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# Fall 2019 Newsletter: National Neutropenia Network

25 Years Strong!      Virtual Event    Survey    Conference Dates

## Congratulations on 25 Years

October 2019 marks the 25th year of the National Neutropenia Network! Congratulations to all of you for your support in keeping it strong!

To celebrate and raise awareness, we will be hosting Steps for Neutropenia, a virtual event-participate from anywhere- and sharing personal stories with local media and hospitals/clinics.

## Steps for Neutropenia

### Join us for our 1st Virtual Event!

'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, 2019 through October 31, 2019. 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 150 participate, connect with 3,000 friends and raise \$20,000.

[Registration is open now.](#)

Each participant will receive a National Neutropenia Network key chain.

For those that raise \$150 or more, we will send you a 25th Anniversary Custom Coin.

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

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

## New Survey!

The Use of the Immunosuppressed Diet in Hematology/Oncology Patients

## 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](#)

## 2020 Family Retreat

The dates have been announced for the 2020 Family Retreat. The conference will be Friday, July 24 - Sunday, July 26, 2020.

The retreat will be held in Ohio and has narrowed down to two locations in the Great Lakes Region. We will keep you posted with additional details as they become available.

## Bobby McGuinness New Board Member

First and foremost, Bobby is the proud father of Ella Jewell, Alexa Noelle and Keira Ann McGuinness and husband / teammate / best friend of Kristin McGuinness. The McGuinness family lives in Fairfield County CT where they've been since 2010, one year after their eldest, Ella, was born. He and his family have been active in the Neutropenia Community since Ella's birth and diagnosis in 2009. They have attended several Family Conferences since then, starting with San Diego back in 2010, and have met some fantastic friends which they now share this life journey with.

Bobby is currently an Asset Manager and leads the Sustainability Program for Kite Realty Group, an Indianapolis-based Real

Alexa Viniotis, a medical student from the Western University of Health Sciences is conducting research on the "Use of the Immunosuppressed Diet in Hematology/Oncology Patients." She also has autoimmune idiopathic Neutropenia, diagnosed in 2006. The objective of this survey is to gather current information on how many clinicians still recommend a low bacterial diet such as the Neutropenic diet to their patients and under what circumstances they recommend it.

[Please click here to participate in the survey.](#)

Thank you for your cooperation.

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## Meet our Junior Ambassadors

[Check out our first Junior Ambassadors!](#)

They are all rock stars advocating on behalf of Neutropenia!

Way to go Ella, Jaiya, Kara, Liam, and Lukas! On behalf of the National Neutropenia Network and those that struggle with neutropenia, thank you for raising awareness and funds for the rare condition we all share.

Congratulations!

## 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.

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Quarterly Newsletter

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Estate Investment Trust that specializes in Shopping Center ownership. His office is in White Plains, NY but his work takes him around the US as Kite owns and operates properties most major US markets.

Bobby is thrilled to join the NNN Board and brings with him experience of co-founding and running a Neutropenia-focused non-profit, the Ella Jewell Foundation. Bobby & Kristin founded the Ella Jewell Foundation shortly after Ella's birth and with the help of several Neutropenia families they have since raised and donated over \$500,000 to Neutropenia research and family support services.



## 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](#).