

Winter 2019 Newsletter

Rare Disease Day February 28, 2019

The National Neutropenia Network was a part of the "Rare Disease Day" at the National Institutes on Health (NIH) in Maryland. Our posters, made by Sarah Mullady, marketing & communications volunteer, were hung alongside other rare disease posters for the annual event.

Rare disease day takes place annually around the world on the last day in February. Events such as these promote awareness of rare diseases to policymakers and to the public, sharing the impact rare disease can have on individuals.

According to the National Institute on Health, about 7,000 rare diseases affect humans, of which only a few hundred have any treatment. Although each rare disease affects fewer than 200,000 Americans, in total, these illnesses affect an estimated 30 million people in the United States.

Rare diseases are difficult to diagnose, often taking years to obtain a diagnosis. In addition, treatment is unavailable, because only about 5 percent of rare diseases have a treatment approved by the Food and Drug Administration.

If you wish to promote neutropenia awareness, click [here](#) & [here](#) to download the posters (seen in picture below). A huge thanks to Ashley Cornett for hanging our posters at the event!

Many have us have neutropenia or know someone who does. We can make a difference by raising awareness of this rare condition.

New! Support Our Work Just By Donating Your Change

We have partnered with a new mobile app and website that allows you to automatically donate the change from your card purchases to support our work. It's small change for you, but a game changer for us! [You can check it out](#) and search for "RoundUp App" in the App Store or Google Play Store to download to your phone.

Make a Difference! Volunteer

Become a part of our network. Give your time and make a difference for individuals with neutropenia and their loved ones. Our network relies on

Helpful Resources

Emergency Room Card
[English ER card \(PDF\)](#)
[Español ER tarjeta \(PDF\)](#)

[ANC Calculator](#)

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

Information on types of neutropenia, management, and more at:
[The Severe Chronic Neutropenia International Registry](#)

[Ella Jewel Foundation](#)
[Cohen Syndrome Association](#)

Sharing his Story: Taylor Carlton

Taylor Carlton was a healthy, active kid... until middle school. Around 12 years old, he contracted a severe eye infection that caused his whole life to change. The doctors treated the infection aggressively- instead of focusing on his grades and social life, Taylor was reduced to visiting the nurse's office hourly for eyedrops. At night, he was waking up every other hour to continue treatment. In the end, Taylor had to have a cornea transplant to save his eye. Afterwards, the doctors discovered Taylor had contracted a common water born infection, one that his body should have been able to fight off. As he would later discover, the infection was not the only culprit.. [Read his full story here.](#)

Doctor's Corner

Question: How can cyclic neutropenia can be inherited if no one had ever had it before in the family? Was the Gene always there and then another was born and it changed just a little to create a child with cyclic neutropenia?

Answer: Dominantly inherited disorders often arise by new mutation in the affected child. Previous generations do not have the disease, but the affected individual's future children have a 50-50 chance of having it.

Alternatively, a dominant disorder can have "incomplete penetrance" as proposed by the question writer, so some past family members have the gene mutation but don't show the disease. However, we have not seen that in cyclic neutropenia.

Thank to Dr. Peter Newburger for providing our answer. Peter E. Newburger, MD, is the vice chair of pediatrics and director of the Division of Pediatric Hematology and Oncology at the University of

volunteers for many roles. If you have skills and availability, let us know. We are currently looking for the following needs:

- Social Media-Twitter
- Fundraising Research
- Publicity Team
- Salesforce Setup
- Marketing Communication
- Neutropenia Ambassadors-spreading the awareness of neutropenia in your area by holding an event, booth, or other idea

If you are interested in the above opportunities-or have other skills you believe would help the Network, please contact [Kate](#). Thank you!

- Over 110 individuals contacted us for patient or peer support
- 80 individuals attended our Conference in July
- invited & attended the Cohen Syndrome Association's conference in June
- Attended the SCNIR Business & Scientific Meeting in November
- Updated our Peer Support Volunteer Handbook & training
- Created e-cards through our website

Thanks for supporting us and making 2018 a great year!
We look forward to supporting you in 2019!

Give Today

The National Neutropenia Network depends on support from the friends and families of those whose lives have been forever changed and challenged by this rare disease. Thank you for your support.

Massachusetts Medical School. He also serves as professor of Pediatrics and Molecular GeneticsMicrobiology and professor of Pediatrics and Cancer Biology at University of Massachusetts Medical School and Graduate School of Biomedical Sciences. Dr. Newburger serves on the scientific advisory board and executive committee of the Severe Chronic Neutropenia International Registry.



Thanks for Subscribing

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](#).