demands or growth by myself.

Margaret and Bridget pose with Peyton and DeDe at the 2008 CCA/FNMS conference in Myrtle Beach, South Carolina.

I think Dede demands a lot of herself and has high standards, and we at FNMS benefit from that type of director. She continually offers new perspectives and approaches to matters that I am grateful for.

It's a little-known joke that DeDe has the worst of luck with electronics and air travel and yet never gives up! That tenacity, along with the above mentioned qualities, is why I feel 100% pleased and thankful that what I humbly started 20 years ago is in the most capable hands possible. Her only fault is that she is too humble! DeDe is married, has three kids, has a real job outside of FNMS, rescues big dogs, hosts family holidays, plans international family conferences, all while managing to look like a runway model! Also, my thanks especially to Ryan, Peyton, Paris and Jack for sharing her with all of us at FNMS. Last, but not least, the most important reason DeDe is such an effective director is that she cares — and she even does that very well, too.

FNMS Yearbook

Following are recent updates from a handful of our members around the world. We hope to hear from more members in time for the next issue!

Maria-Nefeli Athanasiou: Difficult to sum up our updates in a paragraph, especially when pretty much everything has changed in our lives! My baby girl is no longer a baby. She is a teenager with the reputation that goes with the name. Maria is turning 11 this February and I'm starting to believe that it is only a matter of time before she announces that she's dropping out of school to backpack in Europe. We certainly did our best to empower our little girl, but I honestly believe that we might have overdone it as sometimes she is more self-confident than her actual age allows her to be. She is always a genuinely affective person and we highly value this quality of hers; she is always thinking of every possible way to be the center of attention and we involuntarily tolerate this vagary of hers and she is always very difficult to find when it comes to doing her homework, which is something that we've simply learnt to live with over the years! As for how well she's handling her differences, well I would just say that some days are worse than others. When these days come we try to focus on the good things that happen in our lives and most of the times it works. When it doesn't we all have these days mentioned above when Maria is troubled and I stubbornly refuse to accept for my little girl that being sad sometimes is only part of being human after all. What's more, Maria has been learning to share her mommy with my husband of over a year. He is a coordinator for the institution for children with disabilities where we met and where I met Maria 8 years ago. Last but not least Maria is about to learn how to share mommy's love with her little sister Chloe, whom we're expecting. Maria is absolutely ecstatic at the idea of finally getting the present she's being asking for years, a little baby sister. Happy 20th anniversary to FNMS, which has been a blessing to the lives of all of us.


Maria, Greece

Dylan Baker: Dylan turns 5 years old in December, he's been through two jaw distractions and is currently eating soft foods (e.g., ice cream, pudding, Gerber baby snacks, pureed yams, mashed potatos, etc.), he drinks his 8 ounce can of milk throughout the day and gets tube fed only at night. He continues to fight off germs cycling Tobramycin nebulized treatments on and off cycles. Dylan loves school (he gets to go on a school bus) and he is anticipating a trip to Arizona to visit his grandparents for the holidays. We tell everyone that Dylan is your typical 4-and-a-half year old with just a few extra accessories. He is proud to assist in all his tracheostomy and g-tube care, and is actually very protective of his trach tube. We found that Dylan's upper extremities are abnormal and will eventually require surgery when he gets into his teens, and that his ROM on the left ankle is abnormal and the bones in his toes on both feet are also abnormal, leading to some mild discomfort after walking for long periods of time. At this point in time we are just watching and seeing how Dylan is growing and enjoying life. We as a family try to lead as normal a life as possible for all of us. Dylan currently is very interested in Transformers and dinosaurs. He loves animals and plays with all our pets regularly. We are very proud of Dylan and how far he has come. We do so often turn to the Nager and Miller Foundation website to try to stay informed. We hope all is well with all the other families out there who are as courageous as our Dylan.


Dylan, Rhode Island

Julia Bednarek: Julia goes to a school for handicapped children and is in the 6th grade. Her hobbies include painting, reading and making herself beautiful. She's also had several operations over the years, including an operation to get screws implanted for the BAHA when she was 4 years old. Since that surgery she has had a chronic problem with infection at the surgery site. I believe she may be allergic to the titanium screws, but the doctors don't agree. We will investigate that possibility more next year. For now, I just hope that it will be over someday because Julia has a lot of pain from this.


Julia, Germany

Saul Beranek: Saul turned 5 years old in June and is really becoming a big kid. He attends preschool 3 days a week at our local elementary school. He also goes to school the other two afternoons of the week to work on his physical, occupational and speech therapies. He really likes school and everyone there seems to know his name! The biggest events in his life lately have been getting glasses and being diagnosed as having multiple food sensitivities. He has a coloboma of his left iris and that caused astigmatism in that eye. He was very excited that he needed glasses and right away said he wanted "rock star" glasses with guitars on them. We didn't find frames like that, but he settled on a pair with stars on the bows. We're just starting the new challenge of his food sensitivities, so Saul will have many appointments and dietary changes to look forward to. Saul's favorite things to do are playing with cars, vacuuming, going to the pool, goofing around with his three older siblings and rocking out to a good song.


Saul, Wisconsin

Michele Biasini: Michele is 7 years old and has a tracheostomy. We are not anticipating any surgeries in the near future. However, the first and most important problem is that Michele doesn't open his mouth very well and the doctors want to do surgery when he is about 14–15 years old. He currently has an opening of 15 mm and his diet is soft foods or "food milkshakes". Michele is in the first year of primary school and his favorite subjects are Science and English, because his aunt lives in Baltimore and works at John Hopkins Hospital and he wants to visit her when he is older. He likes to fish for trout in the pond and play with radio-controlled cars. He likes playing with his sister Sara, especially on the swing. We have a dog, named Kimba, that he often takes for walks.

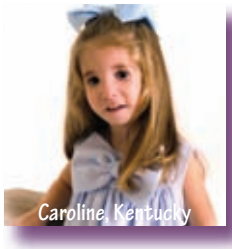

Michele, Italy

Lucas Bueno: Hi, my name is Lucas and I am 10 years old. I'm in fourth grade at Emerald Coast Christian School. Now I live in Florida, very close to the beautiful, white, snowy colored beaches. I like the beach, but my favorite thing that I do right now is take care of a horse named Elvis. Every Sunday I get to ride Elvis after I help groom him and clean four stalls. I rode last Sunday on Elvis and flat walked (a little like trotting). It was very fast and fun. It wasn't even bumpy! Here's a little about myself. I was born with a very serious syndrome called Nager Syndrome. I needed a trach so I could breathe better. I also needed hearing aids and a g-tube for eating. But I didn't need any artificial thumbs or hand surgeries, because I can do everything with my four fingers! I did have many surgeries. After I had a distraction on my jaw when I was one and a half, I was able to take my trach out. But I still had a hole in my neck that wouldn't close. When I was four and a half, I got my trach stoma closed and now I breathe without my trach. I also am able to eat all of my food by my mouth. Eating by mouth is good exercise for stretching my jaw, and I love eating so much. I still have a g-tube, just in case, but I never get Pediasure in my g-tube anymore. I know that God has been watching over me and my family. If there are any little babies that have Nager Syndrome right now, just remember that God loves them, too. Soon they will be big just like me!

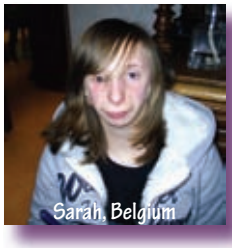

Lucas, Florida

Caroline Carwile: Caroline celebrated her third birthday in September. The year between Caroline's second and third birthdays has been quite eventful. After her second birthday, Caroline was able to remove her g-tube, which was a huge victory for all of us. Another high point of the year has been Caroline's preschool experience. She is attending a traditional private preschool 3 days a week. Caroline is the youngest in her class and has shown no delay behind her peers beyond speech articulation. In fact, her teachers say she is the best scissor cutter in her

class! Three years ago in the NICU I wouldn't have believed that possible. Caroline also attends a university preschool with a speech focus 1 day a week and is in individual speech therapy 4–5 times a week, so she has a very busy schedule. Caroline has also had a couple of low spots this year. Caroline's hearing in her right ear changed from normal to a moderate conductive loss, so she began wearing an aid on that ear. We, of course, were initially sad for the change, but she has done great with her aid and her speech and language are continuing to develop. Caroline was also the first of our four children to break a bone — she broke her elbow in September after falling off an ottoman. Never a dull moment! Caroline's personality has really blossomed this year, and it has been a joy to watch some of our hopes and dreams for her to become a reality. I love to watch Caroline eat and listen to her talk — things I don't take for granted in the way I did with her older brother and two sisters. Caroline is crazy about swimming and dancing, and can't wait to start taking dance classes like her sisters.


Caroline, Kentucky

Sarah De Cubber: I am writing to you from Belgium. Our Sarah is now 17 years old and was diagnosed with a mild form of Nager Syndrome when she was 1.5 years old. She is 60% deaf and has no smell. In those days not much was known about the syndrome in Europe, so it took the University Hospital Ghent, where she is still being treated, quite some time to make the correct diagnosis. Thanks to the Internet, which was still in its early stages in 1992, they were able to do that. Sarah also suffers from a mild form of epilepsy and fairly recently from hyperventilation. We don't believe these issues are related to her syndrome. Otherwise Sarah is doing great! She is studying to become a nurse in a child-care center. She went to a special school for children with hearing problems for several years. A few years ago, however, she had surgery to implant the BAHA hearing device and now she goes to a regular school. She has a dog, Aiko, that she is very fond of and in general she is very fond of all animals, which she nurtures with a lot of dedication and love. She has several cats and a rabbit. She's also taken horseback riding lessons since she was 2 years old. Sarah works in a bakery in our small village every Sunday where she prepares the pastries. She has a very down-to-earth and caring personality and is loved by everyone. She has many friends in school, too.


Sarah, Belgium

Anna Franklin: The last year has been very busy for Anna, but full of exciting developments. In April Anna had her right hand pollicization surgery to follow her equally successful left hand operation from the previous year. Now, with two great hands, she can feed herself, zip zippers, brush her baby doll's hair and color beautiful masterpieces (unfortunately many are on the walls). Last July Anna completed the Richmond Children's Hospital's feeding program and went from being almost completely g-tube dependent to 100% oral fed. It is a huge accomplishment for Anna and we are so proud of her hard work. This program truly changed her life (read her story on page 18)! Since graduation Anna has come out of her shell tremendously and has become our funny comedienne, always trying to make people laugh and bring a smile to everyone's face. She loves music and dancing and has just mastered jumping with both feet, which she is quite delighted with when she's not busy climbing on all the furniture. Anna turned 2 years old in August and is set to start preschool in January and will receive speech therapy, occupational therapy, physical therapy and a hearing impaired instructor. Although Anna hears very well with the BAHA hearing aid she received last December, we have decided to work with a hearing impaired instructor to further strengthen Anna's ability to communicate. The sign language she currently knows along with her developing speech has given her a way to express just how smart and funny she is. We are enjoying watching Anna grow into an incredible little girl and can't wait to see what lies ahead for her in the coming year!


Anna, Virginia

Tinka Gaffney: This past year has been intense on the surgery front for Tinka, who will be 7 years old in January. We traveled out-of-state for two surgeries, and now we are on an equally intense regimen of speech and physical therapy that will continue indefinitely. Tinka generally stays healthy throughout the year but battles with chronic ear infections. Although she has had a difficult year you wouldn't know it from her. She is happy and playful — a constant joker. She loves school and is an excellent student. She loves to read and is into chapter books, detective stories and magic. She loves to play and "make things", including her own "inventions" that are often aimed at solving her mother's work and housekeeping dilemmas. She loves her friends and TV almost equally. She dislikes hospitals and she dreads having to get anesthesia (or "sleep medicine" as she refers to it). And she's as sweet as she is a dickens, but what 6-year-old isn't.


Tinka, Massachusetts

David Gonzalez: Last month David went to Vancouver, Canada, to an International Piano Festival for people with disabilities where he won the Junior Gold Prize in the competition — First Place! He played the piano with his father. He is so happy of this achievement and now he is invited to play at the winners' concert in Tokyo, Japan, in December 2009. He is 12 years old now and we are very proud to know that he is a very secure boy who does not see obstacles in life. And this is due to all the people who have supported him over the years. The first FNMS meeting we attended was also in Vancouver — such a good memory.


David, Mexico

Theo De Heer: Theo is now a happy, mischievous 2-and-a-half year old who has lots of smiles for everyone in his family, especially his new little brother Codie. He has had a quiet year for surgeries in the last year since his second distraction using internal distractors. Unfortunately there was not enough movement in his jaw to achieve decannulation, so we are now waiting to hear when his next distraction will be — sometime before March 2010. He has also recently met a hand specialist who is going to try and reconstruct his left hand first, separating the two fused bones in his hand (thumb and index finger) to create more use in his thumb, which has limited movement now. If this is successful we may decide to do the same on his right hand. Theo is also going to have his BAHA abutment attached in the next 6 months to the mastoid bone behind his ear. He has perfect hearing with the BAHA on the soft band and hates not having his aid on — he knows he is missing out on so much when it is not on. Our stubborn little boy even fights us every night because he wants to wear it in the bath and he insists on going to sleep with it on! So it's going to be a very busy time with surgeries for Theo, something that he fights and hates but recovers from in record time. He is growing well, keeping up with all his milestones, and is communicating so well using New Zealand Sign Language. We are so proud of our brave little guy and are blessed to watch him grow and change and learn.


Theo, New Zealand

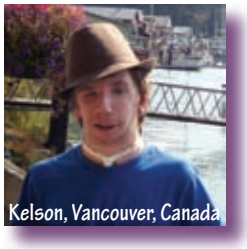
Bridget Ieronimo: Everyone wonders if us kids will be able to get our drivers' license. I can happily say that I did! I took drivers' education when I was 16 years old but really didn't have an interest in driving then, so I waited until I was 19 to take the test and passed it the first time. A few months later I got my car. I have a black Saturn VUE with no adaption's needed. Now I enjoy driving around town and going to friend's houses without having to depend anyone else to get me there. I also had my braces finally taken off my top teeth after having them on for about a year. At first I was against getting braces, but when I finally had them taken off and saw the difference in my teeth, I was happy I did it. Now I find it a lot easier to brush my teeth since they've been straightened. Over the summer I went on two road trips. One trip was with my dad to visit my brother in Colorado, who just graduated from


Bridget, Illinois

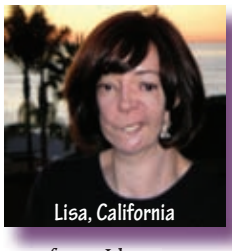
college. On our drive out there we I stopped in St. Louis to see the arch, then to Pikes Peak, and to the Royal Gorge. Another trip I took was with my mom to our house near Asheville, North Carolina. While there, we drove to the biggest pottery town, called Sea Grove, so we could visit lots of galleries and get inspired by the beautiful ceramic works of art. After the summer it was time for me start my sophomore year at college. I am going to a community college not far from home. Right now I'm taking art history, math and psychology. I'm still not completely sure on what I would like to study, but I think I may want to pursue psychology or something in the arts. Outside of these big events I still love doing ceramics, playing tennis and spending time with our 5-month-old Labrador puppy named Buck.


MacKenzie, Alberta, Canada

MacKenzie Kehler: MacKenzie is currently 12 years old and is happy, healthy and enjoying life. His favorite activities include playing PlayStation, and watching every sport imaginable on TV — hockey and Nascar top the list. He is in grade 7 at the local middle school, participating fully in a regular classroom. Mac is still dependent on his trach for breathing at night and his g-tube for feeding. Mackenzie has been surgery free for many years. His last surgeries took place when he was 5 years old and included: a tendon transfer in his right foot, the mounting of a bone-anchored hearing aid (BAHA), and a mandibular jaw distraction. The doctors have been discussing Mackenzie's future surgeries, which will include another distraction and orthodontic work. Mackenzie was just recently granted a wish with the Rainbow Society of Alberta. He had many wonderful ideas on his list, including meeting Sidney Crosby (of the Pittsburgh Penguins), attending a Nascar race, and seeing inside a space shuttle. The wish that the society chose to grant him was the construction of a custom-designed bicycle to meet his special needs. Once the snow disappears we hope to see Mackenzie pedaling away on the local bike paths!

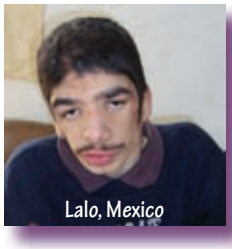

Kelson, Vancouver, Canada

Kelson Konowalchuk: Kelson is a well adjusted 15 year old from Vancouver, Canada. To date he has undergone 22 surgeries and will need more to correct his jaw and also repair a deviated septum. We feel very optimistic that one day he will get decannulated as he has had a trach since he was 5 months old. But, for now, Kelson keeps very busy with a small but wonderful group of friends. He is very creative and loves to play his guitar, watch his favorite hockey team, "The Vancouver Canucks", read lots of books, tell very funny jokes, sculpt, design video games, and hang out with his mom, dad and younger brother Kaedin. He is wonderful teenager who, despite his long list of medical issues, makes the most of each day, enjoys life and is very thankful for the friends and connections he has made through FNMS.


Lisa, California

Lisa Stansfield-Lakritz: Eighteen years have passed since I first learned of FNMS. In 1991 I spent the summer working in San Francisco before graduating from college. There I met five families, each affected by Nager syndrome. The children ranged in age from 4–12 years of age. I have had the opportunity to watch many of these children grow up to become independent and productive adults. I have moved on as well. I became an occupational therapist specializing in adolescence and young adulthood. I have been married 6 years and live in San Diego, California. Life has been good.

Luis "Lalo" Lapham: Lalo is doing well. He went to school here in Mexico, but never more than kindergarten because he never advanced more than that. He's had therapies for a long time trying to help him do things on his own, however, he still needs a lot of help from us. It was difficult to accept his condition for my husband and myself. He is the only FNMS child I have seen that, besides having Nager syndrome, has mental retardation, convulsive syndrome and autism. As a family we have done our best for him. Lalo doesn't work, but he has been a master and an angel for myself and my family by putting us with people and in situations where we grow and learn in a spiritual way. This is his job.


Lalo, Mexico

Claire Leon: Clara (previously known as Claire), age 24, is now living in Lyon, France! She is working this year as an English language teaching assistant in the French elementary schools. She loves Lyon (she spent a year there during college on a study abroad program) and would like to live there permanently. She hopes to attend graduate school there next year, working on a master's degree in international communication or translation (the current job is a one-year position). Clara graduated in June 2009 from the University of Oregon with a double major in Comparative Literature and French. In addition to being named to Phi Beta Kappa, she was selected as one of the 2009 Oregon Six — the six most outstanding graduating seniors — from a class of nearly 4000 students. Clara is totally fluent in French, nearly fluent in Russian and is now learning Romanian. She has a certificate to teach English as a foreign language and hopes to work in tourism or as a teacher or translator.


Claire, France

Sarah Leone: I was born with Nager syndrome and am 25 years old. Since graduating from high school I went to art college for a year in Ohio (Columbus College of Art & Design), then a year or so later I went to a 16-week graphic and web design school that was closer to home called Goodbrain Academy of Web and Graphic Design. In late 2006 I decided to start my own art business. I started out selling custom-designed Christmas cards and have since branched out to other occasions of greeting cards. I also plan on doing other art-related things besides greeting cards in the future. Last year, Sierra Adoptions from California chose my design to be used as their 2008 Christmas card to send to their clients (or people who have adopted through them). That was the biggest order I have ever received from one person or one group or one company ... so far. This year I will have my website fully up and running (in that, everyone can finally order online and easily get in touch with me online: http://www.sarahleone.com/). Besides greeting cards I also do freelance stuff. My interests are animations, movies, illustrating, drawing, reading, writing and much more. I am still currently living in Nottingham, New Hampshire, with my parents but am aiming to move out at some point.

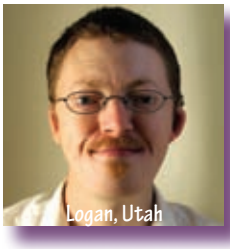

Sarah, New Hampshire

Heather Madsen: I'm Heather Madsen and I'm 32 years old. I spend my evenings and weekends with my life partner, Rubin. We live in a nice apartment in a community with beautiful trees and ponds. Writing brings me satisfaction, joy and peace. I've had some of my writings published in the Art Access Gallery publication "Desert Wanderings". Art Access also recently spotlighted me in their newsletter. Seeing expressions from my heart in print brings me joy because I'm sharing myself. I'm assisting my mother in writing a book about how accepting life's challenges makes them easier. Our goal is to have our book published in 2010. Through being autistic, looking and being different, having sickness, and through being fascinated by everything and having a desire to learn, I am learning about the connection between people as well as who I am as an individual. Living with disabilities and lung disease and accepting the challenges these bring helps me pay more attention to what is most important to me. I love to write because writing is teaching. My passion is teaching about autism. I am arranging meetings to teach some of my mother's customers who are parents and grandparents of children with autism about all the different characteristics of the condition.

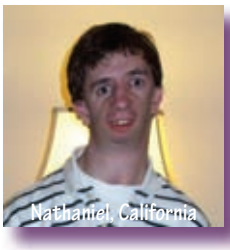

Heather, Utah

Logan Madsen: I am a self-employed, 29-year-old artist working from my art studio located in my apartment. I live with my best friend, Charlie — my little dog who is part Chihuahua. Living with multiple disabilities is certainly challenging. Through accepting these challenges — by focusing on what I can do something about and trying not to focus on

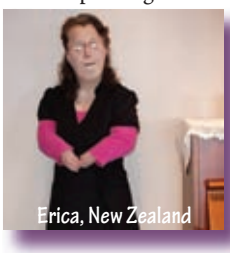
the things I can't change — I'm able to awaken each morning looking forward to painting, taking care of my dog, and taking care of my physical and emotional needs. I use my creative talents to modify items manufactured for people with typical bodies so I can use these items more effectively to avoid back pain. I have fun sawing, gluing, taping, bending and hammering together many materials to achieve my goal. Currently I am working with oil paints on a commissioned piece for a customer who is a designer; he is excited about selling my art and telling people about me. I've found peace and contentment while alone because I know myself better and now know what kinds of personalities I enjoy being around. I'm working on creating avenues to meet new friends and a possible partner.


Logan, Utah

Nathaniel Myall: Nathaniel is 26 years old and currently in his third-year of medical school at Stanford University. He delayed the start of school this past summer to undergo his first craniofacial surgery, which was performed by Dr. Stephen Schendel at Stanford Hospital. The surgery involved releasing the bone in the lower jaw from the base of the skull and forming a new joint, extracting some teeth and moving his tongue forward. Before the surgery Nathaniel's oral opening was 4 mm and it is now 33 mm. Nathaniel recently traveled to Boston and attended a medical college conference where he participated in a panel discussion focusing on medical students with disabilities.


Nathaniel, California

Erica Perry: Hi, my name is Erica Perry and I am 24 years old and have Miller syndrome. I also live in New Zealand. I just got my full drivers' license, which means I can now drive at all times and have passengers in my car with me while I am driving. I am just about to finish my study of business administration and computing Level 3. I completed Level 2 last year. I think it's amazing to have been a part of FNMS now for 20 years — we can do anything we put our minds to. We have courage, love and attitude, and most of all we have each other!

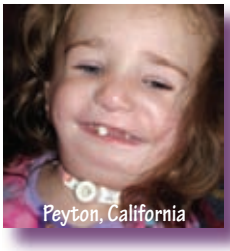

Erica, New Zealand

Monica Quinn: I am thrilled to let you all know what I'm doing now since we last spent time together at the FNMS 2006 conference in San Francisco. What a blast we had then! I am 30 years old and currently work as a clerical associate at the Rebuilding Alliance in Palo Alto, California. It's my fourth year and I try to do an amazing job there 4 days a week. Our local nonprofit rebuilds war-torn communities in the Middle East and my job is to process all incoming donations. I also organize and speak, with the help of my boss, at Rotary Club meetings in the Bay Area to tell folks about our work. For the past couple weeks I have been learning to commute by train from my home in Burlingame to Palo Alto. I want to have more independence, so I look forward to doing this on my own pretty soon. My major surgeries are basically over, but I still need dental work every now and then. I am glad I don't need to be in the hospital that much anymore. I also just became an aunt this week! It's quite remarkable how far we have come, despite our challenges.


Monica, California

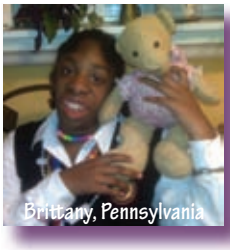
Kolton Ryba: I am 7 years old and live in Lincoln, Nebraska. I was diagnosed with Nager syndrome when I was 1 day old. I have had the opportunity to explore many different states, and doctors, to help me in my journey. This past summer I spent almost 6 weeks in Texas having jaw reconstructive surgery. In my spare time I like to play the Wii and play with my two dogs.

Peyton Smith: Hi, I'm Peyton Smith and I turned 2 years old in August. Like most 2 year olds, I am exploring and getting into lots of trouble around the house! There were a lot of firsts in the last year: I learned to walk, crawl and climb stairs. My parents are becoming more adventurous with me so I experienced a lot of new things. I went on a carousel, a pony ride and a train ride. Although I am an excellent signer (200+ right now), I have decided I want to start talking, too. My parents are excited to hear me starting to say my first words and laugh by occluding my trach or wearing a speaking valve. I had one hand surgery this year but my cast didn't slow me down a bit! I love to swing, slide and run after my two dachshunds. I am also a Signing Time and Elmo's World fanatic! This next year is going to be really exciting as I have surgery on my jaw and my hand coming up in 2010. My parents are going to be working with me on potty training because next summer I will be starting preschool. I blog daily about my progress so check me out at www.peytonsparents.blogspot.com!

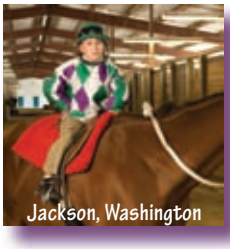

Peyton, California


Kolton, Nebraska

Brittany Stevens: FNMS became a part of our lives when Brittany was 5 years old. I was told she had Nager syndrome by a medical professional who didn't have much information. After contacting NORD my family was blessed to speak with and meet Margaret Ieronimo, her wonderful family, and a host of other unique families who understood "our world". Today Brittany is a 19-year-old junior at Northeast High School in Philadelphia. She has grown socially and academically in the Life Skills Program at this progressive, urban high school. She has also been blessed to attend Variety Club Camp and Developmental Center the past 8 years. This overnight camp has also helped Britt grow into the awesome young lady she is today! Her infectious laugh and loving spirit bring joy and happiness to all who know her. In addition, she is surrounded by a large, supportive family who helped her get through 28 surgeries. Her protective brother Quinn is her biggest fan, always making sure she is treated well! Finally, as the mother of this remarkable young woman, my life has been enriched via Miss Brittany in ways that have made me a better parent, better high school counselor, and knowledgeable, patient person. And our faith in God has helped us through many trying medical challenges over the years. Thank you FNMS and continue to share our beautiful children with the world!


Brittany, Pennsylvania

Jackson Van Quill: Hi, my name is Jackson. I am 10 years old and am in the fourth grade. I was born with Miller syndrome. I used to have a g-tube but had it taken out a few years ago. I love to ride horses and rode from the time I was 1.5 years old until I was 6. But this year I got to have my picture taken on a retired race horse named Ozzie on the closing day of Horse Racing at Emerald Downs. I was nervous at first but it was a lot of fun. I also got to stay and watch the races that day. I have had about seven surgeries since I was born but have over 20 scars. My most recent surgery was done on both of my ankles and heels. The surgery was done a year ago but I am still not quite back to normal and had to miss the fall soccer season. I have been playing soccer since I was 3 years old but it started to cause problems with my knees and ankles. I have my own business, it is called Whack-A-Mole and I catch moles for my neighbors and friends. It is a nice little business that I hope will pay my way through college.


Jackson, Washington

Aiden Vrey: Aidan is doing very well and will be 11 years old on the 1st of December! How time has flown! He is in Grade 4 now and doing very well at school. He has a new hearing aid, the BAHA Divino, but still prefers the old Compact one. New technology is too "new" for him. The sound is so much clearer, so it's a huge adjustment for him, but we are getting there slowly. He is still not eating, only taking water by mouth in small amounts. He is still on the peg/Mickey feeds four times daily, but is in good health and gaining weight, textbook style. He is getting a bit shy and self-conscious, not wanting me to give his feeds in public, etc., but I am sure that's inevitable. As they get older they become more aware of how "different" they are. Aiden is an expert in Playstation games and loves building these huge Lego Star Wars structures with his four little fingers. Otherwise, he is an absolute angel!


Aiden, South Africa

Genève: A love story

by Carole Moreau
Quebec, Canada

How can I write Genève's life story in only a few paragraphs — an extraordinarily uncommon love story! I will try to relay the story of my not-quite 3-year-old little girl and the lives of her parents, even if, sometimes, words cannot express all the emotions involved.

First, you have to know that it took me 6 years to get pregnant. All those years of hoping and praying to have what is so *natural* in life — a baby. All the monthly failures were adding up, month by month, until 2005 when I finally became pregnant. But after 10 weeks of pregnancy I miscarried. We were so disappointed. I cried a lot and called my parents right away. My mother was crying on the phone and that stressed my father, who was already sick from his battle with scleroderma. He died the same weekend as my miscarriage.

It took me a year to become pregnant again, but I was so happy! I don't know why but my husband was scared that this time the baby might have health problems. It's like he knew what was coming for our baby. I told him that no matter what happened I would have this baby. The first 20 weeks were ripe with joy and happiness, beautiful summer vacation, no problems at all! I was the happiest woman in the world! We even listened the heartbeat of our baby and it was real — he or she was alive!

. . . I would give my baby girl the chance to be born and she would have to decide which way she wanted to go.

But the second part of my pregnancy was the most stressful period of my life at that time. When I had an ultrasound scan to check if everything was all right and to know the baby's sex, the radiologist stopped the video and said the baby had a problem — a diaphragmatic hernia. A surgeon later told us that our baby had only a 15% chance of surviving. It was a very big hernia: her stomach, bowels and liver passed through into her rib cage and occupied the place her left lung should. It also pushed her heart a little to the right, so her right lung didn't have enough space to be fully developed either. Doctors told us there were no links between the hernia and a possible syndrome after they made an amniocentesis exam.

From that day I had many exams of all kinds. I cried often, but it was clear in my mind that I would give my baby girl the chance to be born and she would have to decide which way she wanted to go.

I was anxious to give birth but was scared of my baby suffering … a strange feeling for a future mother. And speaking of mothers, I lost mine 5 days before giving birth. We knew she wouldn't survive much longer; her doctors said about 3–6 months. I was freaking out because when I became pregnant the first time I lost my father and now I would soon lose my mother only 2 years later. I remember saying to her that maybe she wouldn't see my baby and she used to tell me, "Are you crazy, for sure I will live when you give birth." But she didn't. I delivered the day after her funeral.

Genève came into the world on February 8th, at 36 weeks and 5 days, by a shortcut — she was delivered by emergency caesarean because her heartbeat was going down with every contraction. When I woke up from delivery a doctor told me that our baby was alive and that she weighed 3 pounds, 6 ounces. She was that little because of a problem in the umbilical cord. I was just opening my eyes when someone told me that my baby had Pierre Robin Sequence. What? She said that she had a recessed chin and also her ears were lower and her left eye, too. I thought these issues were only aesthetic concerns, I didn't knew that they would be a problem for Genève.

Genève was supposedly between life and death and the staff had already prepared the palliative department. Surprise! My little girl was a fighter. She decided to live and was stable enough to have her first surgery at 2 days old. Her surgeon, Dr. Sarah Bouchard, put her organs in the right place and put on a patch. She said she never saw a diaphragmatic hernia that big. The surgery took several hours and, finally, she saved her life. Day after day Genève was getting better and better!

Other than that the genetics team was in total darkness — the whole team was searching for a syndrome or something else. It took 6 endless weeks to finally know what was "wrong" with our baby — she had Nager syndrome. They said it was a mild case and no clear link with the diaphragmatic hernia … it was like 2-for-1 for us. They added: "Don't worry, it is not an illness, it's only a name that we put on what we see on her clinically."

We never imagined at that time that a jaw problem could affect the way she would talk, breathe and eat.

Genève has almost all the characteristics of Nager except both thumbs are functional (even though she doesn't have a joint near her nails) and she does not have a cleft palate.

My husband and I were not aware of health problems in either of our families so we were completely disconcerted. The first reaction is always: "Why did it happen to our baby?" In the beginning no one told us about all the problems that Genève would probably have because of her small jaw. None of the doctors knew about Nager; it appears to be the first case in our province. Of course, that knowledge did not make us feel very secure. We never imagined at that time that a jaw problem could affect the way she would talk, breathe and eat — things that are so normal they are taken for granted.

A couple days after giving birth a doctor told me it was possible that Genève had a problem with the optic nerve in her right eye. We were freaking out because it was adding to everything else. Finally, they decided her eye was okay. I lost so many hairs and pounds during those weeks. When people told me I was lucky to have a little waist I told them that I would have preferred to have my parents and a healthy baby next to me and have 100 pounds to lose.

It was also very painful to be informed that our baby couldn't hear us. I was shocked and didn't talk to Genève for a whole day — it was like I was paralyzed. The next day I spoke to her as though she could hear me and it helped me get closer to her. Finally, she started to hear us around 8 months old. What a joy! She had developed a visual way to compensate for her hearing loss, needing eye contact with everyone she met.

Genève had to stay in an incubator for almost 2 weeks and it took 3 weeks before I could hold my baby in my arms next to my heart. What a joy, even if I had to deal with all her tubes. She needed oxygen 24 hours a day until she was around 18 months old and during the night for another year.

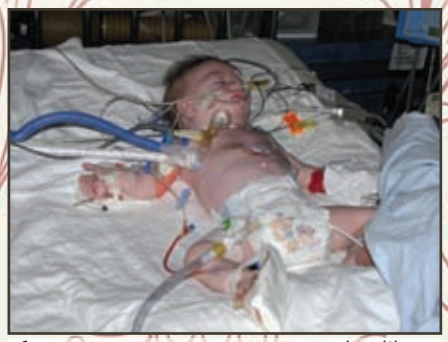
My baby has had so much blood taken during her life. Before she weighed 10 pounds they would take the blood from one of her heels, then from the end of her fingers. When she cried I would tell her, "Don't cry, it won't be long," and I would cry with her. It was so painful to watch my baby suffer, I would have wanted to have all her pain. Strangely she got used to it and didn't cry anymore by the time she was 1 year old, which is so odd in a way.

When she was 2.5 months old Geneve had another surgery that was supposed to help with her feeding. Her plastic surgeon cut Genève under her chin to release her "plancher buccal" muscle ("floor of the mouth"). She said that maybe after the surgery, Genève would drink her milk better because Genève tried to suck her bottle with a lot of effort and no significant results. Genève had to go to the intensive care and it was painful to watch her there. She was sulking at us —refusing to look at our face even at that age.

It took 4 months before we could take Genève home where she belonged. But at home my little girl wasn't gaining much weight. She threw up fairly often out of her nose, which was complicated because I had to change her oxygen tubes without taking her feeding tube away because it was in her nose, too. All of the tape would come off when she sweated … it was awful. Her nasogastric feeding tube came out a couple of times and I had to put it in again through her nose. Genève was crying, which made me upset and emotional to cause her pain. I was crying with her. It is not normal for a mother to do those things.

Genève was home 5 weeks and I barely slept during that time. My husband and I were so tired. We were irritable and impatient, the alarms would ring almost all night long — it was horrible, and we had no help from anyone. I remember my sister telling me that maybe Genève wasn't ready to leave the hospital. Maybe she was right, but it's so hard to be separated from your baby, the one you love more than yourself. I would give both my legs for her to get healthy.

We finally had to return her to the hospital because her lung specialist wanted to verify the reason for all the alarms during the night. That morning Genève started to have green/yellow reflux … very worrisome to see. The hospitalization was only supposed to be for a couple of days. I cried so much despite being so exhausted. After 2 days Genève's ENT informed us that she had a bowel occlusion because some stitches had dropped from her diaphragmatic patch. There were periods where Genève was suffering so much that she wasn't able to breathe; she was turning grey and blue. I felt so scared. So Genève had her third surgery when she was only 5 months old. They had so much trouble intubating her that when it was time to get her tube out after a few days they were scared because Genève's mouth was not opening enough. So they suggested we give her a tracheotomy. I was on my way to the hospital when her ENT called me on my cellular phone. It was another shock because nobody told us anything before about that possibility. Also, I didn't realize that she wouldn't be able to talk after it and all the infections that she would probably get because of it. When I was supposed to finally take my baby in my arms I still had to wait another 10 days. I remember that it was the most horrible time of my life and I was near a depression.



After surgery August 2007; we saw her like this too often her first 7 months of life.

Genève was in the hospital on my birthday, so I dressed her like she was my little gift.

How can a child learn to walk dragging this machine around?

The summer before she was averse to the texture of sand ... this summer she loved it.

October 2009 we went on a day trip to visit a lake — she loves water and nature!

That's not all, because 1 month later her stitches dropped again. When I heard the news I almost fell on the floor and cried. She had another surgery to change the patch and give her a g-tube at the same time. She had had a feeding tube in her nose for 6 months, so you can understand why she used to hate when we had to wipe her nose!

After five general anesthesias in 7 months of life her body became so stressed that blood was coming out of her. Her diaper was full of red and black blood. It was a stress ulcer. It's like she was telling to us: "Give my body a break!" Most people don't have so many surgeries in such a short period.

It took 13 months after that surgery to bring her back home with us for good because she had a few pneumonias, a rotavirus and a type of influenza. A couple of times there were dates set to bring Genève back home with us, but then she would get a new infection, so our emotions were going up and down like a roller coaster.

In February 2008 a doctor had said that she was healthy enough to return home, even though she needed medication for her lung infection. She was a little sick but that everything should have been all right with Genève. She said that if we were waiting for the perfect conditions for our little girl to leave the hospital we would probably have to keep waiting. So we brought her home full of excitement and joy, but it was horrible at home. Her cough was terrible and we had so much stress with all the machines at home, like the oxygen. We could only give 40% oxygen to Genève at home and it was not enough … after 3 days we went back to the hospital. The doctor who had given her the okay to leave admitted that she made a mistake, that she looked at only one lung x-ray and forgot the other one. Unbelievable! Genève went to intensive care because she needed almost 100% oxygen. I was scared of losing my baby, no one knew if it was a bacteria or virus problem. But she finally got better after antibiotic treatment.

Genève stayed 8 months in intensive care because she needed to be on a ventilator. After contracting three lung infections in March and one in April she was dependent on her CPAP machine. Doctors tried to wean her off the vent but without success. She was sweating a lot and got tired quickly. I have to mention how lucky we were to have the most wonderful doctor in the intensive care unit who offered to be Genève's doctor. Her name is Dr. Catherine Litalien and we rather think

that she is her angel watching over Genève. She made a difference in our lives and she is the most human and competent doctor we've ever met. We thought it was important to mention because they are rare.

Since birth Genève has also had severe lung hypertension, which means that her heart was working very hard to let the blood pass into her lungs because of her lung underdevelopment (hypoplasia). Genève's surgeon, Dr. Bouchard, told me when I was pregnant that the combination of the hernia and lung hypertension was the #1 cause of mortality in babies and that my daughter would need surgery immediately after birth. That's why Genève had only a 15% chance of staying alive after birth. At 7.5 months old she started to get medication for her lung hypertension. We also had to keep her attached to her ventilator 24 hours a day. My husband and I had to learn how the machine worked. It was scary at the beginning but we didn't have a choice. We wanted our daughter with us at home so we decided to learn whatever it took for that to happen. We had to learn many things just to have a kind of a "normal" life. It's crazy when you think about it, but it was worth it! On October 16th of last year we finally brought Genève where she belonged — at home! It was exceptional! We celebrated the Christmas holidays and her second birth day at home, what a joy! That joy lasted 6.5 months.

Genève returned to the hospital in May 2009 because of a bad cold and needed intravenous antibiotics. We thought it would be for a maximum of 10 days at the hospital, but she stayed 68 days because of a large granuloma just inside her trachea. The month before Genève had gotten her trach out by accident at 5:00 in the morning and stopped breathing. She was banging her head on the side of the bed and by the time I cut the trach ties and lay her on the floor, she lost consciousness and turned blue. My husband abruptly put a trach in, we put her back in her bed and connected her oxygen. Normally she should have been able to breathe, but because of the granuloma tissue no air was able to pass through to her lungs. I don't have to tell you how I felt at that time, but then we brought her back to life. It's crazy how fragile we are ... how fragile life is.

It's crazy how fragile we are . . . how fragile life is.

Afterward, Genève's ENT did a bronchoscopy. When she put the camera into her nose she discovered a plastic penny in the back of Genève's throat! She had put it in her mouth 4 months before, the day after Christmas, and it was still there. At the time we had gone to the emergency room by ambulance, but the doctor there told us that nothing was in Genève's mouth. So we were surprised to know that the penny was stuck there so long and Genève never complained about it. We even gave her some pureed food and water by mouth and never noticed anything. Her ENT told us that it probably was very uncomfortable, but Genève never stopped smiling and must have learned to live with it.

Anyway, the ENT had to take it out, but how? Genève's mouth opens only about 4 mm in the center. The doctor started giving her steroid injections every month since last May to try to shrink the granuloma tissue. Genève's had to receive six general anesthesias, but, unfortunately, the granuloma is still there. My husband and I decided to see another ENT elsewhere to see if there is a better solution. We wonder if it is the time now for Genève to have her first jaw distraction? Maybe, we'll see.

When Genève was vented during the day as well as night and wanted to play, like go under the table or elsewhere, we had to follow her step by step because the machine only had 6 feet of tubing and was very heavy. We got very tired. Now she is completely off oxygen but while she's sleeping, I still need to connect her to a CPAP machine. It's giving her a pressure when she wants to breathe. And she started to walk at 2.5 years old. It was much easier for her to learn without the vent machine!

Now Genève is 2 years and 9 months and she is so alive! She doesn't sleep at all during the day. I put her down for a nap but she stays awake, and she's been doing this since she was 1.5 years old. She sleeps at night, but when the sun is "awake" she is too! She is so sensitive about all that concerns nature: trees, flowers, rainbows, wind, rain, birds, animals, bugs, grass, sand, rivers, clouds … also vehicles, like trains and planes! She appreciates everything that we appreciate, like music, movies, houses … she is so easy, she is really wonderful. I don't think she is like that because of her 22 months in the hospital, but she definitely wants to live and she doesn't have 1 second to lose! She is like her father and grandfather, she likes to laugh and to tease! We've never regretted giving her the chance to live, and if we had to do it again for her we would do it for sure. She has brought so much joy and pure love into our lives, she's already given me back all those days and nights I spent next to her in the hospital, and much more! Of course I did complain a little, like having to wait to decorate and buy baby furniture like other pregnant women, or instead of bringing my baby home after a couple of days after giving birth I had to wait weeks before taking Genève in my arms. I had to be a mother in an abnormal background (the hospital) without having my parents by my side. I had many huge fears of losing my baby, I put my "women" life on the side to be as fully a mommy and wife as possible, but I find myself lucky to have the chance to know what *pure love* is and I thank God for bringing Genève into our lives.

In Memoriam: Beloved FNMS Member, Steven Tibbett

It is with much sorrow and heavy hearts that we announce the passing of Steven Tibbett. Steven, beloved father of Syrus and Zachary Tibbett and husband of Dawn Tibbett, will be deeply missed by all who knew him.

I first met Steven and Dawn at a seminar in Seattle given by the Cleft Palate Foundation. We were brand-new members of FNMS, joining that weekend after meeting both Margaret and the Tibbetts for the very first time. Steven and Dawn both instantly greeted us as if they had known us for the longest time. As parents of children with serious medical issues we had an instant connection and bond and they welcomed us into the fraternity. We were nervous, and perhaps Steven could tell this about us as he cracked a few doctor jokes and instantly put us at ease. This seemed to be his way with people and it was endearing to say the least. It was a few years later when we met up again at the 2004 FNMS Family Conference at the Flying L Dude Ranch in Bandera, Texas. We sat next to him on the hay wagon ride to the horse back riding venue and he noticed that my daughter, Peyton, was very nervous about the prospect of riding a horse for the first time. Steven joked with her and talked to her the whole ride. When we finally arrived at the horse stalls, Peyton was inspired to at least attempt the ride. She never left the barn, but I know that we would never even have gotten her up in the saddle without Steven's efforts to put her at ease. The last time that we crossed paths with Steven was in 2006 at the FNMS Family Conference in San Francisco. When we were greeted by Steven and Syrus at breakfast on the first morning, we knew the party had started. Steven was always willing to get involved, be positive and jovial. I will never forget the sight of Steven jumping for joy as a demonstration for one of our speakers that had addressed our families at the conference. That is how I will remember him, always.

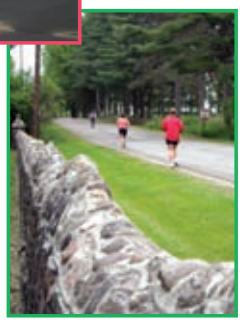
DeDe

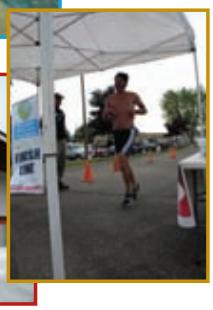
Steven and Dawn Tibbett with Ryan and DeDe Van Quill.

"TRI"-ing for FNMS

Submitted by Lara Beranek

On June 6, 2009, we hosted our fourth fundraiser for FMNS. We put on a triathlon here in our little town of Marathon, Wisconsin, USA. We have been fundraising for FNMS in honor of our son Saul's birthday each year. We had two divisions again this year, a novice division and an athlete division. We designed the novice division to be fun for families, but also challenging enough for people to use it as a gateway into triathlons. The athlete division is a typical sprint length, with quarter-mile swim, 20-kilometer bike, and 5-kilometer run portions. Our big improvement this year was hiring a professional timer to time the athlete division.





Unfortunately the weather was unseasonably cool for June, with our high that day reaching only 48 degrees. To top it off, rain was coming. For anyone unfamiliar with a triathlon, I should tell you that the first event is the swim. So these participants come right from the pool, wet, and get on their bikes and ride, wet. Then they dismount their bikes (in a very stiff fashion, as they are now half frozen) to go out and run. You might then be shocked to know we still had a few brave, day-of registrants in the athlete division. They knew that the weather stunk, but they came anyway. This didn't surprise us as we've found that there are many people who truly enjoy challenging themselves, and bad weather just adds to the sense of accomplishment at the end of the course! I'll give you a few examples. We had one guy cross the finish line with both shoes untied. He told us his fingers were so cold after the bike portion that he couldn't tie his shoes, so he just ran with them untied. See, now that's the type of guy who likes a challenge, and now someday he can tell his grandchildren about how he finished the race with numb fingers and untied shoes! Our first place finisher did the entire race wearing only a pair of spandex shorts. He had no shirt, let alone gloves, hat and pants that many others wore. And he broke our course record by nearly 15 minutes. Maybe he was just so cold he wanted to finish so he could put on some sweats and drink hot cocoa.

Even though our registration numbers were down this year, we finished the day with a donation of around $5000 for FNMS. We had asked local businesses to sponsor the event and received donations ranging from $25 to $500 from many places. We also held a raffle for a hand-crafted knife, money, food baskets, Christmas- and exercise-related items. In addition, we raised money from registrations for the event. This was not the best year, with the economy being down and so many people cutting any extra spending they could, so we were very happy with the final amount raised.

Doing this event is an absolute joy for our family. We all pitch in for a cause we truly believe in, and it brings together a wonderful group of volunteers and athletes on a (usually) beautiful June day. The end result is a big check for FNMS and feeling like we've just been a part of something great. I so look forward to continuing this as our kids get older and more involved. It's now a Beranek family tradition!

If you'd like to join us next year, the date's been set for June 12, 2010. Check out our website as the date gets closer: **www.ultraminitri.org**.

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Aaron Zimmel

Anna and the feeding clinic

by Ashley Franklin
Jeffersonton, Virginia

Our 2-year-old daughter Anna, who has Nager syndrome, was born with an underdeveloped jaw, a high arched palate and a short soft palate. These features created feeding difficulties for Anna from birth. She spent the first 3 weeks of her life in the newborn intensive care unit (NICU), mainly learning to feed from a Haberman feeder, which is a bottle with a special nipple that allows you to assist and control the flow of the milk. At the time Anna was discharged she was able to finish a full 2-ounce bottle of breast milk, but once we got home her milk intake did not increase. Anna was not gaining weight and this obviously concerned us quite a bit. We went to the craniofacial surgeon we consulted with in the NICU to see what our options were. At 2.5 months of age, Anna had the surgery to have a g-tube placed. We still bottle fed Anna for every meal, but would supplement with the tube when she got fatigued to ensure she was getting enough calories. When Anna was about 8 months old, a geneticist at Johns Hopkins advised us to have a swallow study for Anna. The study revealed that when Anna bottle-fed she was having micro-aspirations of milk. The therapist who performed the study advised us of the risk this posed to Anna and suggested we refrain from bottle feeding all together. The therapist did say, however, that it would be safe to feed Anna solid food. So for the next year Anna was primarily fed through her g-tube with the occasional snack of pureed fruit, vegetables or yogurt, none of which was accepted with great enthusiasm. We felt like we were moving backward.

Then I began hearing about a feeding program in Richmond, Virginia. I heard stories of children with complete oral aversion completing the 8-week program taking 100% of their nutrition orally. It sounded amazing! And even better, we live in Virginia, less than 2 hours from Richmond Children's Hospital where the program was located. Hearing these stories we decided to start researching all the feeding programs in our region, including those at the University of Virginia, Johns Hopkins and Richmond Children's Hospital (RCH). In April 2009, after Anna's jaw distraction and hand surgeries were completed, we felt we had the information we needed to choose a program and scheduled an evaluation for Anna at RCH.

For the evaluation, we met with a pediatrician, a psychologist, a nurse practitioner and a dietitian — all at the same time. They took a thorough record of Anna's medical and feeding history and a quick physical assessment. Finally, we were left with just the psychologist, who brought in a high chair so that she could observe as I fed Anna the foods I had packed. At first Anna was timid being watched so closely by a stranger, especially while doing something she wasn't very comfortable with in the first place. The psychologist decided she would step out of the room to see if I could get Anna more comfortable eating. When she came back in she found Anna accepting spoonfuls of yogurt. The session ended after only a few minutes and I waited to hear the verdict.

It was a huge surprise when she told me that Anna would benefit from their intensive 6–8 week program. I wasn't sure what she was basing this decision on. "She just saw her eat, what's the problem?" I wondered. Then she began to explain how when Anna ate she held the food in her mouth for an extended time in a protective manner and then slowly swallowed. Anna lacked oral motor skills and would not be able to eat large volumes or varied consistencies until she gained the skills to do so, and this was going to take some work. She sent me home with a few handouts of the Beckman Oral Motor Exercises, which are an integral part of their feeding program. These are assisted exercises that isolate different muscles in the mouth and face that help with movement, strength and prepare the mouth for eating. She wanted me to begin doing these exercises with Anna daily to get a jump-start on her new eating skills. She also gave us something called a tri-chew teether to start having Anna practice chewing, which would be totally new to her. At this point I knew we had quite a road ahead of us.

The first day was nerve wracking. After getting Anna's weight and measurements we met with Anna's feeding therapist, who immediately gave me a sense of confidence. She explained that the first day would just be her observing me feed Anna alone in the feeding room that had a video camera in it; she would be watching from another room on a monitor. The pressure was on! Anna — with her look of "what the heck is going on here" — and I got set up in the room. They had a whole assortment of foods of different consistencies and textures, from thickened formula to waffles with syrup. I saw some pureed apples so I decided to try that first. Anna began shaking her head vigorously. I tried again, this time she was vocal about her refusal. I couldn't believe she was acting like this. I tried a different food and this time she ducked beneath the high chair tray. This was going much worse than I had expected. I was supposed to offer her each food item on the tray to see how she would respond. It became apparent that Anna was not interested in eating any of the foods, so the session was curtailed. Later that day, Anna's therapist went into the feeding room alone with her so that she could assess Anna's response to her offering the foods. Anna had a look of overwhelming fear. When Anna gets nervous, her whole body is completely still and she will just move her eyes. This is what I was watching on the monitor. I was dying inside. The therapist would offer Anna the food, hold it up close to her mouth for a certain number of seconds, while saying nothing, then take it away and try again with a different food. The point was to see how Anna would respond without any encouragement or praise (this is actually very hard on the therapist too). The first day was complete and Anna had not taken one bite of food. It was disheartening.

After a much-needed pep talk from my husband that night I was able to arrive the next day optimistic and ready to trust the process. The therapists did not seem rattled at all by Anna's refusals the previous day. The plan for Day 2 was that her therapist would do all the feeding and I could watch on the monitor in the viewing room. Because Anna had not accepted any foods the previous day she decided to begin by just offering her an empty spoon. She started the session by doing the Beckman Oral motor exercises. Anna was much more amenable today because now they had toys, a movie and a peppy demeanor. When the "feeding" began the therapist would say "take your bite", and when Anna would take her bite she would cheer, offer a toy to play with and un-pause the movie. There was a lot going on, but Anna was looking much more comfortable. In the first session that day, Anna was accepting the empty spoon and actually looking as if she was enjoying herself. Meanwhile the psychologist was sitting with me out in the viewing area, explaining methods, and I am pretty sure checking to see if mom was holding it together. Anna took her empty spoons brilliantly that day. So well, in fact, that by Day 3 there were plans to add food. I was so proud!

Anna's progress continued steadily. Although 2–3 therapists would rotate, Anna had a primary therapist who would make the plan, with consultation from the medical team, and troubleshoot any obstacles she faced. One great thing about this program is that they tailor their approach to each child. There is by no means a cookie-cutter approach to the therapy. Every Wednesday the team would meet with the parents individually to discuss their child's progress and explain the updated plan for their child. I was so impressed by the experience and knowledge they all possessed. Anna was making progress every day. By the end of Week 2 she was taking 3 ounces of pureed foods with formula, most of which she had never had before. This was more than she had ever eaten in one meal in her life. By this point we had discovered that all Anna needed for positive reinforcement was a "Barney" movie. Yes, the

one unfortunate outcome from the program was an unabashed "Barney" obsession. But it was worth every second. I was starting to see my timid little girl come out of her shell.

Because the day program was at least 6 hours a day, the hospital had a family lounge with a little kitchen, toys and books for the kids, computer with Internet access and napping rooms. This is also where the social worker's office was. She would chat with us and was available to privately and confidentially discuss any issues we may have had. Most days they offered an event for the parents as well. We also had one day a week that we would all, as a group, have lunch with the social worker. This would give us a chance to discuss different topics and unwind a little. The hospital also had a time slot for each child to go down to a large playroom each day with the Child Life Specialists and get individualized play therapy and music therapy. This was great, because although the parents are stressed the kids are the ones doing all the hard work! And on top of all the great things they provide for the families at the hospital, nothing can beat the friendships that are made while in the program. Without the other families this would have been a much more difficult process for Anna and me. On the contrary, however, we were actually having a great time.

As Anna's meal volumes increased, the dietitian would give us updated feeding schedules to follow at night and on weekends. I was surprised at how quickly we were able to decrease her tube feedings. At one meeting our therapist expressed that it may not be possible to wean Anna completely off of her tube because she was volume sensitive and unable to get enough fluid. Because of Anna's previous swallow study results showing micro-aspiration, her milk was being thickened quite a bit and therefore had fewer calories per ounce. They decided to order another swallow study for Anna and this time the results were great: no aspiration. We were able to give her thin liquids and she did great with them.

There were other occasional obstacles that we faced while there, but they always had a new idea to try to overcome them. Thankfully they were all successful. But each family's experience there is different. What I can say for sure is that they take what they do very seriously and truly want the children to succeed. And Anna did. On July 10, 2009, Anna graduated from the program taking 100% of her food by mouth. I must be honest, though, it was (and still is) a lot of hard work once we got home. We were on our own. No one to prepare the meals for us, and then so much time spent feeding the frequent meals. We don't get every day perfect and her g-tube does get used on those crazy days, but Anna continues to receive feeding therapy as an outpatient in Richmond and continues to make progress. We are also part of a virtual support group through Yahoo exclusively for families who have gone through this program.

Anna has increased her desire and ability to eat all kinds of foods. Her hands-down-favorite food is cheese, but she will now ask for chicken nuggets, ravioli and crackers — and she now even eats pizza, none of which we puree. Just 6 months ago I would have not thought it possible. But with consistency and trust (which can be difficult at times), we continue to move forward. I can't thank Richmond Children's Hospital and the families who led us to them enough for all that they did for our family. We look forward to the day Anna will be completely tube free (maybe next newsletter). But for now we are just thankful she has come so far!

RCH feeding program:
Children's Hospital, 2924 Brook Road, Richmond, Virginia 23220 U.S.A.
http://www.childrenshosp-richmond.org/CMS/index.php/services/feeding/

Beckman Oral Motor Therapy: http://www.beckmanoralmotor.com/

The P.O.P.S.I.C.L.E. Center: http://www.popsiclecenter.org/index.asp

Fundraising update: Heart of Glenview

The Heart of Glenview event, hosted by the Glenview Giving Foundation (GGF), on February 2, 2009, was a great success. At this annual event, numerous area restaurants served their tastiest dishes in appetizer portions. Needless to say, the great food was the biggest attraction! The participating Glenview charities received generous checks from the GGF after the event. FNMS was kindly sponsored in this event by the Perkaus and Stefani families. We managed to sell 50 admission and 50 raffle tickets for the event, and solicited and received a variety of desirable items for our auction table, which was run by expert volunteers Beth Atkins, Susie Cummings and Essie Streicher. The large, colorful FNMS heart that was auctioned off that night was hand painted and created by the children of FNMS, showing their hands coming together as a group.

On the Glenview Giving Foundation's website there is a video clip that was filmed at FNMS's 2008 Myrtle Beach conference. To see this FNMS video check out the following link and then click onto FNMS: http://www.glenviewgivingfoundation.org/.

FNMS has the best supporters and volunteers!

Margaret with Cathy Cerone, Mitch Abrams and best-pasta-server-of-the-night Karen Stefani.

Ann, Meg, Mike, Kathleen and Audrey of the Hogan clan. Hey, where's Hulk?

Long-time FNMS supporters Joan Troka and Charlie Kuhn.

Feasting for charity were Rick Kweilford, Mike Russell, Jay Ieronimo and Merrilee Kweilford.

Supporters Debbie Morrisson and Pasty Caruso.

Melinda Taylor displays her FNMS pin!

We couldn't do it without our volunteers!

Look who purchased the FNMS heart!

The FNMS heart graces a carport in North Carolina.

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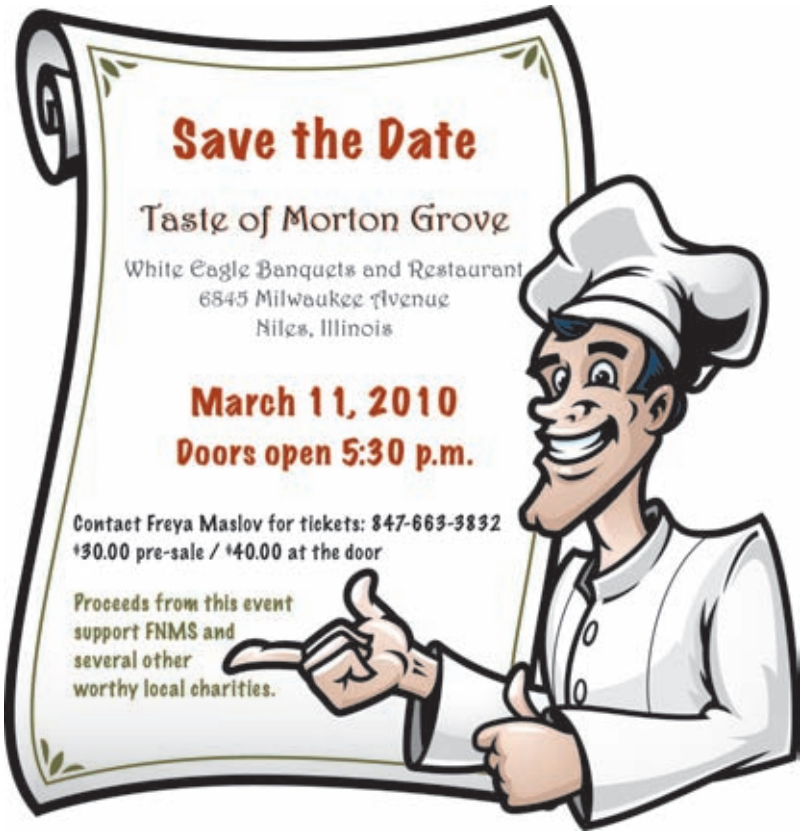

Many thanks to the following individuals who supported FNMS by purchasing an FNMS pin:

Ann Riegert Dudley, Linda Halevy, Gregory Reynolds

The FNMS Logo pin is handcrafted in sterling silver by Katy Boldt Designs.

Contact Margaret Hogan at fnms4u@ameritech.net for more information.

Cuisine served by many of our area's finest restaurants

Raffles * Silent Auction * Live Auction

The following restaurants will participate in the Taste:

Bringer Inn, McCormick & Schmick's Seafood, Maggiano's, El Sol, Wa-Pa-Ghetti, Graziano's, Panera Bread, Catering by Michaels, Costco, Catered by Design, Edible Arrangements, Maier's Bakery, the Morton Grove Fire Department, Orchard Village, Dairy Queen, Howard Street Inn and The White Eagle.

The Morton Grove Foundation's "Taste of Paradise" was held Thursday, March 5, 2009.

On behalf of FNMS, Bridget Ieronimo accepts a check from The Morton Grove Foundation. Pictured with Bridget are Board Members Jeff Fougerousse, Al Weel and Mike Simkins.

FNMS THANKS YOU VERY MUCH!

2009 recipients announced:
http://www.mortongroveil.org/resident/about/news/article.asp?ARTICLE_ID=107