

All About Us

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

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

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

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

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

All About Me

Hi! My name is Anna Franklin. I am 15 months old, but don't let that fool you. I have seen much and done much in my life so far! I was born in Houston, Texas, but moved to a town called Jeffersonton, Virginia, when I was only 4 months old. I live with my mommy, daddy, and my big sister Reese. We live very close to my Omi and Poppy, which is nice because they like to spoil me and my sister. My family tells me I am the light of their life!

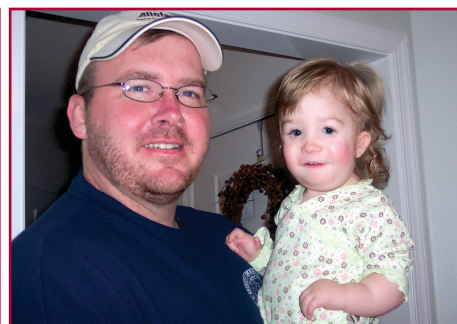
I have Nager syndrome, so this means I have a few challenges in my life. I was born without a thumb on my left hand, but I had a surgery to make my finger work like a thumb. So far it's been very helpful, because I can pick up my toys more easily and can even pick stickers off to put on me and my family. I love stickers! I will probably have to have the same surgery on my other hand this spring. I have a thumb there, but it just doesn't work very well. I just recently had a jaw surgery to help me breathe better. It worked, so now I do not have to wear my CPAP at night anymore. I am very happy about that! I am learning to eat right now, too. My favorite foods so far are yogurt, mashed potatoes, Jello, and last, but certainly not least...ice cream!

It's been a busy year, but I'm doing great. Although I have to see a lot of doctors, I spend most of my time playing with my family. I have a playroom with lots of toys that I "share" with my sister. I have been walking all by myself now for a couple of months, so I have gotten really good at finding where all of the cool stuff is in the house. One of my favorite things to do is to watch the deer that come in my backyard. Sometimes I get to help feed them apples with my mommy and Reese.

Most people who know me say that I am a very inquisitive and strong-willed little girl. I do not let much slow me down, that's for sure! I have many people who love me and I know I have a big life ahead of me.



Sisters Anna and Reese Franklin.



Anna and her daddy share a moment.

All About Us

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

We got the genome out of the bottle — now what?

by Leslie Gaffney

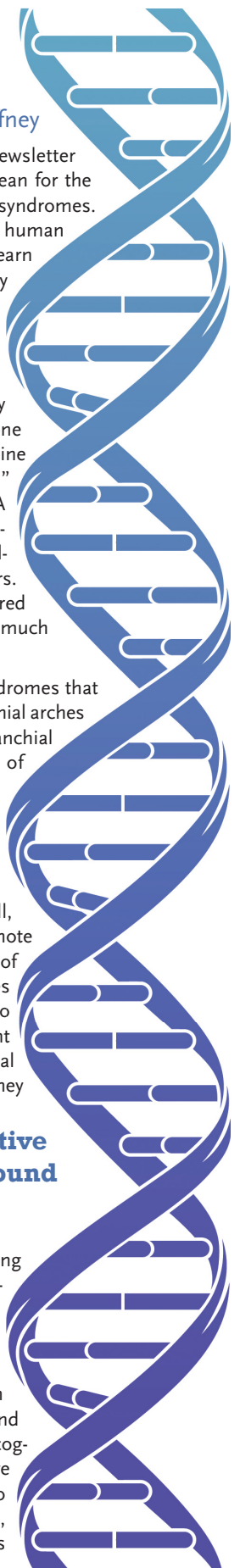
About 8 years ago, founder Margaret Ieronimo Hogan mused in this newsletter about the completion of the Human Genome Project and what it might mean for the possibility of curing disease and finding the causative genes for multiple syndromes. All the while researchers have continued analyzing the sequence from the human genome and have been comparing it with a multitude of other organisms to learn about conservation of that genetic code across species. Not only have they learned that we share many of the same genes, but that our sequence is the same across much of the genome. Studying the development of disorders in animal models is one way scientists can understand the structure and function of human genes. Researchers have also found many different ways to look at the human genome, particularly in relation to human health. By describing a detailed map of the human genome, risk genes for more than one dozen human diseases have been discovered. Also during this period, a new line of sequencing machines has been marched out, and these “next-generation” technologies have been driving down the cost of sequencing. New DNA profiling technologies based on microarrays are rapidly moving from the research field to the clinical diagnostic arena. Such technologies show great advantage in detecting genomic imbalances associated with genomic disorders. Researchers have learned much since 2001, when the genomic era was ushered in with the publication of the human genome sequence — but there is still so much to learn that the next era of discovery may be even more exciting.

The disorders that affect our families, Nager and Miller, are rare genetic syndromes that disrupt the development of structures derived from the first and second branchial arches during the early weeks of embryonic development. The first and second branchial arches give rise to such structures as the bones of the lower two-thirds of the face, the jaw, and the middle ear. No one knows what causes things to go awry in the developing embryo, but what happens when they do and how that can cause disease can be described with a quick “Genetics 101” lesson. Each cell in the human body contains 22 pairs of chromosomes, plus two X sex chromosomes for females and an X and Y for men. Genes are strings of DNA in each chromosome. There are about 20,000 genes in each cell, occurring in pairs. These genes make all the proteins in the body, which promote development and growth and carry out all body functions. When one or more of these genes or chromosomes are missing or mutated, or if extra chromosomes are present, the proteins may not get made, may be made incorrectly, or too many may be made. Any of these situations can cause abnormal development and growth and can result in a genetic syndrome. Sometimes these abnormal genes or chromosomes are passed down from a parent, and sometimes they

“Researchers seem to agree that the causative gene or genes for Nager syndrome will be found in the chromosomal location of 9q32.”

occur spontaneously without a known reason. When more than one identifying feature or symptom of a disorder happens together it is sometimes identified as a syndrome. Each particular genetic syndrome will have many typical features, depending on which aspects of development are affected by the abnormal genes or chromosomes.

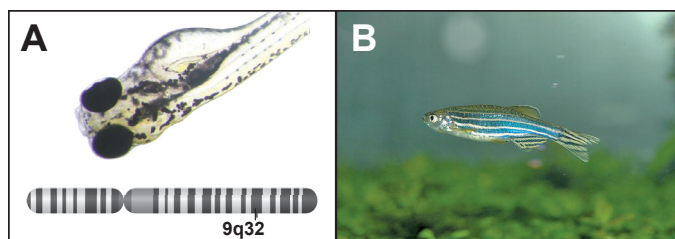
Skeletal development entails numerous, complex genetic interactions, which have been, in part, understood by the identification of mutations. Nager and Miller are 2 of 372 distinct genetic skeletal disorders that are currently recognized. Of these, 215 are known to be caused by mutations in one or more genes (1). Researchers have studied these syndromes either clinically, to describe how best to manage respiratory issues and timing of surgeries (2–8), or in the laboratory, looking for candidate genes and testing their hypotheses



on animal models (9,10). About an equal number of papers have been published on what may be a candidate gene for these syndromes (9,10) as have been on what definitely is not (11,12). In general, researchers seem to agree that the causative gene or genes for Nager syndrome will be found in the chromosomal location of 9q32. In 1998, Dreyer et al. published their finding that the gene *ZFP-37* could be a candidate gene for Nager based on its map location and expression pattern (9). That was 10 years ago, but there doesn't seem to be any evidence that anyone has looked more closely at that particular gene.

The laboratory of Ethlyn Wang Jabs, MD, has been studying craniofacial anomalies for almost 20 years and has recruited a number of our families to contribute blood samples to its studies at Johns Hopkins in Baltimore, Maryland. Her laboratory was first to clone and identify three craniofacial disease-causing genes and the first to identify mutations in genes causing at least 11 different craniofacial disorders. They cloned the full-length gene, *TCOF1*, and identified mutations in patients with Treacher Collins syndrome and, with collaborators, showed that the protein coded by this gene is nucleolar phosphoprotein. Dr. Jabs's laboratory screened Nager and Miller syndrome patients for mutations in *TCOF1* due to the anomalies these syndromes have in common, but they did not identify any mutations (12) (in other words, a candidate gene that wasn't).

Dr. Jabs moved to Mount Sinai School of Medicine in New York a year ago where she continues the same research program and continues to see patients with craniofacial anomalies as a clinical geneticist. Her lab maintains a DNA and cell line repository on families with individuals affected with Nager and Miller syndrome, and they are still attempting to find the disease genes causing these conditions, though they are not recruiting new patient samples.



Panel A: A zebrafish embryo is shown alongside a diagram of chromosome 9 with the region of the suspected Nager gene highlighted.

Panel B: Animal models, such as the zebrafish, can help further the research of craniofacial disorders.

Way over on the opposite coast in the Department of Pathology at the University of Washington in Seattle, the laboratory of James Pace, PhD, is actively recruiting blood samples from patients and families affected with either Nager or Miller. His lab recently discovered and characterized a previously unrecognized collagen — type XXVII collagen — that is a constituent of the developing skeleton. It belongs to a large family of proteins whose members provide structural support and strength to the bone, cartilage, skin, blood vessels, and most other connective tissues. The significance of collagens in the development of the tissues in which they are expressed is illustrated by the broad spectrum of developmental abnormalities and disease phenotypes associated with defects of each of these proteins. Mutations in collagen genes account for 27 of the 215 skeletal disorders that are associated with a gene (1).

Dr. Pace's laboratory genetically modified zebrafish, a common laboratory model, to develop in the absence of *COL27A1*, the type XXVII collagen gene. The zebrafish that developed from this gene knockout exhibited developmental delay, misplaced bones, cranio-

HEART OF GLENVIEW

Glenview's Tastiest Night

Wyndam Glenview Suites, Glenview, Illinois

Monday, February 2, 2009

5:30 p.m. – 8:00 p.m.

MANY THANKS TO OUR SPONSORS!

Mr. & Mrs. Robert Perkaus, Jr., and Phil Stefani's Children's Charities are the FNMS sponsors for this year's Heart of Glenview on February 9, 2008. Their generous donations helped us secure a place at this wonderful event.

HERE'S HOW YOU CAN HELP

Heart of Glenview is a charity fundraising event held in Glenview, Illinois, and all proceeds benefit eight local charities — of which FNMS is one! This is one of our best chances to raise significant funds, but we need your help to get there. We need to sell 50 admission tickets at \$40 each and 50 raffle tickets (even if you can't get to Glenview you can still win big at the raffle, and the money you donate will help FNMS earn thousands more!). We also really need donated items for the silent auction. Everyone can make a difference! Please contact Margaret for more information and to find out how you can help.



Admission tickets are \$40 each.

Raffle tickets are 1 ticket for \$25 or 5 tickets for \$100.

You could win: 1st prize: \$2500 3rd prize: \$500
2nd prize: \$1000 4th prize: \$250

Contact Margaret Hogan

fnms4u@ameritech.net

847-729-2011 ph

to purchase admission or raffle tickets
and information on volunteering!

“There’s no way to predict where this research will lead and what it will mean for our families — or for our children’s future families.”

facial defects, scoliosis, and delayed mineralization of bones and teeth. *COL27A1* is on chromosome 9q32 — the location of the suspected Nager gene. This, together with the zebrafish phenotype, support the hypothesis that *COL27A1* is the disease gene. Encouraged by these results, Dr. Pace thinks it is possible to find the same mutation in the patient blood samples he, along with graduate student Helena Telfer, sequences from individuals with Nager and Miller syndromes.

There’s no way to predict where this research will lead and what it will mean for our families — or for our children’s future families. Developmental abnormalities are very hard to cure, but scientific understanding of the causes might well help to prevent the problem from occurring, or identify parents who have an enhanced risk of having children with craniofacial disorders. It is encouraging that costs for genetic testing and analysis are falling rapidly. A simple genetic test for a particular known genetic risk may not cost more than about one hundred dollars (U.S.), and screening a sample for much of the human variation we know currently costs a few hundred dollars. Even “sequencing” — recovering all 3 billion bases of DNA for a given individual — will shortly cost a few thousand dollars. That is still expensive, but the Human Genome Project cost tens of millions of dollars when it was completed less than 10 years ago. It is obvious that there is a huge amount of progress in the field. Progress in certain areas should also benefit the research being done on craniofacial disorders, such as Nager and Miller syndromes. We will continue to bring you any updates or breakthroughs that we can via this newsletter.

For those wanting to learn more, there are some very good explanations of genetics and gene mutations from the National Institutes of Health.

Handbook: Help Me Understand Genetics:

<http://ghr.nlm.nih.gov/handbook>.

Understanding Cancer Series: Gene Testing (the first part before gene testing section gives a good, general description):

<http://www.cancer.gov/cancertopics/understandingcancer/genetesting>.

More links

For information on the University of Washington study contact the genetic counselors working on the program, Dru Leistritz or Melanie Pepin, at 206-543-5464 or toll free 1-888-288-7362.

Johns Hopkins Collaboration for Craniofacial Development and Disorders: <http://www.hopkinsmedicine.org/craniofacial/Home/>

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**Please remember FNMS
when making your
end-of-year donations**

(of course we're happy to be
remembered any time of year!)

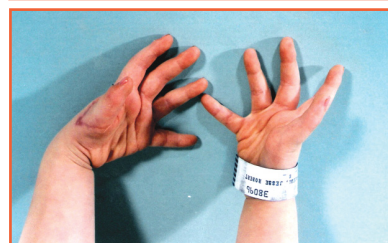
A donation envelope is in this issue.

You can also donate online at
<http://www.fnms.net>

*Happy Holidays
from FNMS*

The “capable” hands of the Ojeda-Gallego family

My name is Kim Gallego and my significant other is Jesse Ojeda. He was born with Nager Syndrome, although he did not know it until we had children. When I met Jesse he already had two children: Nathan (21) and Jessica (17). I have a daughter, Brittany (15), and a son, Christopher (13), from another marriage. None of these children have Nager syndrome. Together we have two sons, Jesse and Justice, both with Nager syndrome. When I was pregnant with Jesse we were told we had nothing to worry about — our blood tests and ultrasounds were that of a healthy baby. On October 7, 1997, I gave birth to Jesse Jr. The doctor and nurses said nothing of our son’s abnormalities. We were told, “You have a healthy baby boy”. As Jesse was holding him, he unwrapped him from the receiving blanket to find our son had the same hands as he had. He cried as he told me. I was surprised that an entire medical staff could miss such a thing.



Top: Jesse Jr. getting a cast off after surgery, age 3.

Bottom: Jesse Jr.’s hands after surgery.

We took our son home and were referred to a geneticist in Las Vegas, who told us that Jesse and Jesse Jr. had Holt-Oram syndrome. We found out after our second child that it was Nager syndrome, not Holt-Oram. We were then sent to the Shriners Hospital. We have been to Los Angeles Shriners as well as Portland Shriners — they are amazing. Jesse Jr. has few of the facial characteristics of Nager, but he was born with a fifth, finger-like digit instead of a thumb, and fusions at the radius and ulna giving him limited arm rotation. He had gastroesophageal reflux disease (GERD) at birth. We had to thicken his formula so he wouldn’t aspirate. After over a dozen surgeries he is a typical 10-year-old boy who loves music and skateboards.

In 2001 I found out I was pregnant with Justice. My emotions were everywhere. I wanted to be happy but felt it was unfair to have another child that may have the same medical needs as Jesse Jr., if not more. We chose to keep what God gave us. My pregnancy was anything but easy. Early on I was diagnosed with evasive placenta previa and put on bed rest. That wasn’t enough;

I began bleeding and was hospitalized for the duration of the last trimester. Justice was born 7 weeks early by c-section. He looked so tiny. He was 5 pounds,

8 ounces. In the few seconds I was allowed to see him I was crying. The first thing I said to Jesse was, “What’s wrong with his head?” I knew something was wrong. Justice has underdeveloped facial bones and a tiny mouth. He has the same hand and arms problems, except they have diagnosed him inoperable due to lack of muscles. He hasn’t had surgery on his hands, but they have changed on their own, and he has created a web span just from using them.

He is adapting to his hands very well and doesn’t let much stop him. Justice may hold things different, but that’s okay. It makes him who he is. He requires help with buttons and such, but we are working on it.

Justice remains small. He has gained 18 pound in four-and-a-half years. He is on health supplement drinks and a high-fat, high-calorie diet. He is going to be 6 this year and weighs 34 pounds.

My family has grown so much stronger since our boys were born. The older kids have become such good helpers. We, as a family, have a new outlook on life. We believe we were given these boys by God for a reason. We like to say at home: “We are not handicapped, we are handi-capable”. If society saw more of what people can do instead of can’t do our world would be better off. No taunting and teasing.

Jesse Sr. is collecting auction items for a fundraiser for FNMS. We will auction signed guitars by famous people, such as Eddie Money, Mel Tillis, the Bellamy Brothers, BB King and the Smothers Brothers. We are looking for more donations of signed guitars and drum heads, which can be in working order or not. You can contact Jesse at jroojeda2001@yahoo.com. We’ll be sure to announce when the auction takes place.

With the love and support of our families as well as FNMS we are ready for whatever our future holds. Thank you and God bless all the families out there.

— Kim Gallego
Salem, Oregon

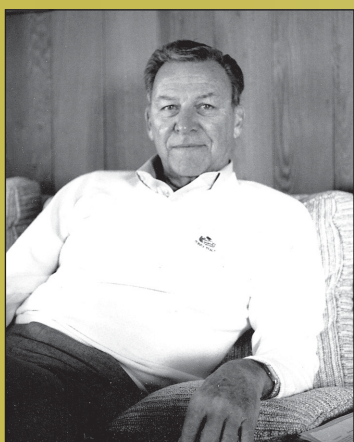


Back row: Jesse Sr., Kim and Jesse Jr.

Front row: Christopher, Jessica and Justice.



Justice and Kim share a ride on the carousel.

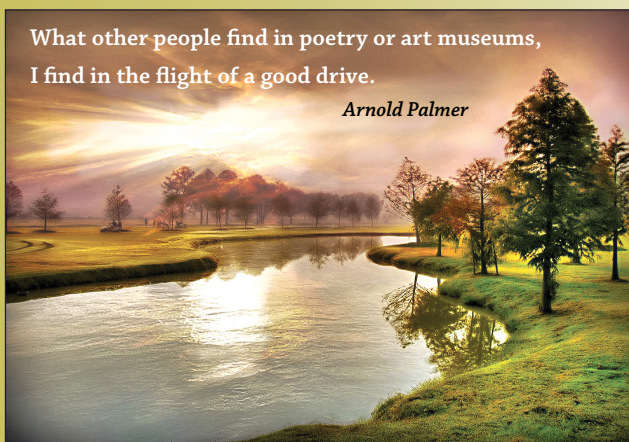


George D. Strickland

Jan. 17, 1929 – Aug. 21, 2008

What other people find in poetry or art museums,
I find in the flight of a good drive.

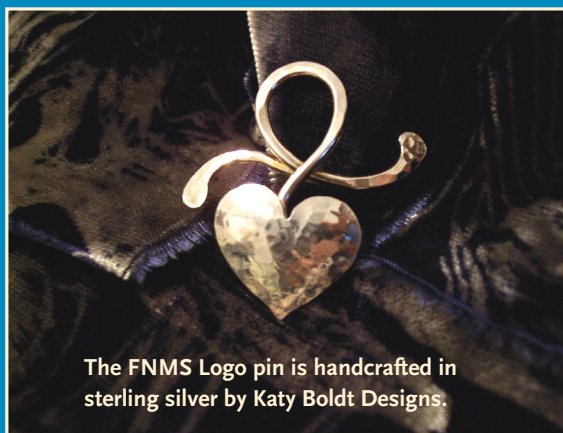
Arnold Palmer



We wish to thank the following persons who generously donated to FNMS in honor of Margaret Hogan's Uncle George. Rest in peace dear uncle.

Robert Albert, Polar Hardware
Michael P. Atkins
Steve Boron, Contractors Adjustment Co.
Lawrence Cairo
Bruce Crown
Margaret & Mike Hogan
Jay Ieronimo
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M.H. Wade



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

Purchase your pin, raise awareness and support FNMS while looking stylish with these unique silver pins. Money from the sale of these pins will help fund our various services. With FNMS's growth, the need to fund our scholarship program is greater than ever. It is always a challenge to raise funds for conditions that are lesser known to the general public, such as Nager and Miller Syndromes, so all methods to do so are worthwhile.

The cost is \$50 plus shipping and you are sure to receive compliments. They are shipped to you in a little black gift box and make wonderful gifts.

Contact Margaret Hogan at fnms4u@ameritech.net.

Thank You Jared!

We send enormous thanks out to videographer Jared Ewing who produced the 2-minute FNMS video we needed to submit for our Heart of Glenview application.

FNMS will post a link to the video on our website soon at www.fnms.net. We temporarily have the movie linked at this site:

http://s377.photobucket.com/albums/00213/FNMS_movie/?action=view¤t=FNMSWEBVersion300kbps.flv

Jared Ewing
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Glenview, IL
224-220-6073
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Have you seen our website lately?



Rose Memije has done a stunning redesign of the FNMS website. Some areas are still under construction, so check back often.

Thank you Rose!

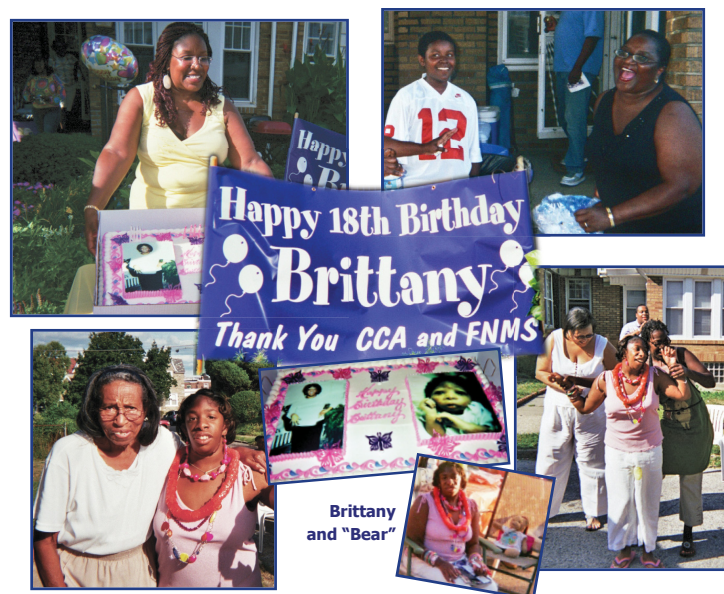
<http://www.fnms.net/>

Brittany's FNMS and CCA fundraiser

by Harlena Morton

Brittany Stevens was born on **August 23, 1990**, at 5:36 a.m. She was very tiny: 3 lbs. 14 oz., all eyes, only 16 inches long, an 11-inch head and given almost no chance of survival or possible decent quality of life. At age five, two major events happened: Brittany spoke her first word and she was finally diagnosed with an extremely rare condition — Nager Syndrome, a craniofacial and skeletal anomaly that affects speech, hearing, walking and, for some, cognitive development. Approximately 120 adults and children around the world live with this rare syndrome. Over the past 13 years, the Foundation for Nager and Miller Syndromes (FNMS) and Children's Craniofacial Association (CCA) have supported Brittany with medical treatments, scholarships for retreats, family network support, love and friendship.

On **August 23, 2008**, a birthday barbeque fundraiser was held in Philadelphia, Pennsylvania, in honor of Brittany Stevens's 18th year of "living a special life on the planet!" Approximately 50 of Brittany's favorite family members and friends attended this lively celebration and more than \$1400 was raised and donated to CCA and FNMS. Brittany was the ultimate hostess on this warm, sunny



day! She and "Bear" greeted everyone with enthusiastic hugs and kisses. Brittany's family extends special gratitude to neighbors, family and friends who donated tables, chairs, umbrellas, time, food and drinks. All funds raised will help CCA and FNMS continue to spread awareness about craniofacial anomalies.

Consumerism with a heartfelt twist

by Lorraine Weiss

An open letter to anyone interested in blending a "good deed" with some heartfelt and beautiful "consumerism".

The first FNMS pin I purchased was for myself. Being a jewelry addict, I fell in love with the stunning simplicity of the FNMS logo when I saw my friend and FNMS founder, Margaret Ieronimo Hogan, wearing an FNMS pin on her lapel. She explained that the pin had been specially created for her with the FNMS logo in appreciation of her pioneer efforts with the Foundation, but was now available in sterling silver for purchase as an FNMS fundraising project.

After people repeatedly admired the beauty and craftsmanship of my pin, it didn't take me long to realize that this was "the perfect gift" that I, too, wanted to share with others. What better way to say thank you than to give a beautiful piece of jewelry that represents arms reaching out and wrapping around

a heart to show my appreciation for someone's act of kindness, generous spirit, or heartfelt care and concern given to me or someone in my family. The fact that funds generated by sales of the pin were used to help supplement the FNMS scholarship fund further sealed my love and commitment to use the pin as a gift for special people in my life.

Since then, I keep a stock of pins on hand all the time to give whenever I want to say thanks to someone special in my life. I've given the pin to countless female friends as well as people in the health care, beauty and fashion fields, or anyone who has extended themselves in some extra or special way. I also enclose a note with the pin that not only provides some background and meaning about the origins of the pin, but also provides information about the incredible work and efforts of FNMS.

To date, the reaction of whomever I have given the pin to is always the same — "What a beautiful piece, what a lovely sentiment". For me, I have never found a gift that I enjoyed giving or that people have enjoyed receiving as much.

KUDOS and thanks to FNMS for sharing this wonderful "gift".



FNMS supporters (L to R): Virginia Khamis (whose idea it was to first have the FNMS logo made into a pin for FNMS founder, Margaret Hogan), Sonia (who handcrafts each and every sterling silver FNMS logo pin at Katy Boldt Jewelry Design in Glenview, Illinois), and Katy Boldt, business owner. Bridget Ieronimo, front row, whose pottery is used in the jewelry display cases (shown at right).



FNMS Donor Recognition (July 2008 through December 2008)

GENERAL DONATIONS

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*Joan Troka donated to FNMS in memory of Rosalie Happ, John Murray, and John Purcell
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