Researh, 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 research that could transform the way we treat neutropenia. 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.

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.

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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,
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 increasingly 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.”

Though he is not totally symptom-free Trent has noticed a marked decrease in symptoms. He lives a very normal life now and is able to be the wonderful father he always was. "I’m glad for a chance to give back, to have a part in assuring that the NNN is available for people when they need it most." Trent still credits his wife for much of his good attitude and fortune to his wife who has always been his greatest supporter and encouraged him to serve on the NNN board.

One root canal after another, all told, 6 root canals over a 5 month period... 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 increasingly difficult. At one point he was barely eating or sleeping and on New Years Eve he nearly fainted at the family dinner table.

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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 the time to learn about 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.

Northwest Airlines KidCare
KidCare applications can be found at http://www.nwa.com/corporateInformation/facts/KidCare_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.aac.com/content/amrcorp/corporateInformation/facts/ amrcorp.html.

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) 621-7717 or visit http://aircharitynetwork.org/Home/tabid/90/Default.aspx.