

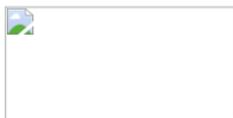
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# Spring 2020 Newsletter

## 2020 Virtual Conference

Friday, June 12, 2020

Thanks to our conference sponsors, X4 Pharmaceuticals.



The 2020 Neutropenia Virtual Conference is a time for individuals and families of all ages and all types of neutropenia to come to listen to experts, learn, and spend time together. This conference will be held through Zoom, courtesy of the University of Michigan-Ann Arbor.

Attendees will have a chance to hear presentations covering COVID-19 precautions, diagnostics, and participate in breakout sessions.

[Visit our website for schedule and registration.](#)

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## Update from the SCNIR

### Message for patients with neutropenia and their families

by David C. Dale MD for the SCNIR

The staff and physicians for the Severe Chronic Neutropenia International Registry (SCNIR) continue to work very hard on your behalf to understand neutropenia and to find best ways for its diagnosis and treatment. Our principal offices are in Seattle WA and Hannover Germany. The Registry depends upon voluntary participation of hundreds of patients, families, nurses, physicians, and other healthcare providers in more than 60 countries, held together for more than 25 years by a shared commitment to improving the lives of patients with neutropenia through clinical trials and basic research.

## Helpful Resources

Emergency Room Card

[English ER card \(PDF\)](#)

[Español ER tarjeta \(PDF\)](#)

Need another language,

[Contact us.](#)

[ANC Calculator](#)

[E-Cards: submit & send](#)

[SCNIR](#)

Information on types of neutropenia, management, and more at:

[National Neutropenia Network](#)

## Checking In

with our Junior Ambassadors

Back in the Fall we proudly introduced our inaugural Junior Ambassadors. You can read about how their inspiring works have had an impact on our Neutropenia community [here](#). We recently touched base with our Junior Ambassadors to see what they have been up to since then. Not only do we find their dedication to the Neutropenia community to be refreshing, but we LOVE hearing about their "everyday" lives too!

Ella Jewell has been busy "starting my own Instagram account to encourage all people to stay positive." You can follow Ella @ellajewell2.

Jaija started her next service project of hand knitting blankets and scarves for sick children in the hospital.

Kara is a sophomore in high school and decided to apply for college credit. We cannot wait to see what's next for her.

Liam had the opportunity to run on his high school's varsity cross country team with his bother, Evan. Be sure to read what they received at the end of their season. P.S. Way to go, Liam & Evan!

Lukas has been busy with his twin sister doing many fun activities, including the chance to feed one of his favorite animals at the zoo--- the giraffe.

The Registry provides valuable information on the effectiveness and long-term outcomes for patients treated with G-CSF. Your annual reports and communications to us about how well you are doing and adverse events are extremely valuable. Please keep them coming. The long-term follow-up information is really important. We have several recent published reports listed on the website on the effectiveness and safety of Neupogen for severe chronic neutropenia.

What's New for the SCNIR: Updated website, working with Athelas on a home-monitoring device, and updating information regarding transplants, WHIM Syndrome, ELANE neutropenia, gene editing, and study with X4.

Many of you have been very generous in supporting the SCNIR. Right now because of a gap in our NIH support, your gifts are particularly meaningful. Utilizing your previous gifts we have sufficient funds to continue of our current activities until the NIH application is reviewed and score in June 2020. Thank you very much. (There is an opportunity to give to the SCNIR through the virtual conference registration).

NNN Summer 2020 Update Meeting: We have a Zoom meeting set for Friday, June 12, 2020 to catch up with you and answer questions. We look forward to talking with you.

The National Neutropenia Network truly appreciates the vital partnership we have with the SCNIR.

Thank you for all you do for us.

[Please read their full update here.](#)

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The Rare Diseases Clinical Research Network launched a research survey for rare disease patients and their families about the impacts of COVID-19. Thank you for helping with this important research initiative.

[Please follow this link to participate:](#)

Give Today

Volunteer

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The team at [National Neutropenia Network](#) wants to extend a hearty 'thank you' to all of our wonderful readers. You've helped make our community shine, and we want to keep that going! For more information on our mission and how you can help visit [our website](#).

Thank you to all of our Junior Ambassador's for being awesome role models for the other Neutropenia kids in our community!! Do you have a child who would like to be a Junior Ambassador for the National Neutropenia Network?

Read their full stories and find out more information about our ambassador program [here](#).

## Karen's Story

Let's start with the good news. Those big events you are afraid you are going to miss, I'm here to tell you that you can be there and participate in all of them. After your diagnosis, life can be "normal" and, with a little luck, extraordinary.

In my late twenties, I began to get sick often. In my early thirties I was dealing with some sort of illness and fatigue most of the time. My husband and I were raising two young children, and I was just so tired. In 1996, I was hospitalized with strep and mononucleosis, and that was the first time that G-CSF was used successfully to help me fight an infection.

After the hospitalization, we began to search in earnest for an answer for my symptoms. Over the next couple of years we met with several experts who ordered bone marrow biopsies and countless blood tests looking for answers. Like many of you, we were given a variety of misdiagnosis, the worst of which was terminal cancer. Finally a hematologist gave us a diagnosis of a chronic blood condition.

[Read the rest of Karen's story](#)

