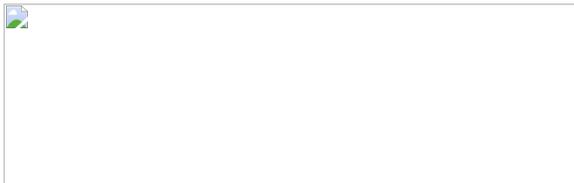


# Fall 2020 Newsletter: National Neutropenia Network



## Genetic Testing available for those with Neutropenia

Free genetic testing is available for people living with congenital, chronic, and/or idiopathic neutropenia to help them learn more about their condition.

There are 407 genes known to cause primary immune deficiencies (PIDs), some of which may cause neutropenia. This genetic testing is only looking at the 407 genes known to cause PIDs and won't tell you if you're at risk for other conditions.

You can take the test at your doctor's office or at home. And there is no cost to you for this testing.

[Click here to visit our website where you will find a flyer with complete information.](#)

Click here to see [Flyer](#).

## COVID-19 Patient Survey Report Results

In April 2020, many participated in surveys regarding how you felt participating in clinical trials during a world-wide health pandemic. The results were summarized for the following;

- Severe Congenital Neutropenia
- WHIM Syndrome
- Waldenstroms Macroglobulinemia

[Click on the links to see results.](#)

## Steps for Neutropenia

### Join us for our Virtual Event!

Registration begins September 15th

'Steps for Neutropenia' is a virtual race to connect your family and friends across the world to help raise awareness about neutropenia and raise funds to keep it strong. Your contributions will enable us to provide education, support, and connections to experts for children and adults with chronic neutropenia.

This virtual event takes place anywhere and takes place from October 1 through October 31, 2020.

## 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](#)

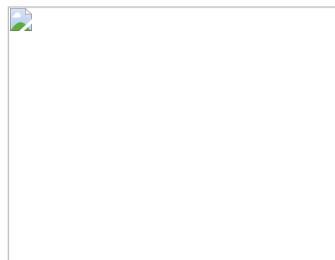
## Clinical Trials Webinar

### September 18 3pm ET

Registration is open for our 'Clinical Trial's webinar featuring James Connelly, MD, BS on Friday, September 18, 2020 at 3:00 pm ET.

The goal is to provide a general primer on clinical trials, including what they are and why they are needed, with a focus on empowering viewers with information on participation in a clinical trial including expectations, benefits, and risks; and why should people consider joining a trial. Hope you can join us!

[Register here.](#)



## Meet our 2020-2021 Junior Ambassadors

They are all rock stars advocating on

Set a target to reach 10,000 steps each day! You can run, walk, swim, bike, dance, knit, read-create your own path to support those with neutropenia and help the network stay strong! Teams can be formed as well! You can also connect it to your Fitbit if you have one!

Our goal is to have 50 participate, connect with 2,000 friends and raise \$15,000.

[Registration opens September 15th and is open through October 31, 2020.](#)

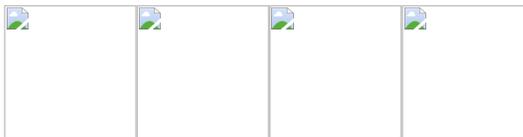
Each participant will receive a National Neutropenia Network key chain.

For those that raise \$150 or more, we will send you a Anniversary Custom Coin.

[You can also find the information through our website.](#)

Join the fun, raise awareness, and earn those steps!

Thank you for supporting the National Neutropenia Network.



## Restored Naturally

Nail Polish proceeds benefit National Neutropenia Network  
Begins September 18th

Restored Naturally is a business Jacqueline Aspley and Krista McTeer started six years ago; it began with the proceeds go to help aged-out of foster youth in our local area.

They have a [YouTube channel](#) where they discuss how polish can support our well-being.

Each owner lives with a chronic health condition, Neutropenia and Crohn's disease. So, they want to help individuals deal with various conditions and illnesses. Their plan is to feature one condition/disease a month and they will donate the proceeds to the featured disease/condition.

Their polish is a 10 free polish- meaning that it is free of the 10 most harmful chemicals usually found in nail polish. It is also vegan and cruelty free. nail polishes can be purchased as a set or individually.

To purchase their polish, visit [their website](#). You can also find them on [Etsy](#).

All of the neutropenia awareness polishes sold will benefit the NNN.

Thank you, Jacqueline & Krista for supporting the NNN!

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Quarterly Newsletter

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behalf of Neutropenia!

Way to go Ella, Jaiya, Kara, Liam, Lukas, and Tate!

On behalf of the National Neutropenia Network and those that struggle with neutropenia, thank you for raising awareness for the rare condition we all share.

[Check out our Junior Ambassadors!](#)

Congratulations!



## 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](#).

## 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.