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# Newsletter: National Neutropenia Network

Summer 2020

## Junior Ambassador Program

### Applications due August 15, 2020

As we all know, Neutropenia is very rare which makes it often times an unknown medical condition in our communities. This can make it difficult for children and their families to find appropriate medical care and peer support. In addition, rare diseases are not as commonly funded for research to help in the advancement of diagnosis and treatment to allow for cutting edge medical management.

Our children have a rare opportunity to turn their Neutropenia journey into something positive. By becoming involved in community outreach, education and fundraising, our hope is that children with Neutropenia will discover an upside, if you will, to what they have been given in life. We hope that they will not only learn to advocate for themselves and others, but that they will also help to define the role Neutropenia will play in their lives instead of allowing their Neutropenia to define it for them. Additionally, we hope they will gain a sense of pride in making a difference in their Neutropenia community.

High School age or younger children with Neutropenia who have met the indicated qualifications and submitted the application are eligible to be a Junior Ambassador.

The term for a Junior Ambassador will be one year (September 1 of the current year- August 31 of next year, so as to correspond with the typical school year) and will be based upon the qualifying activities that occurred in the year immediately prior to the start of the new Junior Ambassador term.

The application deadline for each new term will be August 15th.

[Click here for complete guidelines & application.](#)

[Click here for PDF version.](#)

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## 2020 Virtual Conference Materials

The PowerPoint presentations from the June 12, 2020 virtual conference have been posted to our website. If we are able to obtain additional material, we will post it. The materials we have permission to share are [posted here](#). Thank you.

We want to share our gratitude to the doctors and others who made this virtual conference possible:

Maryann Bonilla, MD  
James Connolly, MD  
David Dale, MD  
David Frame, PharmD  
Mark Hannibal, MD, PhD

## Helpful Resources

Emergency Room Card

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

[Español ER tarjeta \(PDF\)](#)

If you need other languages, [please contact us](#)

[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](#)

Ways to Support the NNN

[Round Up App](#)

[Shop for T-shirts](#)

[Giving Assistant-Shop & Save](#)

Meet Macayla. She's seven years old, and she's from Phoenix, Arizona.

Ever since she was a baby, Macayla constantly got infections. She suffered through several bouts of sinus infection, bacterial infection, upper respiratory infection, pneumonia, unexplained fevers - a list that most children her age barely encounter one part of. She's also had to battle many strains of the flu during the past three years, often several within the same flu season.

For a while, doctors prescribed antibiotics for her. Sometimes they would work, but other times Macayla would just end up back in the emergency department. Finally, when a neurologist decided to run a Complete Blood Count test in addition to her standard genetic test, something interesting was revealed - Macayla's white blood cell count was significantly lower than normal, and she had anemia. She was quickly referred to a hematologist.

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



Kara Loader  
Tom Michniacki, MD  
Peter Newburger, MD  
Eric Scott  
Terri Stillwell, MD  
Kelly Walkovich, MD  
Jolan Walter, MD, PhD  
Sharon White



Our gratitude to the University of Michigan-Ann Arbor and Heather Lewis for providing the HIPAA Compliant Zoom capability for this conference as well.

We also appreciate X4 Pharmaceuticals for their sponsorship of this event. Thank you.

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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**Give Today**

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## 2021 Marrow Failure and Myelodysplasia Patient and Family Conference

Saturday, April 21, 2021  
Registration is free.  
Toronto, Canada

This meeting is for patients and families with bone marrow failure disorders and myelodysplastic syndrome, physicians, other health-care workers, fellows, residents and all others who are interested in the field. Adult patients are also invited.

[Conference flyer](#)

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## 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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