Summer 2024 Newsletter

national neutropenia network

Finding My Voice

Meet Liam Lakhia. Liam was diagnosed with Severe Congenital Neutropenia at one month and is thankful for the care he has received at Cincinnati Children's Hospital. However, he knows that there are other children who are not as fortunate as he was to be quickly diagnosed and receive good care throughout his life. Because of this, he became a Junior Ambassador for NNN and shared the following:

"What started as a simple desire to help others like me, grew into something much bigger. As I began being involved with the NNN, I became a Junior Ambassador which allowed me the opportunity to connect with other patients, families, and professionals in the health community. As a part of this program, I have been able to find my voice by participating in national conferences and speaking to professionals through healthcare webinars. My favorite part of being an ambassador has been the opportunity to make relationships with other kids who have neutropenia. Being able to share stories and understand one another on a deeper level is truly my motivation for being an ambassador for the neutropenia community, as I believe this type of involvement can influence change and make a difference. Although I have outgrown the Junior Ambassador program, I continue to advocate and fundraise for neutropenia peer programs and neutropenia research. Being a part of this neutropenia community has been super meaningful to my life, as it has given me a chance to be part of something bigger... a chance to use my situation to help other people. I hope that the NNN can focus in on this principle and expand to all corners of the globe so that all affected by neutropenia may have the resources and support needed to overcome their battles."

Our Ambassador programs were created to give members of our community an opportunity to turn their neutropenia journey into something positive. By becoming involved in community outreach, education and/or fundraising, our hope is that those affected by neutropenia and their families will develop a strengthened resolve in advocating for themselves and others, find pride in raising awareness of this rare disease, and feel a sense of belonging to a grater cause that in turn brings the neutropenia community closer together.

The Junior and Senior Ambassador programs are accepting applications for new members as well as those who would like to continue in their current role as Ambassadors. Applications are due by September 15.

Learn More

Save the Date

2025
Family Conference

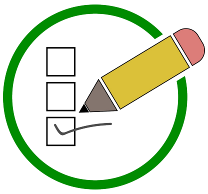
July 11–13, 2025


CINCINNATI, OH

Upcoming Family Conference

We are thrilled to be planning the 2025 Family Conference! Once again, it will be held in Cincinnati, Ohio at [The Graduate Hotel](). More details to come but save the date and we hope to see new and familiar faces next year!

Community Feedback



The mission of the NNN is to promote awareness, education, and research and to provide a support system for SCN patients and their families. As we develop additional resources for the community, we want to hear from you! What topics do you want to hear more about? How can we support you further?

Please take a few minutes to complete this survey. Your participation will help us determine what topics to highlight in upcoming articles and webinars and will help us develop additional resources to support you.

Click for the Survey

Research Updates

X4 PHARMACEUTICALS

The 4WARD Study is a Phase 3 clinical research study that will soon be enrolling people in the U.S. living with chronic neutropenia. Researchers aim to learn if Mavorixafor, the investigative study medicine, may increase neutrophil counts and decrease the chance of getting infections.

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.

Donate Today

Quarterly Newsletter

Our mailing address is:
National Neutropenia Network
PO Box 8291
Cincinnati, OH 45208

866.600.0799
National Neutropenia Network