

National Neutropenia

N E T W O R K

WAY OUT WEST

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 2008 Neutropenia Family Conference Goes Back To Seattle Wash.

We're heading back to the Western side of the U.S. this summer for the 2008 Neutropenia Family Conference, hosted by the National Neutropenia Network (NNN) and the Severe Chronic Neutropenia International Registry (SCNIR)

Last year's conference, which was held in Ann Arbor, Mich., met record attendance and we're looking forward to doing it again.

Join us as we offer the most extensive educational program to date. This family-friendly, intimate atmosphere offers the platform to hear from the top experts in the country who study and treat severe chronic neutropenia.

This year's expert speaker list has some familiar face as well as many new faces.

This year's speakers include:

- Laurence A. Boxer, MD, professor of pediatrics and communicable diseases, and director of pediatric hematology/oncology, University of Michigan, and SCNIR executive board member;
- David C. Dale MD, professor of medicine in the department of medicine at the University of Washington (UW), Seattle, and co-director, SCNIR;
- Peter E. Newburger, MD, Ali and John Pierce professor of pediatric hematology/oncology and vice chair of pediatrics at the University of Massachusetts Medical School, and executive board member, SCNIR;
- Audrey Anna Bolyard, RN, BS, clinical manager, SCNIR.
- Akiko Shimamura MD, PhD, associate professor of pediatrics in the

Schedule~At~A~Glance

July 18

Registration
One-on-Ones
"Meet and Greet" Reception
A 30-Year Journey: The Evolution of SCN
Story Circle

July 19

Breakfast/Registration
Speaker Presentations
SCN Camp
Lunch
Sessions, Breakouts
SCN Camp

July 20

Breakfast, NNN Update,
Conference Wrap-up

See pg. 4 for full schedule

division of hematology/oncology at the University of Washington;

- Siobán B. Keel, MD, acting instructor of medicine in the UW division of hematology; and
- Gad B. Kletter, MD, pediatric endocrinologist, Swedish Hospital in Seattle.

New this year is the SCN Camp for ages 4 to 14 years. The SCN Camp will be age appropriate and led by Amie Pritchett, a child life specialist at Children's Hospital & Regional Medical Center at UW.

(For more on the SCN Camp, see pg. 4)

Conference highlights include:

- >> limited one-on-one sessions with the physician experts,
- >> breakout sessions for each type of neutropenia (cyclic, congenital, idiopathic, autoimmune),
- >> open discussions and networking opportunities to share stories and information,
- >> extensive SCN Camp hosted by professional child life specialists, and
- >> special session for caregivers.

In a look to the future, we will embark on the data and research our experts have uncovered and we will engage in conversation on the very important

topic of bone marrow transplants.

(For a success story on this topic, see pg. 7)

Tons of wonderful networking and story-
continued on pg. 4...

See page 3 for the 2008 Conference Registration Form and the One-on-One Sign-Up Form

~ INSIDE ~

Check Out Our New Web Site!	2
Conference Reg. Forms	3
Full Conference Schedule	4
Meet the Docs	5
Kostmann's No More Wyatt's Journey	7



“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. My son really enjoyed meeting other children with the same condition.”

— Janene Evans-McCullough

Connections Are Everything

Today's technologically-linked world does not always mean freedom from isolation. The diagnosis of a rare disease like neutropenia can still catapult patients and families into an abyss of confusion.



Shay Jones (L) and Lee Reeves (R) at the 2007 Family Conference

I just spoke with the mother of a six-year-old diagnosed with "Kostmann's". He is the only patient his doctor treats with neutropenia.

The mother lauds her doctor's dedication and care, but she is frustrated with the lack of information and advice available regarding the management of her child's disease. She expressed profound gratitude over her recent discovery of the National Neutropenia Network and our new Web site.

By the time she called me she had read every newsletter and could quote from many of the stories. She was determined to get to Seattle this summer. "I'm doing everything I can to get to the conference," she said. "I want my son to meet other children with neutropenia. I don't want him to feel so alone."

She was an inspiration to me as plans for the July conference in Seattle are being finalized. I wish everyone could attend but I know that isn't an option. We will publish a summary with as much detail as possible and in the future we will host it in different cities.

But for those who can attend, I encourage you to make the effort. We have more programs and a greater variety of sessions than ever before, and the youth will be treated to a fun-filled day of interesting and meaningful activities.

You will find more details throughout this newsletter on the programs and events already confirmed. Be sure to check the Web site regularly for updates as several more relevant sessions are still in development.

We have chosen Seattle because it is home to the Severe Chronic Neutropenia International Registry (SCNIR). Attendees will have the chance to meet SCNIR'S clinical manager, Audrey Anna Bolyard and

long-time expert, Dr. David C. Dale; along with some of the top neutropenia specialists in the country.

(Please see page 5 for more on the conference speakers.)

The Network will award a limited number of grants to help cover expenses for those who would like to attend but need financial help. Preference will be given to the applicants with the greatest financial and medical needs as well as first time attendees.

If you would like to be considered, please send an email requesting an application to me: leereeves99@gmail.com or call (810) 229-5797.

Before I close I would like to send kudos to Kim Blanz and her husband Chris who heads up the Web site design company, cabedge. They donated countless hours to the project of updating and upgrading the Web site and will continue to make changes and improvements as needed throughout the year.

Debbie Dicesare also deserves a special thank you for creating the first Web site several years ago, and for making the transition to the new one so easy and seamless.

Our sympathy goes to Tracy Waldron and her family for the recent unexpected loss of her father Richard Sharkey.

Tracy's father told her that his greatest fear was to outlive his grandson, Sam. His concern prompted the family to direct all memorial donations on his behalf to the National Neutropenia Network.

We are deeply grateful.

Lee Reeves is the president of the National Neutropenia Network.

Her daughter Leta had congenital neutropenia.

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

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NNN wishes to send a very special "Thank You!" to Mary Schroeder and her family for their very generous donation of the software used to develop this newsletter.

Comments, contributions, and article suggestions are always welcome and encouraged. Please email us or write to:

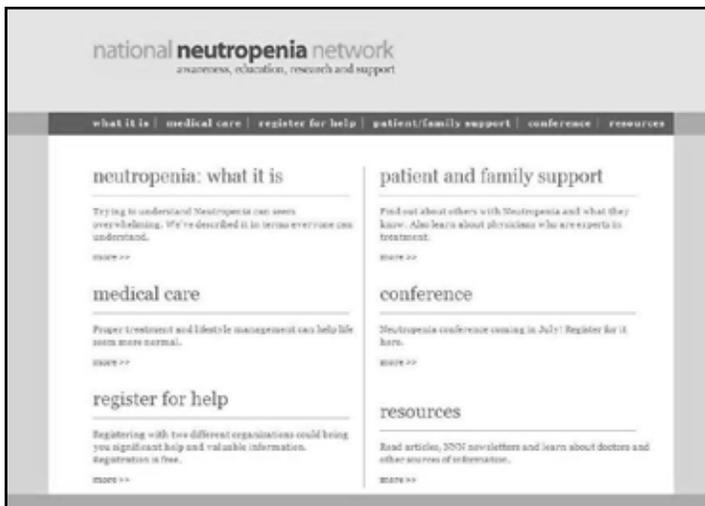
National Neutropenia Network
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(810) 229-5797
<http://neutropenianet.org>

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/>.

WHAT YOU NEED ... WHEN YOU NEED IT



Have you seen our new launch? The National Neutropenia Network's newest home on the Web is located at:

<http://neutropenianet.org>

The new and improved site is user-friendly, easy to navigate and has more information than ever before!

The site is divided into six categories:

- what it is • medical care • register for help • patient/family support • conference • resources

Under each category, we delve into severe chronic neutropenia (SCN) — the diagnoses, the treatment; and we showcase the many offerings of the National Neutropenia

Network (NNN) and the Severe Chronic Neutropenia International Registry (SCNIR).

We offer easy sign-up for the Linking Families program, to receive this newsletter and to sign up for the conference.

Moving forward, we will be adding and updating information regularly to the Web site.

In addition, the Web site will be updated with fresh conference information as July nears.

Check out the site soon and check back often!

Visit today: <http://neutropenianet.org>

A very special "Thanks" to cabedge.com.

National Neutropenia Network

The 2008 Neutropenia Family Conference Heads Back To Seattle

...continued from pg. 1

Tons of wonderful networking and story-sharing opportunities are built into the schedule throughout the three-day conference. Many come and meet new friends, and we expect that you will too.

In addition, we encourage all physicians to attend — hematologists and primary care physicians alike. Our experts are onhand to answer their questions too.

Accommodations

Please book your room at DoubleTree Suites in Southcenter (**please note: this is NOT the*

DoubleTree located next to the airport, make sure you verify "Southcenter").

Attendees may make room reservations online or call (206) 575-8220.

Please be sure to mention "NNN" to reserve a room at the special rate of \$139 (plus tax) per day for 1 to 4 persons. Each room is a two room suite and has a refrigerator.

The hotel is just seven minutes from the airport with free shuttle service!

(For tips on free air travel, see below.)

Conference Cost

The conference registration fee is \$80 per

adult and \$30 per child, ages 3 and up. This fee includes all programs, Friday consults with physicians and the minimum of three meals.

Childcare

We regret there will be no childcare for children aged 3 years and under. The SCN Camp will be available all day Saturday for children aged 4 to 14 years.

For more details or to reserve your place at this year's event, contact Mara Lim at nnnconference@live.com or call Lee Reeves at (810) 229-5797.

~ FULL CONFERENCE SCHEDULE ~

JULY 18

Summit Room

Registration (beginning at 1 p.m.)

One-on-One Consultations with the Experts:

Audrey Anna Bolyard, Dr. Boxer, Dr. Dale, Dr. Newburger and Dr. Shimamura

"Meet and Greet" Reception

Relax and meet other attendees over appetizers and cool beverages

A 30-Year Journey: Exploring the Evolution of SCN Dr. Laurence A. Boxer

Story Circle: "Getting to Know You"

JULY 19

Summit Room

Breakfast and Registration

Morning Speaker Presentations and SCN Camp

Welcome and Introductions

My Favorite Cell

Dr. Peter Newburger will present an overview of neutrophil production and function.

Where We've Been, Where We're Going

Dr. David C. Dale will present an update on what has been learned in the past 14 years of data collection at SCNIR.

Break

Beyond the ANC

Audrey Anna Bolyard will talk about managing neutropenia in daily life with attention to finding the right dose of Neupogen for optimum health.

How to Approach the Decision to Transplant

Dr. Akiko Shimamura will address the many issues and criteria to consider when looking at the option of bone marrow transplantation.

Panel Discussion: Dr. Dale, Dr. Shimamura, Dr. Newburger and Audrey Anna Bolyard

Lunch

Bone Health and Neutropenia

Dr. Gad Kletter will start this session with an overview of bone architecture and an explanation of osteoporosis and osteopenia. He will discuss issues of bone density specific to children and adults who live with neutropenia, and will close with treatment options and variables to consider when making treatment choices.

Afternoon Breakout Sessions and SCN Camp

Ask the Doctor: These breakout sessions will focus on specific disease categories and consist of open discussions where attendees can feel free to ask questions.

Congenital: Dr. Akiko Shimamura

Cyclic: Dr. David C. Dale

Autoimmune and Pediatric Idiopathic:

Dr. Peter Newburger

Idiopathic adults: Dr. Siobán Keel

Breakout Sessions (3 choices):

- 1.) Key Strategies for Parenting a Child with Chronic Illness
- 2.) A Special Session for Spouses and Other Caretakers
- 3.) Getting the Most Out of Life When You Have Neutropenia

Dinner and Entertainment

Unwind with us at this family-friendly, fun event!

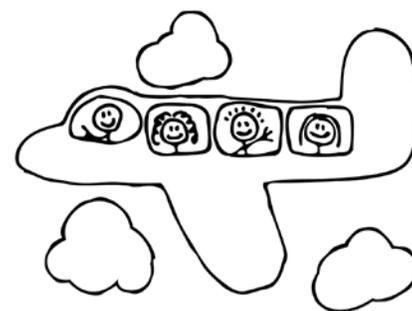
JULY 20

Summit Room

Breakfast & Wrap-up

On Sunday morning, we will wrap-up the conference with inspirational and touching stories. We also offer the platform for you to share with us what you want and need from the NNN in the year ahead. We will discuss coping skills, and expand upon the support, knowledge and most of all the hope we each bring to this annual gathering.

We hope to see you there!



List of Free Medical Flight Offers, Call to See if You Qualify

National Patient Travel HELPLINE Program

Call (800) 296-1217 or visit www.patienttravel.org/resources.html.

Northwest Airlines KidCares

KidCares applications may be found at http://www.nwa.com/corpinfo/aircares/about/KidCares_Application.pdf or call (612) 726-4206.

Miracle Flights for Kids

Reach Miracle Flights for Kids at 1-800-FLY-1711 or visit <http://www.aa.com/content/amrcorp/corporateInformation/facts/amrfoundation.jhtml>.

Miles for Kids in Need

Call (800) 882-8880 or email: miles.kids@aa.com.

Air Charity Network™

To locate the Air Charity Network organization that serves your area, call (877) 621-7177 or visit <http://aircharitynetwork.org/Home/tabid/850/Default.aspx>.

**Please note that the one-on-ones with the conference experts may meet the medical requirements to obtain the above flight services. Please visit <http://neutropenianet.org> for more information.*

MEET THE DOCS

THE DEDICATED PROFESSIONALS WHO EDUCATE OTHERS ON SCN

Audrey Anna Bolyard, RN, BS

Audrey Anna Bolyard helped with the initial development of the Severe Chronic Neutropenia International Registry (SCNIR) and has served as its clinical manager since its inception in 1994. She has been associated with the University of Washington (UW) since 1978; serving as research nurse and post-surgical nurse since 1974. Bolyard received her associate degree in nursing from Weber State University in 1974, and a bachelor of science degree in nursing from the University of Utah in 1977. Bolyard currently focuses on developing the best treatment options for neutropenic patients. She also is co-author of many articles and abstracts on neutropenia.

Laurence A. Boxer, MD

Dr. Boxer is professor of pediatrics and communicable diseases, and director of pediatric hematology/oncology, at the University of Michigan. Dr. Boxer has served as president of the Society for Pediatric Research, was elected to the Council of the American Pediatric Society, and holds an active leadership role in many academic societies including the American Society of Hematology and the American Society of Pediatric Hematology/Oncology. In 1997, Dr. Boxer was elected as a Fellow of the American Association for the Advancement of Science; and in 1998, he received the Founders Award from the Midwest Society for Pediatric Research. He also holds the honor of the Distinguished Faculty Lectureship Award at the University of Michigan Medical School.

Dr. Boxer has served on the executive board of directors since the inception of the SCNIR.



David C. Dale, MD

Dr. Dale has been professor of medicine in the department of medicine at UW, Seattle, for more than 25 years. He received a medical degree from Harvard University, residency training at Massachusetts General Hospital and UW, and served as a senior investigator with the National Institute of Allergy and Infectious Diseases' Laboratory of Clinical Investigation at the National Institutes of Health. Dr. Dale serves as president of the American College of Physicians. His research interests center on neutrophil physiology, neutropenia, and hematopoietic growth factors. Dr. Dale also is active on the National Board of Sponsors for Physicians for Social Responsibility and is co-director of SCNIR.

Siobán B. Keel, MD

Dr. Keel is a graduate of the University of Minnesota, where she also served her residency. Dr. Keel was a clinical hematology fellow in 2002/2003 in the division of hematology, department of medicine at UW, Seattle. She then served as research fellow. Dr. Keel is now acting instructor of medicine in the UW division of hematology.



Gad B. Kletter, MD

Dr. Kletter is a pediatric endocrinologist who also studies other adolescent medicine. He attended medical school and completed his residency in Israel before arriving at the University of Mississippi, Jackson. He then completed a fellowship and served as a lecturer and assistant professor at the University of Michigan, Ann Arbor. Dr. Kletter practiced at Children's Hospital and Regional Medical Center in Seattle for 11 years, and, in 2006, he began his current post with the Swedish Pediatric Specialty Care group at Swedish Hospital in Seattle.

Peter E. Newburger, MD

Dr. Newburger is the Ali and John Pierce professor of pediatric hematology/oncology and vice chair of pediatrics at the University of Massachusetts Medical School. He also serves as professor of pediatrics and molecular genetics/microbiology, and professor of pediatrics and cancer biology at the University of Massachusetts Medical School and Graduate School of Biomedical Sciences. Dr. Newburger serves on the scientific advisory board and executive committee of the SCNIR.



Amie Pritchett, Child Life Specialist

Pritchett is a child life specialist at the Children's Hospital & Regional Medical Center at the University of Washington. Pritchett is a graduate of the University of Idaho.

Akiko Shimamura MD, PhD

Dr. Shimamura is an associate professor of pediatrics in the division of hematology/oncology at the University of Washington. This Harvard graduate served her residency at Johns Hopkins University School of Medicine, Baltimore, and a fellowship at Boston Children's Hospital. Her clinical interests lie within inherited bone marrow failure syndromes and aplastic anemia. Dr. Shimamura specializes in Shwachman-Diamond syndrome, Fanconi anemia and Diamond Blackfan anemia.



“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

News In Brief: Patients Gain More Control Over Lab Reports, Medical Records; Free Sharps Container; Nanobugs and More

NNN Supports Move to Better Access

In March, the National Neutropenia Network (NNN) and Shwachman-Diamond America (SDA) sent out a joint statement endorsing the move to electronic health records (EHRs). In particular, the two groups commended the recent partnership initiative of Google Health and Quest Diagnostics, Inc.

The partnership between Google Health and Quest Diagnostics will allow patients to view their diagnostic laboratory testing information electronically. Under the reported terms of the collaboration, Quest Diagnostics is developing solutions that will allow physicians to provide their patients with easy and secure electronic access to their diagnostic test results.

Quest Diagnostics' proprietary Care360 patient-centric physician portal will serve as the platform for securely transferring patient diagnostic laboratory data into a Google Health account, at the user's request. Google Health will allow patients to manage their health information online.

"This is a wonderful way for technology to impact the lives of those who suffer from serious medical conditions," says Lee Reeves, NNN president. "Our neutropenic patients will benefit from access to their lab records. It will arm them with valuable data and help assure that they make good medical choices based on the most current information."

"This would be a great resource for families dealing with neutropenia," adds SDA president, Pattie Curran. "I think that it is excellent that patients will have access to their lab records and will be able to better manage their own care. With a serious health condition like severe chronic neutropenia, reducing the wait time for results can prove to be mission critical."

Reeves adds, "This will enable SCN patients to track their counts and print reports to present when seeking emergency care or to see other healthcare professionals. It will certainly help to convey the emergent situation these patients often find themselves immersed in."

PatientAssistance.com Helps Uninsured Patients Get Free Medication

Patient assistance programs are services offered by pharmaceutical companies for those who cannot afford their medication. Patient assistance programs are available to low income individuals or families who are under insured or uninsured, and are provided to those who meet the eligibility guidelines. Assistance may range from reduced cost of drugs to free medicine.

Explore the "comprehensive database" at www.patientassistance.com to find out if you may qualify. Qualification for any patient assistance program usual requires a total household income be less than 200 percent of the federal poverty level, the site reads.

Free Sharps Container!

Reportedly, needleusers may obtain a free sharps container through another Amgen-sponsored program. It is not required to become a member.

For more information, visit <https://www.enlivenservices.com/ra/ongoingsupport/forms/sharps-container.jsp> or call toll-free (888) 4ENBREL; (888) 436-2735.



Nanobugs.com Offers Infection Prevention Educational Tools

For products and info geared toward kids, parents, healthcare providers and teachers, visit www.nanobugs.com. The Web site offers Nanobugs songs, videos, coloring books and much more to teach children about bacteria and how to best steer clear of them. Reinforce the importance of thorough hand washing with fun and strategically placed static clings like this one featuring the *Clostridium difficile* bacteria. Each 2½" x 3½" cling attaches easily to mirrors and

windows and can be removed easily for cleaning.

Nanobugs playing cards and temporary tattoos also are available.

SCN Genetic Testing Available At GeneDx

GeneDx specializes in genetic testing for rare hereditary disorders, including severe chronic neutropenia. The company offers testing for the following:

Severe Congenital Neutropenia

ELA2 (Neutrophil Elastase, NE, Elastase 2)

HAX1 (HS1-associated protein X1)

Cyclic Neutropenia

ELA2 (Neutrophil Elastase, NE, Elastase 2)

Sequence analysis of the 5 exons of ELA2 and/or the 7 exons of HAX1 can be ordered on a single specimen, concurrently or sequentially.

The preferred specimen type for optimal turnaround time is blood (EDTA, 1-5 mL), but buccal (cheek) brushes will be accepted. Buccal brushes must be used for any DNA test if the patient has had a blood transfusion within 120 days or a bone marrow graft.

The GeneDx Web site has an ELA2 information sheet, a HAX1 information sheet, and payment options.

For more information, visit http://www.genedx.com/services/dis_cnc.php?gclid=CLLzzKH6uZACFRdPagod0xwpLA.

SCN CAMP: WHERE KIDS CAN LEARN ABOUT SCN



One great highlight of the Family Conference is the Saturday SCN Camp for children age 4 years to 14 years. SCN Camp, which takes place concurrent to the educational sessions, is an important element of this special weekend.

Join us for age-appropriate information for the children regarding their disease. Last year, one activity included "making blood," where the children used Red hot's candy and marshmallows for the red and white cells. The facilitator used this activity to explain and discuss neutropenia.

This year's event will be hosted by the following child life professionals from the Children's Hospital & Regional Medical Center:

- Amie Pritchett, CCLS
- Christa Peterson, CCLS; and
- Sarah DeProdoci

The important thing about the SCN Camp is that children leave feeling better about themselves, and more normal because for the first time in their lives they have interacted with other children who have neutropenia.

Help Us Help You!

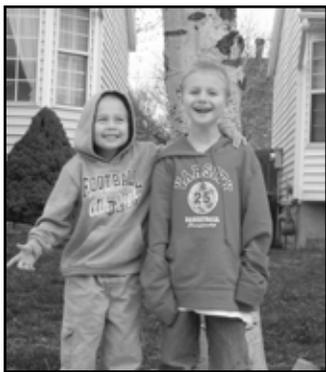
The National Neutropenia Network is working hard to help you.

We want to make a significant difference in the lives of those who suffer from severe chronic neutropenia.

Have an idea? Need something you know we could help with? Want to share a thought?

Please send your suggestions to Lee Reeves at leereeves99@gmail.com or Jennifer Schraag at nnnewsletter@yahoo.com.

Thank you!



Wyatt McPeek and his older brother, bone marrow donor, Kade McPeek

Kostmann's No More

Young Wyatt's Journey Thru Transplant

May 14, 2002 brought the "un-eventful delivery" of Wyatt McPeek, a healthy 5 lb 8 oz baby boy. "So home we went and had a normal ... day and a half," says his mom, Janet Hindmarsh.

"On the second day we took an afternoon nap, for several hours. I was surprised that I woke up before him and even more surprised at how hot he felt," Janet recalls. "His tempera-

ture was 102.5° F and he was not responsive at all. As I was searching for the doctor's phone number, they called me to confirm our appointment for the next day. The doctor happened to be standing next to the receptionist and told us to go immediately to the ER.

"Little did I know this would be the first of many trips," she says.

They checked his blood, urine, and spinal fluid and admitted him to the hospital. It was noted that his white blood cell count was low, and later that day, that he had no neutrophils. "Four days later, all the cultures were negative, his fevers were gone and we were going home under the assumption that this was just a bad virus and his counts would recover in a few weeks.

Janet says the doctor called and had been up all night thinking about "little Wyatt." She said she had done some research and consulted with colleagues and thought that a hematologist should check him over before they went home. "I will forever be grateful for this decision," Janet says.

Dr. Hardeo Panchoosingh, a pediatric hematologist with Arizona Pediatric Hematology/Oncology, PLLC, located in Mesa, Ariz., was called in. Panchoosingh wasn't ready to give Wyatt a solid diagnosis at that time, so he followed up closely; doing regular blood draws and count checks.

Time went on and his counts stayed zero. At age 3 months his umbilical cord still had not healed and was infected. "I was sure he had Kostmann's Syndrome," Wyatt's mom recalls. "For three months I cried every time I looked at him. I couldn't imagine losing him."

The hemot team decided it was time for a bone marrow aspirate, and with that came the diagnosis of congenital neutropenia. "It was another month of constant tears before I got a grip and started actively looking into support groups and figuring out his future," Janet recalls.

By this time, Wyatt was on Neupogen. Janet said it was difficult to keep his counts up. "He got sick with every virus that went around despite my best efforts at avoiding germs. We'd just get a decent neutrophil count, he'd get a virus, the count would drop and soon he'd have a bacterial infection to boot. Chronic ear infections, gingivitis, RSV, frequent fevers of unknown origin, ..."

Further complicating things, Wyatt was born with kidney problems. The valves between his bladder and his kidneys did not function properly, so the urine free-flowed back and forth. He was on daily antibiotics for 14 months to prevent a urinary tract infection. Janet said Wyatt's ANC finally was stable enough to do the surgery to fix this problem. The surgery was a success and he recovered without infection.

"At this point I still was not convinced of his (congenital neutropenia) diagnosis," Janet recalls. "I wanted dead proof. I had myself convinced that this still could be autoimmune and one day would just go away.

"The genetics proved me wrong."

Wyatt had the ELA2 gene mutation, and so did his father, Ryan. It was a 50/50 chance of any of our kids having the same disorder. What a blessing that our first was healthy.

Wyatt continued on with more ear infections, strep throat, cellulitis, infected cuts, etc., etc., until one day again his neutrophil count was zero no matter how much Neupogen he was given. "We tracked the Neupogen

bottles to make sure they weren't bad," Janet recalls.

They were desperate to find an answer.

Dr. Esteban (Steve) Abella, Dr. Panchoosingh's colleague, thought he saw an odd cell on the latest bone marrow aspirate. He said that it looked like parvovirus. "The pathologist essentially told him he was crazy," Janet explains, "but he went with it and did the appropriate testing. Sure enough it was a parvovirus B19 infection, and once it ran its course his counts started to come back up and we did not have to see the transplant doctor."

At least not yet.

Then, pink eye, ear infections, gingivitis, cellulitis, viral pneumonia, sinusitis and bone pain all followed. "I spent many nights massaging his legs and he took a lot of ibuprofen. The constant pain made him fussy and very sensitive. If he got bumped into, no matter how lightly, he cried like he'd been slugged."

Wyatt then had to undergo another urologic surgery, and acquired pneumonia the next week.

"That was my breaking point," Janet asserts. "I couldn't take any more. Surely a bone marrow transplant had to be better than this. Even death had to be better than this. What kind of life was this for him? Not a life I would want to endure, and it was even worse watching him suffer."

The doctors agreed to test the family for a match, although with only one sibling, the family was told not to expect one. "While we waited to find out, he got tonsillitis and the stomach problems worsened. Then miracle of miracles, his older brother was a perfect match!"

Janet says this is when she came to the "most difficult decision I've ever had to make."

"I wanted someone to tell me, 'Yes, you need to do this.' That didn't happen. But we decided to go ahead anyway. The transplant doctors were very supportive of our decision." Although at that time, even the experts at SCNIR didn't recommend this treatment.

Now, the sinus infection he'd had for eight months had to be cleared up before transplant, Janet recalls. So he was started on a preparatory regimen of antibiotics, antifungals and antivirals. "On July 18, 2005 his central line was placed and chemo was started. This was the easiest hospitalization for me of all of them. I think only because it was planned and there was a goal of health at the end of it.

Janet says, "I won't go into transplant details except to say that overall things went very well with few complications. It was a long road to get him through it and recovered from it, but finally, in February of 2006, we had a healthy and pain-free little boy. I decided at that time that even if it only lasted a couple months it was worth it."

Wyatt was cured of Kostmann's Syndrome. Wyatt no longer has the increased risk of leukemia or osteoporosis. He no longer has the regular Neupogen shots and doesn't suffer from the bone pain. He doesn't get sick so often from infections.

"Kade willingly gave his bone marrow so that Wyatt could have a healthy life. Kade was a trooper throughout the entire process. What little angels I have been blessed with."

So how have things been over the past year?

"Wonderful," Janet says. "I will never take for granted watching Wyatt run and play without pain or constant illness. His big brother is his best friend and still looks out for him."

For a full update on how Wyatt is doing, and to read a Q&A with Janet on how she made her decision and the challenges and triumphs she faced, visit the "Success Stories" page at <http://neutropenianet.org>.

To learn more about bone marrow transplants in patients with severe chronic neutropenia, join us in Seattle for a thorough discussion on Saturday afternoon, July 19.

Help Is Out There

Conference Helps Bring People Together to Share Tips, Information

By Cyndi Lieske

Tammy Loader logged 8,000 miles and paid an extra \$1,000 in medical copays the year her daughter, Kara, was diagnosed with Kostmann's Syndrome. Knowing that other families may be facing similar struggles, Loader is encouraging them to search the Internet for financial resources.

In Ohio, where the Loader family lives, there is a "Bureau for Children with Medical Handicaps." The office provides financial support for families meeting a specific income limit. Other states may have similar organizations set up to assist families, Loader said.

During the Friday night meeting at the 2007 Neutropenia Family Conference many families discussed ways to find financial resources. Loader said local health departments are a good place to start a search for information.

"A lot of areas have resources available that people don't tap into," she said. The Loaders have not qualified for aid in the past, but they may be looking into it again. "I know there were three other families from Ohio at the conference," she said. "They might be able to benefit from the Bureau for Children with Medical Handicaps."

Loader suggests searching on the Internet on Google or Yahoo! with the key words like "financial resources" for people with "medical conditions." Doing such a search, Loader was able to find other states with programs similar to the one offered in Ohio.

Another way to find help is to look for employment information for adults with neutropenia. In her work as a vocational rehabilitation counselor,

Loader works with individuals with disabilities. When she tells others of the programs and what they offer, many are surprised to know that they exist.

"A lot of people call it Ohio's best-kept secret," she said. "Most people don't pay attention to information about what is available to people with disabilities until they have one."

She said she talked with others at the conference that had employment questions. She said she would encourage them to look into vocational rehabilitation programs for assistance with employers.

"They can work with the employers to find a good fit with a person's abilities," she said. "Employers are required to make accommodations. There can be things like flexible scheduling – there are a lot of different types of accommodations. If someone with neutropenia needs to do injections, and their injection time comes when they are at work, they can take a break so that they can go do that."

Every state has a vocational rehabilitation program, most are divided by county. The Job Accommodation Network at www.jan.wvu.edu has many resources to help with questions about employment. It also has a link to www.disabilityinfo.gov, a federal Web site with information of interest to people with disabilities, their families, employers and service providers. The site has a links to local programs for each state.

"You can go to the map and click on your location and it will give you information," Loader offered. "Every state has a vocational rehabilitation program."

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