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# Spring 2021 Newsletter: National Neutropenia Network

## Save the Date: June 18, 2021

### Neutropenia Virtual Conference

We are excited to announce the date of our virtual Neutropenia Conference, Friday, June 18, 2021, 1pm-6pm ET. Please mark your calendars.

Information regarding topics, breakout sessions, and registration will be posted in our next newsletter.

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## Introducing RareConnect

A safe, easy to use platform where rare disease patients, families and patient organizations can develop online communities and conversations across continents and languages. RareConnect partners with the leading rare disease patient groups to offer global online communities allowing people to connect around issues which affect them while living with a rare disease.

[A neutropenia community as been created to share stories, resources, and on-line community for you.](#)

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## Q & A: COVID Vaccines

by Peter E. Newburger, MD & David C. Dale, MD

**Question: are there any special precautions that an individual with neutropenia needs to take after they have received their vaccine(s)?**

Answer: Our advice is to follow [the standard CDC guidelines](#) for those who have received the COVID-19 vaccine: If you are already observing additional precautions because of neutropenia, those can and should be maintained.

Neutropenia patients should get immunized as we have no information to indicate that they will have unusual reactions to the vaccines.

## 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](#)

[Barth Syndrome Foundation](#)

## MAVORIXAFOR Clinical Trial

A study of Mavorixafor in participants with Severe Congenital Neutropenia and Chronic Neutropenia disorders.

This Phase 1b study will determine the safety and tolerability of Mavorixafor in participants with severe chronic idiopathic neutropenia (CIN) and selected congenital neutropenia disorders. The anticipated enrollment is up to 45 participants.

Four sites have opened for this clinical trial: Ann Arbor, Michigan; Seattle, Washington; Iowa City, Iowa; and St. Louis, Missouri.

*To learn more about this study, you or your doctor may contact the study research staff using the contact information provided by the sponsor. Please refer to this study*

**Question: should individuals with any type of neutropenia follow a 'neutropenic diet'?**

Answer: Individuals with neutropenia should not be advised to follow a neutropenic diet, which was once thought to prevent infections. Individuals should make sure to properly handle and wash fruits and vegetables, follow safe handling to prevent contamination, and focus on safe food-handling practices

by its [ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT04154488) identifier (NCT number): **NCT04154488**

Please visit [our website](#) for additional information regarding criteria and exclusions.

Please [visit the clinical trial website](#) for additional criteria, exclusions, and additional information.

**Webinar: The Natural History of WHIM Syndrome: Learnings From an International Cohort**

- Wednesday, April 7, 2021, 8pm ET (5pm PT) ,
- Wednesday, April 28, 2021, 12pm ET (9am PT)

X4 Pharmaceuticals invites you to join them for a 1-hour, educational webinar titled **THE NATURAL HISTORY OF WHIM SYNDROME: Learnings From an International Cohort**. This webinar aims to provide an overview of WHIM syndrome, focusing on a recent study evaluating the natural history and the impact of delayed diagnosis on morbidities in the WHIM syndrome patient population. The clinical presentation and diagnostic journey of WHIM syndrome will be highlighted through the case study of a family with WHIM syndrome. An audience Q&A will follow the presentation. This webinar will be relevant to health care providers who specialize in immunologic, hematologic, or dermatologic disorders.

Faculty presenters include:

- Dr. Jolan Walter – Division Chief, Pediatric Allergy and Immunology, University of South Florida and Johns Hopkins All Children’s
- Dr. Christoph B. Geier – Research Associate, Immunology Outpatient Clinic, Vienna

[Full PDF Flyer](#)

[Register here.](#)

**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](#).

**Vivien's Story**

My name is Vivien and I have Cyclic Neutropenia, which is a rare blood disorder. Its a disorder of the white blood cells, neutrophils, which fight bacterial infections. My count goes up and down in a 21 day-cycle, and usually lasts for about three to six days. And at the dangerously low point, without treatment, something simple as a cold could kill me.

[Click here](#) to read Vivien's full story.



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.

**Give Today**

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Quarterly Newsletter

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