

Meet our New Executive Director Stephanie Long

Stephanie Long is a small-town, Appalachian girl with a big heart and even bigger determination. Most importantly, Stephanie is the mother of three wonderful and very entertaining children. Her youngest child was diagnosed with severe congenital neutropenia at the age of five. She also work full-time as an administrative assistant at a local school and runs a part-time lawn service. When she is not working or taking care of my children, she enjoys running, reading, and going to baseball games.

Welcome, Stephanie!



Junior Ambassadors

Two of our Junior Ambassadors would like to share their updated story as they will be ending their time with us as Junior Ambassadors:

Kara Loader

First I wanted to say thank you for the opportunity to be in the junior ambassador program. The NNN has been an important part of my life and I'm glad to have supported the NNN through the junior ambassador program. I am so grateful for everything that the NNN has done to help people with neutropenia. My family and I attended many family conferences before the pandemic, and I have participated in two virtual conferences in providing my experiences as an individual with neutropenia. My family and I have completed fundraisers for the neutropenia community over the years and we plan to continue to do so. I have participated in studies with the SCNIR and also with researchers at the Cleveland Clinic. It is my hope that my participation in the research will enable there to be better treatments with individuals with neutropenia in the future. As I'm transitioning out of the junior ambassador program, I want to continue my efforts of spreading awareness for neutropenia I'm looking forward to participating in the senior ambassador program in the future.

We wish you the best, Kara!

Helpful Resources

[The Severe Chronic Neutropenia International Registry](#)

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

New Look to our Website

Be sure to check out our new look!

[Check out our updated website](#)

We have a fresh, new look. Be sure to check out the website. We also have new colors and a logo.

2022 NICER Symposium

A 3-day virtual experience happening September 28-30, 2022 via Zoom

Welcome to the 2022 NICER Virtual Symposium, "The Lion, the Witch and the Wardrobe: Neutrophils, Macrophages and the Inflammasome – Stepping into Innate Immunity."

The 2022 symposium will be host to fan favorites such as the "Pro-Con Debates" and "Tales of the Case Conference" where we will emphasize the multi-specialty nature of immuno-heme disorders and highlight recent advances along with ongoing knowledge gaps. There will also be mentoring and career development opportunities through "Speed Networking" and "Peer Mentoring," which we hope you will thoroughly enjoy. Additionally, we are introducing new sessions focusing on giving back to both our academic peers and the patient communities on Wednesday through a morning primary-care oriented Immuno-Hematology 101 style course followed by a patient-directed afternoon co-hosted by Race for Immunology featuring a panel discussion on "Rare Disease: Breaking through Communication Barriers" alongside break out sessions on oral health, understanding genetic testing and navigating the transition from pediatric to adult care.

[Click for more information or to register](#)

Junior Ambassador Applications

Due October 15th

Neutropenia is very rare which can make it difficult for children and families to find appropriate medical care and peer support.

Our children have the opportunity to turn their neutropenia journey into something positive by becoming involved in community outreach, education, and fundraising. We hope that they will learn to advocate for themselves and others, define the role neutropenia will play in their lives, and gain a sense of pride in making a difference.



Lukas

Luke's neutropenia journey started when he was about 15 months old, after he had a severe lymph node infection. After many tests and hospital visits, Luke was diagnosed with idiopathic Neutropenia and then Chronic Benign Neutropenia of Childhood. The severity of Luke's neutropenia caused us to change our lifestyle and affected almost every aspect of our lives. He has been hospitalized many times since his diagnosis. While his condition was limiting, scary and very isolating, we wanted to make the best of the situation. That is when we got involved with the National Neutropenia Network. My family is very thankful for the NNN. We used the website to learn more about neutropenia, how to manage our new lifestyle, and it gave us amazing resources. To help spread awareness about this rare disease and raise funds for the NNN, Luke and I decided to design some shirts to sell as a fundraiser. Since then, we've created and sold several different shirt designs, hats, and masks. Through fundraising, we have raised more than \$2,100 that was donated all to the National Neutropenia Network and have countless supporters wearing neutropenia gear. Luke has also had the pleasure of being a junior ambassador for the past 3 years. At our regular Hematology appointments, Luke's ANC has been consistently over 1000 for the past year. And it is with great pleasure to say that he has been officially discharged from Hematology!!! Luke has been a neutropenia warrior for over 5 years and it is finally time to close this chapter of his life. Thank you to the National Neutropenia Network for all you have done for us. We will be forever grateful.

Wonderful news, Luke!

[Our current Junior Ambassadors have updated their stories. Check them out here.](#)

If you are interested in joining our Junior Ambassador program, applications have been extended through October 15, 2022 for the next term. [Click here for our guidelines and application.](#)



Amanda's Story

I have lived with diagnosed chronic neutropenia since 2006. The first signs were fatigue and repeated infections, where I was hospitalized due to infection spreading rapidly.

I currently manage my neutropenia through 1-2 injections of G-CSF per week. I have been on this therapy since around 2015 and it has been life changing, being able to manage my neutrophil count which sits at around 1, which for folks with chronic neutropenia is better than 0.04! I can tell when my counts are dropping as I become faint, very sleepy, and just don't feel right. I have regular blood work as well as a bone marrow biopsy every 3-5 years. If I do not feel well, I go to hospital.

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

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.

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](#).



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Quarterly Newsletter

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