

National Neutropenia

N E T W O R K

2009 Conference: “Great Success”

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.

The 2009 Neutropenia Family Conference was a huge success. People from east to west – and as far off as Puerto Rico – traveled to Ann Arbor, Michigan last July to join together and learn from the experts what they can do to live a better life with severe chronic neutropenia.



The conference kicked off with the annual one-on-one sessions that are offered each year at the Neutropenia Family Conference. This is an opportunity for attendees

to have individualized discussions with the attending experts concerning their medical course with severe chronic neutropenia.

This year, 20 families were able to participate!

Throughout this newsletter you will find much of the information that was shared over the three-day event.



SCNIR Rewrites Patient Handbook

Thanks to a project lead by Dr. Peter Newburger, “A handbook for patients and their families” will be available soon. The handbook explains the many types of Neutropenia, the genetics behind it all and the current treatments. The handbook was written for the Severe Chronic Neutropenia International Registry by Audrey Anna Bolyard, R.N., B.S.; Mary Ann Bonilla, M.D.; Laurence A. Boxer, M.D.; Tammy Cottle, Carole Edwards, R.G.N./R.S.C.N., BSc.; Sally Kinsey, M.D.; Peter Newburger, M.D.; Beate Schwinzer, Ph.D.; and Cornelia Zeidler, M.D. Dr. Newburger was the lead on the project and he graciously allowed the NNN input and editing opportunities. The handbook will be available online at www.neutropenianet.org and on the SCNIR Web site.

“You’re here, but think of all the other people who aren’t here. We have a huge job to get the information out there. It is my hope that each of you will take seriously, participation in making sure to let somebody else know about SCN, the NNN and the SCNIR.”

— Dr. David C. Dale

~ INSIDE ~

- Still Much To Do 2
- Living with Chronic Illness 3
- Parenting Children with SCN 3
- SCN Kids Camp Helps Kids Share 4
- What to Look Forward to in 2010 and Beyond 4

Decade of Learning, Fellowship

NNN to Hold 10th Annual Neutropenia Family Conference

The 10th annual Neutropenia Family Conference is set for July 16-18 at Rancho Bernardo Inn, a resort about 30 minutes outside of San Diego, California.

This annual tradition is hosted by the National Neutropenia Network, in conjunction with the Severe Chronic Neutropenia International Registry.

The conference will once again feature one-on-one consultations with our expert physicians, presentations and research updates from top

hematologists and other professionals from across the U.S., and the SCN Kids Camp for children and youth.

For more details and updates leading up to the conference, please visit www.neutropenianet.org regularly.

Be sure to mark your calendars and **Save the Date!**

Neutropenia Family Conference
July 16-18
Rancho Bernardo Inn
San Diego, Calif.



There Still Is Much To Do

Since Dr. David C. Dale founded the Severe Chronic Neutropenia International registry over 10 years ago, it has been a Godsend for families whose lives have been impacted by neutropenia. The Registry has served as a conduit for the research exchange among experts, a hotline for Neupogen takers whose comfort and survival depends upon proper dosing and a source of extensive data on neutropenia. In addition to advancing research on bone marrow failure conditions, the Registry distributes Neupogen to its members, many who would be unable to access this lifesaving medicine without such aid.

It's no wonder that last spring I found myself waiting nervously for word on the grant Dr. Dale submitted to the National Institutes of Health for the renewal of our precious Registry. It seemed to take forever to get final approval which happened early this summer and was announced at the 2009 Neutropenia Family Conference in Ann Arbor. In a year as challenging as 2009, especially for those who face chronic health issues, it's wonderful to celebrate some good news, news that brings peace of mind to the readers of this newsletter

As I look back on 2009 I think about the many emails I've received from people recently diagnosed with neutropenia. They turn to our Network for support and information; for someone supportive to talk to, and for access to a doctor who knows how to treat their rare disease. Sometimes it's hard to hear from so many people struggling with a serious disease, but it is gratifying to be able to help. I often think back to the days when my daughter was a child and how much it would have meant to find something as amazing as a website with information on her disease; just a click away from another person who would actually understand my plight. The idea of a conference where I could meet other parents and talk to experts was unimaginable at that time.

We've come a long way since those information-deprived years. This year, we will host our 10th annual Neutropenia Family Conference! Last summer we

were able to award six grants to families to help them to attend our conference in Ann Arbor. Many of the nearly 100 people who attended wrote and told us it was a life-changing event for them.

This was especially true for the children. Most had never met another child who takes shots. The SCN Kids Camp gave them a chance to form friendships and play, while learning about their disease in a safe and comfortable setting. One moment that stands out for me is when I went to pay one of the assistants we hired to help for her eight hour day. As I went to hand her the check, she reached her arm out gently and stopped me. "I can't take any money for this. I really want to donate it back. I've learned so much today and these kids are so courageous." She looked at me, her eyes serious, almost pleading. At the start of the day she knew nothing about neutropenia but after eight hours she understood how serious it is and how challenging it makes life for our kids. She told me she was amazed at their courage and resilience.

As Mara Lim and I work on plans for the 2010 conference, these memories of a wonderful weekend in Ann Arbor inspire us. We are excited about the California location where a good number of Registry patients live. Tanya Goldman who attended the 2007 conference has helped us in securing a good rate at the stunningly beautiful, child-friendly Rancho Bernardo resort in the San Diego area. I hope many who read this will be able to join us this year.

As always the conference will provide access to expert physicians, information on the latest research and plenty of opportunities for those who attend to get to know each other. Check out our website, www.neutropenianet.org for more details and the registration forms.

I hope to see you then!

Lee Reeves is the president of the National Neutropenia Network.

Her daughter Leta had congenital neutropenia.

The National Neutropenia Network newsletter is published twice a year.

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Linking Families Program

The NNN Linking Families Program links individuals with similar diagnosis and life situations.

If you are interested in contacting individuals and families with the same type of neutropenia you or a loved one is facing, please email Lucy at: lucyly3@aol.com, or sign up online at <http://neutropenianet.org/patient-family-support/find-someone-me/>.

From the MAILROOM:



"We just wanted to say thank you for all of the work you put into this year's conference. The top-notch venue, material, and administration demonstrated what must have been an incredible amount of preparation and planning. We greatly enjoyed meeting new families, sharing stories, speaking with the doctors, and learning about the latest research.

"We look forward to following up on this lead. These conferences are extremely powerful. Thank you again for your tireless devotion to this cause.

Sincerely,
Nancy and Eric

"I just wanted to thank you all for such an amazing and wonderful conference! I tried to be rather collect through it all and didn't mean to tear up at the end, but honestly, I have never seen Derek open up like that or play with other children without being persuaded, coaxed, etc., and it just had me so overwhelmed.

"I hope you continue to do the kids camps every year. That was truly amazing for all those children. Every parent talked about how their child came out of their shell and couldn't believe the difference in them.

Thank you, again and again!
Lisa, Derek's mom

"We just wanted to send an enormous thank you to you for all of your hard work, time, and dedication to the Network. We thoroughly enjoyed ourselves at our first conference attendance last weekend and came away with a wealth of knowledge, tips, and new, supportive friends.

Thank you so much for that!
Kelly and John, parents of Keatin

VISIT US:
<http://neutropenianet.org>
A very special "Thanks" to cubedge.com.

Living with Chronic Illness

Author Shares Usable Tips in Program for Adults

Joy Selak, author of the book “You Don’t Look Sick” was one of the speakers at the 2009 Neutropenia Family Conference.

She told those attending her breakout session that she’d akin getting sick to a “long fall into what seems like a bottomless pit.” She points out that living life at peace means understanding societal bias against illness.

“Doctors are trained to intervene or suppress,” she shared. “Chronically ill patients frustrate doctors. Seek the gift of grace: because that what is given to someone to sustain them, then that is not earned.”

Top 10 Tips for Living Well

- 1.) Put yourself first.
- 2.) Never, never, never give up.
- 3.) Know who you are now, and let others know who you are now.
- 4.) Enroll in the School of Whatever Works.
- 5.) Make friends with fatigue.
- 6.) Live as a child.
- 7.) Step out of the box.
- 8.) Search for the silver linings.
- 9.) Find a way to share your gifts.
- 10.) Find the treatment that works best for YOU.

Thank you!

Special thanks to NNN Board member, Sharon White, who purchased 10 books that were given away at random to the attendees.

Idiopathic Neutropenia

A Q&A with Dr. David C. Dale

Q: Do we need frequent CBCs or can we have fewer?

A: “Two or three times a year to check levels is sufficient. This is a good way to keep you and us informed about what is going on in your body.”

Q: Do idiopathic patients need to have bone marrows once they are stable and on GCSF?

A: “No. We do not recommend it or require it.”

Q: If you are diagnosed with idiopathic Neutropenia, do you need to do genetic testing for AML?

A: “Probably not. We have sequenced 100 and found nothing. There is no advantage to the testing. There is no known risk of leukemia for patients with Idiopathic Neutropenia.

Q: How do we know if we are idiopathic or congenital if we were not diagnosed until we became adults?

A: “Past counts would indicate if the Neutropenia were acquired (idiopathic) as opposed to (always extremely low or non-existent) congenital.”

Q: Can GCSF cause myelodysplasia?

A: “There is no evidence that GCSF causes any dysplasia.”

Q: What is the cause of Idiopathic Neutropenia?

A: “Recognized abnormal lymphocyte sub-types that suppress the development of neutrophil formation.”

Grant Renewal!

Last year, the National Neutropenia Network (NNN) asked many of you for letters that Dr. David C. Dale of the SCNIR could include in his grant renewal request to continue the work of the Registry.

You all were most forthcoming with that task. Thank you!

We are pleased to announce that The National Institutes of Health (NIH) has indeed agreed to renew the grant. therefore, funding for the Severe Chronic Neutropenia International Registry will continue for another five years.

“This is big news since funding across the board for the NIH and other governmental agencies have been slashed in light of today’s economic downturn,” said Dr. Dale.

DID YOU KNOW?

The first finding of Cyclic Neutropenia occurred in 1910.

Parenting Children with SCN

Silke Deeley, MA, LCPC, mother of an adult daughter with idiopathic Neutropenia, held a session on parenting children with severe chronic Neutropenia.

She shared how medical challenges can affect marriages and relationships, in general and she advised open communication – with the child, other caregivers, and the child’s school officials. She also encourages placing responsibility in the child so that he or she may begin caring for himself/herself.

The group discussed children doing their own injections when they become mature enough to do so. “Allowing them to make those decisions makes them realize the

consequences when they fall short of taking care of themselves.”

Silke pointed out that preteens and teens already are experiencing “developmental turmoil” and chronic illness adds another complicating ingredient.

Be patient, but firm.

“Encourage your teen to become educated about his healthcare,” Silke offered.

But most importantly, “Take care of yourself! If you don’t, you won’t have anything left to give to your child.”

“Sometimes kids can’t talk to their parents but they can talk to others. Give them that opportunity,” Silke said.

SCN Kids Camp Helps Kids Share

“Did you know that 7 percent of our body weight is our blood?!” It’s true, and the children attending the SCN Kids Camp learned all about their blood, bone marrow and other topics involving neutropenia.

They even talked about which bones make the most cells – the femur in leg, ribs and front of skull. They also practiced hand hygiene and using a bottle of Purell hand sanitizer, calling it “slime”.

The teenagers participated in other, more age-appropriate games and they talked through their feelings about having neutropenia and often being sick. At the end of the program, they shared their thoughts with us.

SCN children: “Why did I have to be born with this?” ... “When I stay at a friend’s house, I have to hide my shots so they don’t know. I’m embarrassed of them.” ... “I’m scared of getting leukemia.” ... “My illness makes me different from everyone else and my friends don’t understand me.” ... “Parents don’t understand how miserable this is even though they think they do.”

SCN siblings: “It’s very hard for us to see our siblings ill and in the hospital, and the ‘well’ sibling gets pushed to the side and doesn’t get enough attention from parents.” ... “When my sister was in the hospital everything that I did felt like something was missing.” ... “When my sister was in the hospital it was very hard for us going house-to-house because our parents are with our ill siblings.” ... “It’s very hard to always take precautions to make sure our siblings don’t get sick. It puts a lot of pressure on us to be careful.” ... “I feel guilty when I’m sick and feel like I might get them sick. If I get them sick, I feel terrible.”

What to look forward to in the near future...

SCN researchers have many interesting therapy studies and trials to come. They may include:

- 1.) Targeted therapy for the enzyme inhibitor of neutrophil elastase.
- 2.) A trial for an oral drug for Idiopathic Neutropenia patients. According to Dr. Dale, they are working with Merck on a new therapy (pill) for idiopathic neutropenia being produced that is an ELA2-like protein. For more information, access the following study: *NEJ* 2009;360:3-5.
- 3.) Exploration of the successful gene therapy treatment of a Border Collie with a single injection. Researchers are looking for a way it may crossover to humans.

Join us at the 2010 Neutropenia Family Conference in California, July 16-18, to discuss these topics and much, much more!

An important aspect to convey when beginning Neupogen (GCSF) is that doctors should start your dose as low as possible and add as needed to find the right dose for you. You do not necessarily need to be at any magical number (ANC) so much as finding “your number” that keeps you healthy and feeling good with little or no bone pain from the GCSF. — Dr. David C. Dale