

[View this email in your browser](#)

# Winter 2019 Newsletter

## 2020 Neutropenia Retreat

JULY 24-26, 2020



Westfield Center  
9079 South Leroy Road  
Westfield Center, Ohio 44251  
330.887.6511

The Neutropenia Retreat is a time for people and families of all ages and all types of neutropenia to come to share stories, learn, and spend time together. The Neutropenia Retreat will be held at Westfield Inn & Conference Center in Westfield Center, Ohio.

As in past years, participants in the 2020 Neutropenia Family Conference will have a chance to speak with the experts, hear presentations covering the latest treatment and research, and participate in programs geared toward managing life with neutropenia in it.

We are planning a weekend of learning and fun for the children. Kid's Kamp will be available for youth 4 years of age and older.

More details will be sent out in next newsletter and e-mail communications to those who register. Thanks!

Please visit the links below for more information.

[2020 Neutropenia Retreat Information](#)

[2020 Financial Assistance Applications](#)

[2020 One-on-One Consultations with Physician](#)

## Coronavirus

Of late February 2020, the Coronavirus has been detected in 57 locations internationally, including cases in the United States. The virus has been named "SARS-CoV-2" and the disease it causes has been named "coronavirus disease 2019" (abbreviated "COVID-19"). The complete clinical picture with regard to COVID-19 is not fully understood. Reported illnesses have ranged from mild to severe. There are ongoing investigations to learn more. This is a rapidly evolving situation and information will be updated as it becomes available.

While the immediate risk of this new virus to the American public is believed to be low at this time, there is still a much more immediate threat of influenza. It's currently flu and respiratory

## Helpful Resources

Emergency Room Card

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

[Español ER tarjeta \(PDF\)](#)

Need another language,

[Contact us.](#)

[ANC Calculator](#)

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

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

[National Neutropenia Network](#)



Steps for Neutropenia is a virtual event you can do from anywhere! It gives each of us a chance to raise awareness about neutropenia and help raise funds our current programming, raising awareness about Neutropenia, and the Financial Assistance Grants for the 2020 & 2022 conference.

The virtual event takes place anywhere-wherever you are and takes place from April 1, 2020 through April 30, 2020. Set a target to reach 10,000 steps each day! You can run, walk, swim, bike, dance, knit, read-create your own path to supports those with neutropenia and the network stay strong!

You can create a team as well and ask them to join and support this great cause. Choose your favorite activity and connect with your family and friends! We want everyone to be able to join in the fun!

[Register today!](#)

Virtual event begins April 1!

disease season and CDC recommends getting a flu vaccine and taking everyday preventive actions to help stop the spread of germs.

While there is not any warnings for travel within the United States, there are international travel advisories. Please visit the [CDC site for updated travel information](#) and [CDC's website for further updates](#).

Source: [Center for Disease Control & Prevention](#).

## Clinical Trial Information

X4 Pharmaceutical's (Cambridge, MA) Phase 3 WHIM trial is open now for enrollment, entitled "A Phase 3, Randomized, Double-Blind, Placebo-Controlled, Multicenter Trial of mavorixafor (X4P-001) in Patients with WHIM Syndrome with Open-Label Extension".

WHIM (Warts, Hypogammaglobulinemia, Infections and Myelokathexis) is a rare autosomal dominant primary immunodeficiency disease caused by gain-of-function mutations in the chemokine receptor CXCR4. CXCR4 mutations induce increased leukocyte homing and retention in the bone marrow resulting in severe chronic neutropenia and lymphopenia.

---

### PHASE 1B CLINICAL TRIAL FOR THE TREATMENT OF SEVERE CONGENITAL AND CHRONIC IDIOPATHIC NEUTROPENIA

X4 Pharmaceuticals, Inc (Cambridge, MA), a clinical-stage biopharmaceutical company focused on the development of novel therapeutics for the treatment of rare diseases, announced the initiation of a Phase 1b open-label, multicenter clinical trial titled: A Study of Mavorixafor in Participants with Severe Congenital Neutropenia and Chronic Neutropenia Disorders.

The Phase 1b trial is a 14-day, proof-of-concept trial designed to assess the safety and tolerability of daily, oral mavorixafor – an investigational therapy – in up to 45 participants with Severe Congenital Neutropenia (SCN) disorders or Chronic Idiopathic Neutropenia (CIN). In addition, the trial will evaluate the neutrophil response, of mavorixafor, as an independent agent or in combination with granulocyte-colony stimulating factor (G-CSF). SCN are rare disorders; genetic testing can help to confirm the diagnosis and enhance patient access to appropriate care. Through its collaborative PATH4WARD program, X4 provides genetic testing at no cost to patients with severe neutropenia. This initiative provides greater access to faster and earlier diagnosis for individuals who may carry a genetic mutation known to be associated with SCN.

[Please visit 'Clinical Trial Information' on NNN's website.](#)

---

## Roller Family T-shirt Sales

Luke & Ellie Roller have sold over 200 t-shirts to family & friends with their last two fundraisers. In doing so, they have raised over \$1,000 for the National Neutropenia Network!

Luke is one of our Junior Ambassadors! [Read his story here](#).

Way to go, Luke & Ellie!

Thank you for all you do to raise awareness about Neutropenia and the support you have given to the National Neutropenia Network and beyond!

## Volunteer



## Give Today

---

## 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](#).