

## Researcher, Hematologist Dan Link, MD to Share Recent Studies

Daniel Link MD to speak for first time at Family Conference The Network is pleased to announce Daniel Link MD as a featured speaker at the 2010 Family Conference.

Dan is a professor of medicine at Washington University School of Medicine in St. Louis, a board member of Severe Chronic Neutropenia International Registry, and a dedicated researcher of SCN.

“We are fortunate that Dan is able to make it to the conference this year,” says Lee Reeves, “His work is on the cutting edge of research that could transform the way we treat neutropenia.”

Dan’s talk will focus on today’s most exciting and promising medical research; research that has the potential to one day radically change the clinical approach to managing all types of disease.

His presentation will cover two cases where neutrophil development is disrupted. He will discuss how current investigations may lead to novel treatments. In one case a new drug that targets mutations of CXCR4 receptor gene holds promise as a novel therapy for one type of neutropenia.

In another case new therapeutics may be developed as a result of research on an ELANE mutation which is believed to interfere with neutrophil development by overwhelming the cell with misfolded proteins which cause the cell to die.

Dan’s talk will also concentrate on two exciting and innovative approaches to research. The first, stem cells, hold incredible promise for curing disease in the future. Dan will cover how stem cells are being made from adult tissue and how this may one day lead to new therapies and even cures for those who suffer from neutropenia and other diseases.

Whole genome sequencing is another ground-breaking area of research that has the potential to change how neutropenia is treated. Recent advances in our ability to sequence genes on a large scale have made sequencing of entire genomes feasible. This approach has tremendous potential to identify the genes responsible for all types of neutropenia (including idiopathic) as well as the gene mutations that contribute to leukemia development.

Dan will review how whole genome sequencing is done and how it is being applied to cancer and inherited diseases.

### IMPORTANT!

Reserve your room at the beautiful Rancho Bernardo Inn by June 16. That is the cut-off date for the room block reserved by the National Neutropenia Network guaranteeing a room rate of 149.00 plus tax.

Visit us online at: [www.neutropenianet.org](http://www.neutropenianet.org),

# National Neutropenia

## N E T W O R K

### A Decade of Dedication

#### NNN Hosts 10<sup>th</sup> Annual Neutropenia Family Conference

The 10<sup>th</sup> 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 (SCNIR).

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.. A special program for children and youth will be held in conjunction. The SCN Kids Camp is a fun-filled experience for children with SCN and their siblings.

For more details and regular updates, please visit [www.neutropenianet.org](http://www.neutropenianet.org) regularly.

Be sure to mark your calendars and **Join Us at Rancho Bernardo!**

*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.*

#### Neutropenia Family Conference

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

#### Conference Agenda

Friday, July 16

Opening Session  
**Thirty Years of Treating Neutropenia**  
*Mary Ann Bonilla, MD*

This presentation will set the tone for the conference as Dr. Bonilla shares a moving narrative of treating patients in the years before neupogen when antibiotics were the only therapy and individuals with neutropenia lived under the constant threat of life-threatening infections. She will talk about her work with Dr. Karl Welte in early trials of granulocyte colony stimulating factor, her current practice and hopes for the future.

**Meet and Greet Reception**  
Attendees will gather together in an informal setting to enjoy delicious and plentiful appetizers.

**Coping Skills for Challenging Times**  
This get acquainted session will bring patients and families together to share the challenges of living with neutropenia. It will serve as an ice breaker where individuals share their stories, guided by a facilitator who will steer the discussion toward discovering inner strength and developing successful coping skills.

*...continued on page 2*

#### PRIVATE CONSULTATIONS AVAILABLE

Patients may meet with physicians at scheduled intervals throughout Friday afternoon.

Apply online; every effort will be made to accommodate all applicants.

**This is one of the most valuable segments of the program.**

One person said their consultation with an expert “gave them their life back.”

#### PAST ATTENDEES SAY CONFERENCE MADE A DIFFERENCE:

“During the ins and outs of our daughter’s medical history, I grappled with thinking that one day I would have to help her die. In meeting so many people who live with this disease, I now have great hope that this is not the only scenario for my family.”

“I took away the feeling that we are not alone but gaining a bigger and better support group.”

“It is so nice to interact with all the doctors. How did we luck out with so many wonderful ones...they are so accessible and deserve a lot of credit.”

“Very valuable, I learned a lot, met great people.”

“I don’t ever want to miss another conference.”

“I loved the ‘Ask the Doctor’ sessions.”

The doctors have given me so much info to relate to my doctors at home, so I can have better care.

“The conference changed my life.”

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Severe Chronic Neutropenia International Registry  
University District Building  
1107 NE 45th Street, Suite 345  
Seattle, WA 98105

## DID YOU KNOW?

The first finding of Cyclic Neutropenia occurred in 1910.

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### Saturday, July 17

#### My Favorite Cell: Peter Newburger, MD

Dr. Newburger will start off Saturday morning with the basics: a discussion about structure of the neutrophil and how it functions in the body. He will include an explanation of the different types of neutropenia: congenital, idiopathic, cyclic and autoimmune.

#### Current Research on Neutropenia and its Implications for the Future: Daniel Link, MD

Dr. Link will discuss research related to identifying the mechanisms that regulate the trafficking of neutrophils and hematopoietic stem cells from the bone marrow to blood. He will discuss the gene mutations responsible for neutropenia and implications for leukemia progression. He will also share how the latest research in the area of adult stem cells and human genome sequencing may impact patients in the future.

#### Lessons from the Registry: David Dale, MD

Dr. Dale will discuss years of research conducted through the Registry and how it has impacted the way neutropenia is understood and treated. He will talk about current studies and their implications for patients.

#### Beyond the ANC—the Clinical Aspects of Living with Neutropenia: Laurence Boxer, MD

Dr. Boxer will talk about living optimally with neutropenia. He will cover topics including: infection prevention, the importance treating the patient and not the numbers, dosing, pregnancy, and bone health.

#### Managing Oral Health for Neutropenic Patients: (speaker to be confirmed)

Oral health and hygiene is one of the greatest challenges of living with neutropenia. Even with the best care and treatment, some patients experience recurrent mouth sores, chronically inflamed gums and bone loss. The presenter will talk about the role of the neutrophil in oral health and discuss the best hygiene techniques and practices for neutropenic children and adults.

#### Break-out Sessions #1: “Ask the Experts.”

These sessions will address the specific concerns each type of neutropenic patient faces and will be divided into the following categories: congenital, cyclic, idiopathic, autoimmune and pediatric idiopathic.

#### Break-out Sessions #2: “Living with Neutropenia”

- 1.) Key Strategies for Parenting a Child with Chronic Illness: Theodora Alves Craigen, a licensed family therapist, will offer tips to help make life easier for parents of children with neutropenia. Her approach to the topic will be both as a professional therapist and as a mother who has parented a child with neutropenia. The session also will include some time for parents to talk about their concerns.
- 2.) Negotiating Life When it Contains Chronic Illness

#### ~ Saturday Evening ~

Dinner and casual socializing after an information-packed day, a time to relax, debrief and deepen the personal connections made in workshops.

#### SCN Camp for Kids: Saturday Concurrent Children’s Program ~ 9 a.m. to 4 p.m.

One of the highlights of the Conference is the Saturday SCN Camp for children aged 4-14 years which takes place concurrent to the adult program. This is an important event for families. It gives parents a chance to take in educational sessions while knowing their children are in a healthy and stimulating environment. The Rancho Bernardo is a family friendly property with ongoing children’s programs to complement our more specialized program.

The morning session will include activities for all ages. The emphasis is not on sickness but on having a meaningful and fun experience in safe atmosphere where children can meet others who face similar challenges.

Sandy Reid, a children’s art teacher in the San Clemente area

with a degree from the Academy of Social Pedagogy in Munich will be leading the afternoon session where children will be guided to make their own cartoon characters and create a story to go along with them. Sandy approaches the teaching of art to children with an emphasis on freeing the imagination and helping each child to discover his or her own personal style.

She has been recommended for the positive encouragement and gentle guidance she brings to the process of helping children experience their own creative potential. To learn more about Sandy Reid, visit her website at sandysartstudio.com

Throughout the afternoon children will given opportunities to take breaks and participate in other fun activities.

National Neutropenia Network



Lee Reeves at the 2009 Family Conference

The National Neutropenia Network newsletter is published twice a year.

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#### Sunday, July 18 Networking Breakfast and Closing Session: Where Do We Go From Here?

This final session of the conference is facilitated by Lee Reeves of the National Neutropenia Network.

This is primarily an open forum where attendees are invited to share their ideas to improve future conferences and to let us know how the NNN can better serve them.

## TRENT OVERCOMES SHOCK, FEAR TO LEAD NEAR-NORMAL LIFE WITH NEUTROPENIA

Trent Roehler experienced a healthy childhood, rarely getting sick, never seeing the inside of a hospital and enjoying nearly perfect attendance in school. He played sports while growing up and in college he even played for the Chicago White Sox minor league organization. By all accounts Trent was a strong, athletic, healthy person.

Everything changed two months before his 29th birthday when he got a canker sore on his tongue that wouldn’t go away. A quick round of antibiotics and antiviral cleared it up. Trent thought he was back to normal, but the sores came again and again, each time getting worse. His tongue would swell to the point where he couldn’t eat because it hurt too much and sleeping became difficult. At one point he was barely eating or sleeping and on New Years Eve he nearly fainted at the family dinner table.

The next morning he went to the ER where he was told he had either AIDS or leukemia. “My world was shaken to the core. I had a wonderful wife, two young children, how could I leave them without their husband and father? It was the worst day of my life.”

Twenty four hours later AIDS and leukemia were ruled out but Trent’s labs revealed a low neutrophil count, and a bone marrow biopsy confirmed a diagnosis of neutropenia. Fortunately several months after his diagnosis Trent was given Neupogen and his neutrophil count went up. This led him to believe that his condition would magically go away.

Unable to accept the diagnosis as a life-changing event he treated it more like a nuisance believing Neupogen was a cure. That worked for about a year until he began having dental problems, one root canal after another, all told, 6 root canals over a 5 month period and an infection in the jaw bone that lingered for months.

In 2006, when he searched the internet for answers on his new condition, he was frustrated by the lack information. Then he learned about the 2007 Family Conference in Ann Arbor. His wife begged him to go but he insisted he didn’t need to, that he’d done the research and figured there was nothing new to learn. Childcare for their two small children was also a problem since they would

need to travel from Kansas City to Ann Arbor.

By rare coincidence his parents happened to be in Detroit visiting family the same weekend as the conference. “I decided it was a sign that we should go, so we packed up the car and arranged for my parents to stay and watch our kids, while my wife and I attended the conference. We met many people who had been in similar situations, people who led long, healthy lives until one day everything changed, as it did for me. They shared similar experiences, similar misdiagnoses, they shared their fears and their difficulties in finding support.”

At the Conference Trent learned about the Registry and the chance to receive his meds at no cost while contributing to research on neutropenia. Most importantly Dr. Boxer recommended he take smaller doses of Neupogen more frequently. “It was very liberating for me to realize that I was not alone, to learn that although I was taking the medication, my problems were due to an improper dose schedule. It was the best thing I have ever done to help me cope with this disease.”

Though he is not totally symptom-free Trent has noticed a marked decrease in symptoms. He lives a very normal life and now believes he has a manageable disease, “something that is a part of me, but doesn’t define me.”

When Lee Reeves met Trent in Ann Arbor and learned he was a CPA with an interest in helping out the NNN, she asked him if he would serve on the board and he agreed. “Trent’s contribution has been invaluable,” she said. “He brings fiscal oversight and practical input to the Board. Trent is a thoughtful and caring person, someone we can count on.”

Although it has been a scary road for Trent, he feels fortunate to have some great people help him along the way, and credits much of his good attitude and fortune to his wife who has always been his greatest supporter and encouraged him to serve on the Network’s board.

“I’m glad for a chance to give back, to have a part in assuring the NNN is available for people when they need it most.”

“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, at the 2009 Family Conference

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

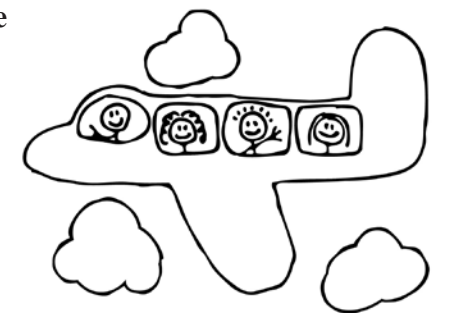
**National Patient Travel HELPLINE Program**  
Call (800) 296-1217 or visit [www.patienttravel.org/resources.html](http://www.patienttravel.org/resources.html).

**Northwest Airlines KidCares**  
KidCares applications may be found at [http://www.nwa.com/corporate/aircares/about/KidCares\\_Application.pdf](http://www.nwa.com/corporate/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](mailto: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 or may not meet the medical requirements to obtain the above flight services. Please research each one carefully.