

National Neutropenia

N E T W O R K

Double Whammy!

Family rallies to care for two daughters with congenital neutropenia; reaches out to others to recruit aid in support of all who are afflicted by SCN

Promoting awareness, education, research and support for people with neutropenia and their families through a national resource network. A volunteer driven 501(c)3 nonprofit organization.

Eric and Nancy Jacobson began their family in 1999 when Katie arrived - healthy and beautiful. Building on that, in December 2001, their second daughter was born. Strangely, Mary developed a severe case of omphalitis, an infection of the umbilical cord, and it continued to worsen as her first week of life went on. The young couple took her to the hospital where they discovered Mary “just didn’t have any neutrophils.”

“So that was kind of the beginning of our journey, just trying to figure out what was wrong,” says Nancy. The doctors said she may have neonatal alloimmune neutropenia, but after six months her counts were still zero. The final diagnosis was congenital neutropenia.

Nancy says Mary remained “pretty healthy,” throughout that time even though she never had any real neutrophils. She did suffer through a couple skin infections, but the Jacobsons remained vigilant with their isolation practices and were able to keep Mary in general good health.

Mary began taking Neupogen, and was on a fairly high dose and getting injections twice a day. “It’s helped quite a bit,” explains Nancy. “She’s still had several illnesses; mostly skin infections that they have been able to treat with antibiotics. Occasionally, we’ve been in the hospital for that.” One of the more serious complications Mary has faced was when she contracted pneumonia at age 3.

A secondary issue popped up for Mary when she was two years old. One day she fell off of a chair and hit her head on the kitchen floor. She ended up with an epidural hematoma - a blood

collection located between the skull and the dura mater, which is the thick covering of the brain. She had a slow bleed, and the incident has since raised suspicion that Mary has a bleeding disorder in addition, but of no connection to, SCN.

They have yet to pinpoint what it is exactly. They later tried to reduce Mary’s Neupogen dosing schedule to once a day, but she ended up sick all the time, according to Nancy, and they had to go back to the original twice a day dosing.

“She is so much healthier with twice a day. She’s doing great - again, with the exception of three current skin infections, but they are healing,” Nancy says.

A third pregnancy came along in 2004 and the Jacobsons’ physicians had suggested that Mary’s condition was just a fluke and that they were “almost positive” that this unborn child would not have neutropenia.

The day Anna was born, on February 24, 2005, “We were surprised with a sweet little neutropenic chicken,” Nancy chuckles in remembrance of the day. “But you know, experience helps and it’s always a little easier the second time around,” she explains.

Anna had zero neutrophils, even on that first day of life outside the womb, so they started her on Neupogen immediately. The Jacobsons saved Anna’s cord blood - originally for Mary, but it is now on hand for either should it ever be needed.

Nancy says Anna has been really healthy up until recently; usually only exhibiting the usual colds, etc. Anna has however had croup four times, and both girls have a lot of trouble with swollen tonsils and adenoids.

Nancy explains that the doctors won’t take Mary’s tonsils out for fear of the suspected bleeding disorder, but they are currently looking at removing Anna’s. The doctors are fairly worried about the procedure, Nancy adds, because of the possibility of Anna having the same bleeding disorder, but Anna’s tonsil and adenoid condition is creating such severe sleep apnea that they are left with no choice but to do the procedure.



Sisterly Love: Anna, Mary and Katie Jacobson

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Letters from Lee

An outsider would be hard pressed to guess what common ...

... denominator united the eclectic gathering at the University of Washington's beautiful South Campus auditorium this August. With its multiple variations, neutropenia spares no age group, race or gender. Yet the power of a common purpose, to gain knowledge and understanding about a bewildering medical condition, rendered the demographic differences among guests at the 2006 Family Conference inconsequential.

Throughout the weekend children played for hours, parents compared notes, and emails and phone numbers were exchanged. I believe everyone went home feeling less isolated after having had the chance to talk with others who know firsthand what they were going through. Attendees were grateful to hear presentations from some of the world's leading experts on neutropenia, to participate in open forums where they could freely ask questions and voice concerns.

It was one of the best conferences ever according to past guests. Newcomers also gave it high marks as you can see by the quotes on pages 5-9.

This year we focused on increasing the comfort level and providing a family friendly venue for our guests. Hundreds of hours, tons of creativity and limitless enthusiasm went into making the event a success. As always the centerpiece and meat of the program emanated from the Registry with the wonderful expertise and support of Dr. David Dale, Dr. Laurence Boxer, clinical manager Audrey Anna Bolyard and her

Lee Reeves is the president of the National Neutropenia Network. Her daughter Leta, who passed away in 1997, had congenital neutropenia.



wonderful assistant Anne Dennis.

Add to that pool of talent the amazing efforts of Mara Lim who coordinated the event with the help of dozens of friends and family members; public relations liaison Jennifer Schraag who put us on the map; and Erin Bogart's tireless work got things moving and she helped us nonstop throughout event.

Time and space won't permit me to thank everyone who helped. Many guests pitched in to assist with registration and cleanup. Others offered donations to offset costs. This can-do attitude will be the essential key to the long term success of the National Neutropenia Network (NNN).

I know that finances, the strain of travel, inflexible schedules and other stressful conditions prohibited the majority who read this column from participating in the conference. In an effort to make the material more widely available we had several sessions video recorded and they are now available on DVD, details on how to purchase them can be found on page 4.

In closing, I would like to share a quote that I feel exemplifies the spirit and attitude of so many people I meet whose lives are touched by neutropenia.

"A wise man should consider that health is the greatest of human blessings, and learn how by his own thought to derive benefit from illness."

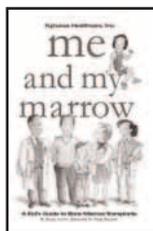
— Hippocrates
400BC-377BC

Me and My Marrow: Free Book Helps Kids Understand

Cristina Cuzzone was 9 years old when she was diagnosed with leukemia, and after six weeks of chemotherapy, she was advised to have a bone marrow transplant.

It was a frightening time for Cristina and her family. They didn't know anyone who had been through a transplant and weren't sure what to expect.

Later, Cristina decided there should be a book for kids that explains all about trans-



plants, so she wrote *Me and My Marrow*.

The book explains what transplants are, how they are done, and what the treatment will feel like.

Throughout the book, Cristina offers helpful tips and explains what she was thinking and feeling during each stage of her own treatment.

To download a free copy of the book, visit www.meandmymarow.com/mainie.html.

Linking Families

Feeling secluded and as if no one understands?

There is no need to feel alone!

Others are facing all the same worries, woes, and challenges as you, and Lucy Lyman can help you find them.

Through *Linking Families*, Lucy is creating a strong network for people with all types of neutropenia. She is linking individuals with similar diagnosis and life situations.

If you are interested in contacting individuals and families with the same condition as you or a loved one is facing, please email Lucy at: lucyly3@aol.com.

"We don't need to be alone anymore," Lucy reminds us.

Lucy Lyman, a mother of two, has cyclic neutropenia and serves as a member of the Board of Directors for the National Neutropenia Network.

The National Neutropenia Network newsletter is published three times a year.

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Flu Season Brings At Least One Extra Poke

The Center for Disease Control and Prevention (CDC)'s Advisory Committee on Immunization Practices (ACIP) has expanded its original routine flu vaccination guidelines to include all household contacts of high-risk individuals, among other important changes; including a booster in some cases.

Immunizing all household contacts, as well as any caregivers, helps stop the spread of the flu to persons considered at high-risk of the disease and its complications, according to the committee. Other changes of note for 2006 are as follows:

> ACIP now recommends that all children aged 6 to 59 months and their household contacts and out-of-home caregivers receive annual vaccinations against influenza. This change extends the recommendations for vaccination of healthy children aged 24 to 59 months.

> ACIP emphasizes that all children aged 6 months to 9 years who have not previously received a flu vaccination at any time with either the live, attenuated influenza vaccine (FluMist) or the trivalent inactivated influenza vaccine (the shot with the dead virus) should receive two (2) doses of vaccine. Those children aged 6 months to 9 years who receive the inactivated vaccine (the shot) should have a booster dose (another shot) administered at least one month after the initial dose and before the onset of influenza season, if possible. Children between the ages of 5 and 9 years who receive the live form (FluMist) should have a second dose 6 to 10 weeks after the initial dose, before influenza season, if possible. *Please note:* only one (1) dose of vaccine is needed for any child that has received either form of the influenza vaccine in past years regardless of whether they received a second shot at that time or not.

> ACIP emphasizes that influenza vaccine should continue to be offered throughout the influenza season even after influenza activity has been documented in a community.

The optimal time to vaccinate is usually during October and November. After November, many who should or want to receive influenza vaccine remain unvaccinated because they think it is either too late to be effective or the resources have been depleted.

However, often, neither case is true. Substantial amounts of vaccine are often left over at the end of the influenza season, and although in the U.S. seasonal influenza activity can begin to increase as early as October or November, influenza activity has not reached peak levels in the majority of recent seasons until late December thru early March.

Therefore, although the timing of influenza activity can vary by region, vaccine administered after November is likely to be beneficial in the majority of influenza seasons. Antibody protection against influenza infection will occur between 10 days and two (2) weeks following vaccination.

Your physician or state and local health departments should be consulted concerning availability of influenza vaccine, access to vaccination programs, information related to state or local influenza activity, and for reporting influenza outbreaks and receiving advice concerning outbreak control.

To keep track of the prevalence of influenza in your area throughout the flu season log onto www.FluStar.com, or for detailed information regarding influenza surveillance, prevention, detection, and control, visit www.cdc.gov/flu/weekly/fluactivity.htm, or call the CDC Voice Information System (influenza update) at (888) 232-3228. Additional information regarding the influenza vaccine is available by calling 800-CDC-INFO (800-232-4636).

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Source: *MMWR Recommendations and Reports "Prevention and Control of Influenza: Recommendations of the Advisory Committee on Immunization Practices."* July 28, 2006. 55(RR10);1-42.

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The girls both currently take Neupogen twice a day - Mary takes a total of 330mcg/day and Anna 72mcgs/day, according to Nancy. Neither tested positive for the elastase gene mutation and Nancy says they differ greatly in their respective illnesses. "Anna seems a little better than Mary. Mary has always been on a higher dose, at the same age and same weight," she shares.

An intriguing aside to the Jacobson family's struggle with neutropenia is their commitment to the success of the Network's revitalization efforts. Their willingness to reach out to friends and family has given the NNN a much needed boost to help with activities like the Family Conference and the distribution of this newsletter.

When Nancy attended the 2005 meeting in Seattle, she listened to NNN board member Lucy Lyman describe the deep need for fundraising efforts to revive the Network to better serve the SCN community. Nancy knew she wanted to do something to help, so she acted on it.

NNN provided a draft letter for the Jacobsons and they personalized it to reflect their situation and the battle their family has faced with SCN. The couple printed the letter on nice stationary, included a self addressed stamped envelope to the NNN home office, and included pictures of their beautiful baby girls.

"We wanted to make it nice because we wanted them to know we were sincere about it and wanted them to appreciate the fact that we were serious," she recalls. "It was a really good experience for us. We sent it out to probably less than 100 people; mainly family, but lots of friends also."

"We were so surprised at just the great generosity that everyone had. Everybody wrote notes to us, sending their thoughts and



Anna Jacobson



Mary Jacobson

prayers and really showing how much they cared and how much they really wanted to help. When people see you going through the things that you have to go through and there's nothing that they can do, I think they want to be asked to help. It's not like they can say, 'Hey, what can I do for you' because there's really nothing that they can do for you - except give money."

"If you just ask, you'll find that people are willing to give way beyond your expectations."

She said they had three people each give a \$1,000 donation, and one of those was matched by their company. Two people did their part through wedding donations where instead of favors; they had a card at each place setting explaining they gave a donation to the NNN in their name and included information about the Network.

Amazingly, one of those two couples didn't even directly know the Jacobsons, they only knew Eric's brother. They gave \$750 and it too was matched by their company.

"If you don't ask, you won't receive," Nancy explains. "If you don't ask your friends and family, then they don't know that you need that and they won't know to give. But if you ask, you will receive - and in much greater amounts than you think."

She continues, "We've been very fortunate and have had good doctors from the get-go. I have heard other stories of people that didn't have access to proper care. I think that is the scariest part; when you don't know and don't have the right treatment."

"We need the money to get the word out to doctors. You can't really educate the world, but if the doctors are learning than you're helping a lot of the people that are in need of better care."

"It really wasn't that hard to do," she concludes. **N**

NEWS IN BRIEF

NEUTROPENIA EDUCATIONAL DVDs NOW AVAILABLE!

The NNN is proud to announce the availability of four educational DVDs. The DVDs are of select sessions from the 2006 Neutropenia Family Conference. They include:

- >> Dr. David C. Dale ~ "Neutropenia: What We've Learned in 12 Years of Data Collection."
- >> Dr. Laurence A. Boxer ~ "The Genetics of Severe Congenital Neutropenia Based on an Unusual Set of Events."
- >> Dr. Frank Roberts ~ "Dental Hygiene for the Neutropenic Patient."
- >> Jennifer L. Schraag ~ "Infection Prevention in the Healthcare Setting."

The DVDs may be purchased for \$10 each or \$30 for the set of four, plus shipping and handling. For more information or to submit an order, contact Lee Reeves by email at leereeves99@comcast.net; by mail at P.O. Box 1693, Brighton, Mich. USA 48116; or by phone at (810) 229-5797.

FOR MEDICAL QUESTIONS CONCERNING NEUTROPENIA OR NEUPOGEN, OR TO FIND A KNOWLEDGEABLE PHYSICIAN IN YOUR AREA, CALL ONE OF THE SEVERE CHRONIC INTERNATIONAL NEUTROPENIA REGISTRY (SCNIR) OFFICES :

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Audrey Anna
Bolyard, RN, BS
Seattle, Wash.
(206) 543-9749
(800) 726-4463

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Beate Schwinzer, PhD
49-511-557105
Connie Zeidler, MD
49-511-546-0918

Australia

Ballarat, Victoria
Australia
George Kannourakis,
MD
61-353-33-4811

Wanna Help Out?

The National Neutropenia Network is always seeking volunteers to assist in various aspects of the functioning of the NNN. In addition, we also are seeking a Web site administrator. If you are interested in helping, in any capacity, please contact Lee Reeves at leereeves99@comcast.net, and specify what aspects may interest you and any experience you have in that area. Thank you!

2006 Neutropenia Family Conference

Seattle, Wash. Aug. 11-13, 2006
Special Conference Wrap-Up Edition

The 2006 Neutropenia Family Conference, hosted by the National Neutropenia Network (NNN) and the Severe Chronic Neutropenia International Registry (SCNIR), held August 11-13 in Seattle, Wash. was a great success! Attendees came from all over the nation to gather and learn more about this condition that weighs so heavily upon their lives.

Festivities kicked-off on Friday afternoon with registration and a "Getting to Know You" reception. Attendees enjoyed a spread of delicious finger foods while mingling at the serene Talaris Conference Center's Pacific Dining Room. Later, they attended "Story Circle" where attendees broke out into two groups: congenital; and cyclic, idiopathic and autoimmune. During "Story Circle," they discussed their challenges and triumphs in dealing with neutropenia and learned how others cope with the disease. It was an emotional and bonding experience for many.

On Saturday morning, everyone gathered at the University of Washington's South Campus Center for a lovely breakfast near Portage Bay. Dr. David C. Dale, co-director of SCNIR, kicked-off the educational sessions with an overview of SCN. Dale's session was enlightening. He shared the impressive progress the Registry has made in researching neutropenia

over the past 12 years, and when explaining the many types of SCN, Dale said, "This is the best that we can do right now and we invite you to help us learn more. You can easily see how far we still need to go and *have* to go in studying this disease."

He continued, "We would like for you and your doctor to know as much as we do about this condition."

Dr. Laurence Boxer, director of pediatric hematology/oncology at the University of Michigan and SCNIR executive board member, then took the podium and explained the mysterious events encircling the Michigan sperm donor that passed on congenital neutropenia to five children. He also explained some of the intricate details of SCN and noted that SCN is "typically not picked up at the newborn stage because we do not

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"I learned so much about what my daughter is going through and how to help her."

— Carol Pierson



- 1.) The gorgeous view at the Talaris Conference Center.
- 2.) Brinley and Arantxa had fun with crafts.
- 3.) Violet enjoying the Saturday evening Luau.
- 4.) Dale and Aisling doing crafts in the kids room.
- 5.) Dr. Dale describes the "cyclic phenomenon" of cyclic neutropenia during a breakout session.
- 6.) (l to r) Tonya, Victor and Janet listen in as Dr Dale addresses the room with info on SCN.
- 7.) Hiawian princess Sadie is decked out in her garb and ready for the Luau!



"From the conference I have once again been reminded that I know the health of my child better than any outsider, and my intuitions are correct."

— Sherri Birkett



2006 Neutropenia Family Conference

Seattle, Wash. Aug. 11-13, 2006
Special Conference Wrap-Up Edition

“We made a lot of new friends that experience similar problems. We now feel that there is more hope in dealing with our daughter’s neutropenic condition. We really appreciate everything.”

— *Victor and Tonya Meyer*

- 1.) Dr. Boxer explains the genetics of neutropenia and shares details on recent case studies.
- 2.) Little Brooklyn entertained the crowd with her own form of Hula dancing.
- 3.) Kimbell looking oh-so-sweet ... as usual!
- 4.) Several conference attendees shared their thoughts on congenital neutropenia during “Story Circle.” Many trials and triumphs were shared at this well-received event that kicked off the conference.
- 5.) Dr. Dale explained the ins and outs of neutropenia; it’s many forms and it’s few treatment options.
- 6.) Erin Bogart and son Braeden having a good time at the Luau.
- 7.) Lee Reeves suggests discussion ideas at Friday’s “Story Circle.”
- 8.) Elizabeth and her husband Ciro enjoying breakfast at the University of Washington on Saturday morning.
- 9.) Conference attendees arrive at the Luau and receive leis.

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typically do blood tests in the nursery.”

“With your cooperation, our research is going to get even better,” he said.

Following Dr. Boxer’s informative discussion, Dr. Frank Roberts, a periodontist, presented an overview of the numerous dental concerns related to neutropenia. Then, attendees gathered for lunch in the Portage Bay Dining Room and enjoyed sandwiches and various cold salads while Jennifer Schraag, NNN communications director, presented tips on infection prevention in the healthcare setting.

The afternoon brought with it a discussion hosted by Dr. Wayne Katon, professor and vice-chair of the department of psychiatry and behavioral sciences at the University of Washington, on depression and the risks associated with it when battling a chronic illness. Audrey Anna Bolyard, RN, BS, clinical manager of SCNIR, then lead a detailed and very informative session on Neupogen dosing, and shared a plethora of helpful tips with conference attendees.

When she addressed Neupogen dosing, she explained “there is no magic number,” and suggested patients work very closely with their doctor to find the right dose and express their own ideas in their dosing.

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“This trip was well worth my time and money. There is a lot of comfort in knowing and meeting people with similar circumstances. I have met friends that I hope to continue communicating with in the future, and my son really enjoyed meeting other children with the same condition. Thank you for all of the effort put into making this a special event for us.”

— *Janene Evans-McCullough*



2006 Neutropenia Family Conference

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Special Conference Wrap-Up Edition

“I really enjoyed the conference because every year I attend it, I learn something new. It really helps me to understand my daughter’s illness a lot more.”

— *Maria Franco*

- 1.) Paige smiles at daughter Kimbell while eating dinner at the Luau.
- 2.) Mara snaps a Luau memoir picture.
- 3.) Dr. Boxer discusses congenital neutropenia during the breakout session on Saturday afternoon.
- 4.) Brooke and daughter Arantxa having lunch.
- 5.) Lee Reeves discusses the future of the NNN with Sunday morning attendees at Talaris.
- 6.) Erin Bogart, Lee Reeves, and Mara Lim
- 7.) Joyce and Samantha enjoying lunch.
- 8.) Taylor and dad Terry at the Luau dinner.
- 9.) Dr. Frank Roberts shared useful dental tips.
- 10.) The volcano was a big hit with the boys! Zach, Brinley and Alex tried in vain to blow it out.

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“You know your number,” she said. She also suggested shots be administered at night to reduce bone pain because, she explained, the bone pain will generally set in around six hours following administration of the dose, thus allowing you to sleep through the majority of the pain. She also said that when monitoring counts, the blood work should be taken when healthy because an ANC will be reactive to an infection (in most SCN types).

On stopping Neupogen, or lowering doses, Audrey Anna Bolyard explains that timing is everything. “Dr. Dale will suggest X, Y, and Z. I always follow that with try X, Y, and Z ‘in the summer,’” she said. She recommends this because summertime generally is a healthier time of year than say the winter/flu season.

Another interesting point she made was that the antineutrophil antibody testing should be done three times within a two-year period to help to attain a true diagnosis. Finally, she suggested SCN patients may want to acquire a standing order from their physician for blood work. She recommended bringing a booklet that contains an explanation of SCN, blood work results, bone marrow results, and a letter from your physician to help streamline care at an emergency room.

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2006 Neutropenia Family Conference

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The peak of the educational offerings were the afternoon break out "Ask the Doctor" sessions. Attendees were able to ask the experts questions specific to their diagnoses. Dr. Boxer hosted the congenital session, Dr. Dale the cyclic session, and Audrey Anna Bolyard the idiopathic group.

The congenital group discussed annual bone marrow biopsies and Dr. Boxer provided a general overview of the different types of congenital neutropenia and explained the intricate details of the risk of transmission to leukemia in this patient group.

Dr. Dale talked about the cyclic phenomenon and explained that the oscillation pattern occurs in some Barth Syndrome patients as well.

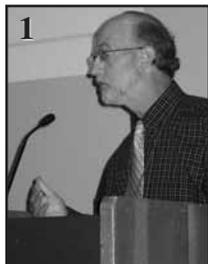
Audrey Anna Bolyard said adults mainly make up the idiopathic group, but SCNIR hopes to move the children out into their own grouping at some point. She also addressed the extreme fatigue SCN brings and offered tips on traveling with Neupogen.

Then, it was time to party!!! The 2006 Neutropenia Family Conference Luau dinner was a smash hit complete with leis and an actual volcano! Attendees dressed in their brightest Hawaiian-style garb and enjoyed an authentic Hawaiian-style meal. The NNN arranged for fun family Polaroid photos with a Hawaiian background for attendees to bring home as a memoir, and every attendee received a gift donated by Amgen, the makers of Neupogen.

Sunday wrapped up the conference with a wonderfully delicious breakfast served in the Pacific Dining Room at the Talaris Conference Center. Attendees relaxed and enjoyed each others company. Lee Reeves, president of NNN, discussed the direction the NNN hopes to take, and Audrey Anna Bolyard was on-hand to answer any lingering questions.

The event was emotional for some. Many tears were shed at the joy of finding others that understand and relate to the challenges SCN presents. Christina Cassidy explained, "I finally got to meet people that know I'm not crazy, and put faces with all

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- 1.) Dr. Wayne Katon addresses depression and chronic illness.
- 2.) Jerry, Angela and Gillian.
- 3.) Saturday Feeding Frenzy: attendees grab some lunch.
- 4.) Brinley and Aisling speak their own language during "Story Circle" on Friday evening.
- 5.) Kent Beall and Dr. Boxer.
- 6.) John watches over young Kimbell as she takes in the beauty of Portage Bay.
- 7.) Dr. Dale addresses the cyclic breakout session attendees.
- 8.) Attendees enjoyed a nice breakfast at Talaris on Sunday.
- 9.) The Luau dinner was delicious, and attendees enjoyed visiting in the relaxed atmosphere.

"Peace of mind, peace of mind, peace of mind. The fact that we had a problem with no permanent answer and no one experiencing anything similar, was helpless and lonely. Having been here for the seminar, we have met wonderful life-long friends, learned volumes, and have a new medical experience fitting more closely to our needs.

Thank you, thank you,
 thank you."

— Bonnie Gernander



2006 Neutropenia Family Conference

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Special Conference Wrap-Up Edition

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my email friends. I learned a lot about what to expect for my future, and about the gene mutation, but mostly, I learned that my family and I can live with this.” Kristin Saleh agreed that meeting other people who have the same condition was one of the best facets of the conference. She said meeting the doctors and experts in the field helped her to better understand SCN, and that she learned of new risks and treatment to improve the quality of life when living with neutropenia.

Toni Gotz offered several reasons why the conference was helpful to her, one being the “boundless amounts of information to take back home to get on the right track to feeling better and steer my physician on the right track to what is best for me,” she said.

“It’s great to know our daughter isn’t alone in this,” explained Jesse and Felima Hohn. “Thank you so much for doing this conference.”

Overall, the 2006 Neutropenia Family Conference was a great success. Many thanks go out to our conference coordinator Mara Lim, who worked tirelessly to make this event such a great success and to Erin Bogart for her many hours of dedication as well. Watch for details on the 2007 Neutropenia Family Conference in the Spring 2007 newsletter. **N**



- 1.) Twins Camille and Susan visit with Corina and David during Saturday’s lunch presentation.
- 2.) Breakfast is a serious matter!
- 3.) The lovely Graciela and mom Maria listen in on a Saturday morning session.
- 4.) Maura Ryan-Donahue shows off one of the Amgen-donated gifts the attendees received.
- 5.) Bonnie and daughter Toni having lunch.
- 6.) Sherri shows off her Luau photo to Mat, Brooke, Arantxa and Dale.
- 7.) Neutropenic Beauties: Aisling, Brooklyn and Amber looking as happy and adorable as ever!
- 8.) There were plenty of leis for everyone!!!
- 9.) Family Fun: The Pope’s cut up during their photo sitting at the Luau.



“As grandma to twins with neutropenia, I came to the conference mainly to help out with the boys; combined with vacation time. I attended the three days and met some wonderful families. I learned a lot of facts about neutropenia; the treatment options or lack thereof, and the large need for research and new options. One of my grandson’s has already lost a leg to infection, but there are so many sadder family stories.

The boys enjoyed meeting all the other children and made new friends.”

— Peggy Guerti

In Good Hands:

Little Gillian's Battle Guardian Goes Above and Beyond

This little five-year-old ball of energy emanates all that is dear in life. Gillian Billingsley is beautiful, bubbly, and full of spirit. So, it's no wonder that those around her have no hesitation in going to great lengths in protecting her and keeping her healthy - even, and especially, her pediatrician.

Gillian's mom, Angela Woodruff, says she spent a lot of time in the emergency room and doctor's office during her first few weeks of motherhood. "Almost on a daily basis," she explains. "I thought maybe I was just going crazy."

It started with ear infections and colds that lasted abnormal lengths of time. Then came a bad case of the croup and her first hospitalization when Gillian was just three months old. Her CBC reflected an ANC of around 1,800 at the time, so no red flags were yet raised.

Two months later, however, double ear infections and pneumonia landed her back in the hospital; this time with zero neutrophils. They ended up shipping her by ambulance to Sacred Heart Hospital in Spokane, Wash. The physicians there too were at a loss. Her bone marrow testing came back abnormal.

That's when the local pediatric hematologist started her on Neupogen, but Gillian did not respond. Puzzled, and making no headway, the Sacred Heart doctors shipped her back to her hometown, and back to her pediatrician.

Joyce Gilbert, MD, FAAP, a pediatrician who has practiced for 22 years in Bonner County in Idaho, had been Angela's doctor throughout her life and was now charged with a puzzling situation that even the big city docs couldn't get a handle on.

"When they sent Gilly back to Sand Point, I was a little frustrated because here was this sick kid with neutropenia, with pneumonia ... I kept treating the pneumonia, but I had no idea how to treat the neutropenia," Dr. Gilbert shares.

She explains that in Spokane they had tried the Neupogen; 5 micrograms per kilogram for two or three days, and they saw no improvement at all, so they stopped giving it to her.

"That's when I started making phone calls," Dr. Gilbert says. After calls all over the country, she finally located Dr. David C. Dale, co-chair of SCNIR.

"So I was able to get him on the phone and tell him what was going on with the baby and he said, 'Oh, you guys have to really try that Neupogen again because that was just not an adequate trial at all. You start with 40 micrograms per kilogram and you go down from there.' I thought 'Oh wow!,' but it worked. We started

with 40 micrograms per kilogram and within a week she had white cells." Angela says "that's what saved her life."

Gillian stayed on that dose quite a while before they were able to start weaning her down and throughout that first year, she still got infections.

"She was just a really sick kid," Dr. Gilbert recalls. "I put them on house arrest frequently. I say, 'I'm sorry you can't go grocery shopping, you can't go visit grandma; you can't go anywhere.' Angie was good. She was a great mom to go through this with."

When Gillian was two and three years old, her severe congenital neutropenia was the causation of her having to endure some pretty traumatic illnesses. She went up to two shots daily.

"That was really hard for her, but, we made it through it," Angela recalls. "She's a really awesome kid. She's really resilient to pain and she keeps her hopes up through everything."

The Woodruffs only visit a hematologist for

Gillian once or twice a year, usually in February, for Gillian's bone marrow testing.

"We just see Dr. Gilbert," Angela says. "We have not found a doctor even a 16th as good as Joyce."

Dr. Gilbert was the "talk of the town" at the 2006 Neutropenia Family Conference in

August because she attended the conference with Gillian and her parents so she could learn all the latest information pertaining to Gillian's condition.

"She is a very wonderful, wonderful woman," reiterates Angela. "She may not give herself the credit that she truly deserves, but she is our guardian angel. She really is. There's not many women in the world that would do what she's done. She is just one of a kind and there is no one I've ever met that is greater than her."

"I don't feel that I am really unique," interjects Dr. Gilbert, "although when I come to places like Seattle and I hear stories from other patients who have other experiences, even in big cities, I think wow, I'm really glad I live in a small town and I can do the practice the way that I want to do it."

"To me it doesn't seem like an unusual way to practice at all. I just don't sit back and let somebody else manage my patients," she adds.

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Five-year-old Gillian Billingsley
Gillian has severe congenital neutropenia



Gillian's Family:
Angela, Jerry, Gillian and lil Grace

Sharps Safety

Many in our neutropenic patient group handle a needle daily. To us, it is our lifeline. And while most of us do not have any transmissible bloodborne diseases - at least to our knowledge - we still need to be aware of and practicing the utmost safety standards when handling these items.

Sharps safety should be a part of a Neupogen-users everyday life. We have to protect ourselves and we need to protect those around us too.

What are sharps?

Sharps include needles, syringes, razor blades, slides, scalpels, pipettes, broken plastic or glassware, and any other devices capable of cutting or piercing the skin.

Best Practices:

Always use the universal precaution principle: "Assume that all contaminated sharps are infectious and treat them accordingly."

Other sharps safety tips include:

- o Discard contaminated sharps immediately into a sharps container.
- o Never force a sharp into a container or attempt to retrieve a sharp from a container.
- o Never bend, break, shear or remove needles from syringes.
- o Do not recap needles or syringes (by hand or otherwise). More sharps injuries and needlesticks occur due to attempted recapping than by any other action.
- o Only work with one uncapped needle at a time.
- o Do not place a needle cap in your mouth in order to remove the cap. Also, make sure needle caps are ALWAYS out of reach of children.
- o Never leave sharps unattended.

What if I am injured by a sharp?

Wash the site right away with soap and water. If the needle was infected by someone with a suspected infectious/transmissible bloodborne pathogen (*i.e.* HIV, hepatitis, etc.), contact your healthcare professional immediately for full directions on testing and possible administration of antiviral drugs. If your doctor is not immediately reachable, report to the nearest emergency room.

Proper disposal:

When working with sharps, dispose of sharps in an infectious waste sharps container.

Infectious waste sharps containers should be placed as close to point of use as possible. The further away the box is the more chance there is for a mishap.

Ensure the sharps container is the appropriate size for the devices you are placing in them. Containers should have a visible opening; be placed below eye level; and should be wall-mounted, if at all possible. (Note: always make sure containers are kept far out of a young child's reach as possible and at all times.)

The Prevention zone



Ensure there is an unobstructed opening that allows devices to drop in easily, and inspect the container weekly; discarding when they become full.

Sharps containers must be non-breakable, leak proof, impervious to moisture, rigid, tightly

lidded, and puncture resistant. They should be red or at least bright in color and should be marked with the universal biohazard symbol or some other obvious warning.

What if my container is full or I am traveling?

There are several household items that come in containers acceptable to act as a sharps container. Bleach bottles, for example, are hard, puncture proof containers you can securely close. When in a pinch these are acceptable alternatives. When disposing of sharps in such a container, make sure the container is closed tightly with tape wrapped securely around the lid.

Never, ever flush syringes or other sharps down the toilet and never discard of them in the trash can. A few states have passed legislation forbidding needle disposal in household trash.

California Governor Arnold Schwarzenegger signed SB 1305 "The Medical Waste Management Act," making California the third state to forbid the placement of used needles in the household trash.

The legislation was enacted because used needles cause a public health hazard.

The legislation, which becomes effective September 1, 2008, will make California residents no longer allowed to dispose of used needles and other sharps waste in solid waste and recycling containers.

The bill also encourages state agencies, local governments, and industry to work cooperatively to publicize sites that are authorized to accept sharps waste and to implement convenient mail-back programs that use containers approved by the U.S. Postal Service.

According to the press release announcing the new California law, it is currently estimated that between eight and nine million people are injecting medicine at home nationwide for

the purpose of treating disease.

"The majority of these needles end up discarded in the household trash and community waste bins," which leaves waste removal personnel at dangerous risk of needlestick injury," the release said. **N**

Jennifer Schraag, mother of two, is a healthcare journalist residing in Chandler, Ariz. Her daughter Brooklyn (pictured above) has autoimmune neutropenia.

Sharps Disposal Programs

Drop Box Collection Points

Sharps users can take their filled sharps container to appropriate collections sites, which may include doctors' offices, hospitals, health clinics, pharmacies, health departments, community organizations, police and fire stations, and medical waste facilities. States where these programs are readily available include Wisconsin, Rhode Island, and Florida.

Household Hazardous Waste Collection Sites

Check with your local waste provider to find out if needles are collected at your local sites.

Mail-back Programs

Home users place used sharps in a special container and return it by mail to a collection site to be disposed of properly. The BD™ Sharps Disposal by Mail system is one such example. For more information call 1-888-BDCARES or visit www.sharpsinc.com.

Residential Special Waste Pick-up Service

Home users place used sharps in a special sharps container and much like a recycling container; it is set outside for pick-up by special waste handlers.

For a list of sharps disposal facilities in your area, check out: www.safeneedledisposal.org/dispcenters.php.

In Good Hands:



A true lifesaver: Dr. Joyce Gilbert

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Dr. Gilbert says the meeting was very helpful to her and mentions her favorite part was Dr. Dale's session.

"Dr. Dale of course is phenomenal to listen to. The other doctors were also very helpful and useful for me.

"The stuff that I got out of the meeting that I didn't know before are, for example, the dosage of Neupogen to aim for."

The docs mentioned that a dose that is less than 8 micrograms per kilogram per day is optimal. Dr. Gilbert says this helps her to know what to aim for with Gillian as she still requires 12 to 15 micrograms per kilogram per day.

In addition, Dr. Gilbert says she feels more "in the loop" by attending the meeting. "All the stuff that they were sharing was their new research stuff so that was really helpful to me. It's great to hear these guys who are gurus in their field, talk," she adds.

Gillian, with much thanks of course to Dr. Gilbert, is doing

great these days. "She's really full of energy and she loves to play outside," Mom says. "She loves to play basketball and ride horses ... she's a doer."

"That's what's so hard about her illness is that she is the exact opposite of what she has. She loves to be around other children, she loves to go to playgrounds, and she likes to help me make things like cookies or any kind of little decorations for the house. She's got a lot of spirit to her."

"She's also gotten to the point where she can pretty much do the shot by herself. She's very, very good with her blood draws and her shots, and she doesn't even flinch anymore. It's great. I wish I was as strong as she is."

Gillian now has a little sister, Grace, who was born in October, 2005. She is just fine; perfectly healthy.

Angela, who is an inspiration to all mothers, leaves us with some lasting thoughts on how she has made it through the past five years dealing with her daughter's illness.

"If you really hope for things, if you really believe that things are going to be OK, they will be," she believes. "I have prayed and prayed and prayed, some nights all night long, and it really worked, and I still have her, and she's the light of my life." **N**