August 2022

Neutropenia Educational Sessions



Neutropenia is a serious health risk. Those who are neutropenic have an increased likelihood of developing life-threatening and potentially fatal sepsis. Chronic neutropenia is a life-long condition that one does not outgrow. Therefore, it is important to be aware of the risks of neutropenia while trying to maintain a balance in living a normal life. The key to this is to be educated about the risks and aware of treatment options for neutropenia. In so doing the individual who has neutropenia and caregivers are equipped with the knowledge they need to make informed healthcare decisions

The concerns a caregiver and the individual who has a health condition where neutropenia is a symptom changes a bit over time. The primary concerns a parent would have for an infant child with neutropenia changes as the child grows older. Eventually the child needs to become an advocate for their own health. Therefore, it is important to pave the way through this transition process so that the young adult is prepared to make informed healthcare decisions about their own health.

The National Neutropenia Network and the Barth Syndrome Foundation will be hosting a neutropenia educational series for the next four months. We invite you to join us as we learn about neutropenia from experts who will focus on the specific concerns patients and parents have expressed about living with or raising a child who suffers with this lifelong condition. The sessions will be segmented in the following age groups.

Newborns Infants Toddlers and Preschoolers with Neutropenia (0 to 4 years)

Thursday, Oct. 27th, 2022, 12:00 PM ET Registration Here Jolan Walter, MD, PhD, FAAAAI, Robert A. Good Endowed Chair, Pediatric Allergy and Immunology, University of South Florida, Tampa, FL

Kelly Jo Walkovich, MD, Clinical Associate Professor,

Helpful Resources

Emergency Room Card
English ER card (PDF)
Español ER tarjeta (PDF)
Need another language?
Contact us.

ANC Calculator

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

National Neutropenia Network

Message from Kate



It has truly been a pleasure working with all of you through the National Neutropenia Network for the past decade. I began as a board member in 2012 and worked with Lee Reeves and many others over the next five years. Then, when Lee retired, I began working as the Executive Director.

During my time with you, we have seen many changes.
From an in-person conference in 2018 to having 3 virtual conferences to keep us all safe. We had to deal with the pandemic and what that means for those with

Pediatric Hematology and Oncology, C.S. Mott Children's Hospital, Ann Arbor, MI

School Age Children with Neutropenia (4 to 10 years)

Friday, Sep. 23rd, 2022, 12:00 PM ET Registration Here James A. Connelly, MD, Pediatric Hematology and Oncology, Vanderbilt University Medical Center, Nashville, TN

<u>Tammy Loader</u>, Parent and Parent and Patient Advocate, Cambridge, OH

Tweens and Teens with Neutropenia (10 to 18 years)

Thursday, Aug. 25th, 2022, 12:00 PM ET Registration Here Thomas Michniacki, MD, Clinical Assistant Professor, Pediatric Hematology and Oncology, C.S. Mott Children's Hospital, Ann Arbor, MI Liam Lakhia, Neutropenia Patient and Patient Advocate,

Adults with Neutropenia (18 + years)

Cincinnati OH

Friday, Nov. 18th, 2022, 12:00 PM ET Registration Here Eric Scott, PhD, Clinical Associate Professor, Pediatric Psychology, C.S. Mott Children's Hospital, Ann Arbor, MI Heidie Rothschild, DHSc. MHA, BS FACCP, Neutropenia Patient and Patient Advocate, Baltimore, MD

COVID Vaccinations & Boosters

The neutropenia "experts" recommend following CDC guidelines, as no modifications are necessary for neutropenia. They all recommend getting the vaccines and booster doses are safer than becoming infected with SARS-CoV-2.

Volunteer

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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.

compromised immune systems. Our peer support and patient support programs grew. An Ambassador program for our teens as well as adults was added. The National Neutropenia Network was able to build and establish great relationships with the Severe Chronic Neutropenia International Registry (SCNIR), Barth Syndrome Foundation X4 Pharmaceuticals, Cohen Syndrome Association, PAN Foundation, and many others.

To the best doctors that I had the privilege of working withyou know who you are! Stay cool.

To our current and past board members, thank you for the honor to work as one of the leaders of this great organization. I cannot wait to watch it grow.

Most importantly, to the many individuals I was able to connect with over the years: keep on advocating for the best care, making sure research is a priority to find better treatments and a cure. and continue to provide awareness and education to patients and medical professionals around the world who need to know about neutropenia and how an individuals feels with this chronic condition. P.S. Fatigue is real! (I had to get that in there).

Truly, it has been a pleasure working with all of you. I wish all of you and the National Neutropenia Network nothing but the best. Take care, Kate

(An introduction to the new Director will be in the next issue).









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