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Newsletter: National Neutropenia Network

Summer 2019

NEW! Junior Ambassador Program

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 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.](#)



Australian Neutropenia Family Conference

September 20-21, 2019

Westgate Vineyard Church

1/100 Champion Road

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](#)

Ways to Support the NNN
[Round Up App](#)
[Shop for T-shirts, sweatshirts, & more](#)
[Giving Assistant-Shop & Save](#)

Amanda

I was first diagnosed with severe chronic neutropenia in 2006- I was in my mid-twenties then. The diagnosis came about when I decided I'd like to try and have a baby. Due to being fatigued, having regular colds, sores popping up that just didn't quite go away, and the feeling of not quite right inside, I thought I should get some blood tests and see a doctor. I thought maybe my iron may be low or maybe I was working too much. After completing the routine blood tests, I received a call the following day from my doctor who asked me to come in to discuss the results in person.

The conversation unraveled that my blood tests were very concerning. That my white blood cells were close to non-existent the doctor cautioning that I was at great risk of developing life-threatening infections due to my severely impaired immune system. She made a few calls and I was sent to a specialist at the cancer care unit within the hospital.

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



T-Shirts & More

Our NEW t-shirts and other fantastic items are in!! [Shop for t-shirts, sweatshirts, stickers, and more!](#)

Feel free to share with your friends and family!

Happy Shopping!

The Australian Neutropenia Family Conference is an event for families and professionals to learn more about Neutropenia and connect with other families. Our keynote speaker is Dr David Dale and Professor Frank Firkin who are both Neutropenia researchers and practitioners. This conference is a great opportunity to connect with others living with Neutropenia and those who support them. It's also an opportunity to learn more about various forms of Neutropenia and the latest management information.

Important Notes

- Participants will need to organize their own accommodations
- Participants will need to organize their own breakfast and dinners
- Included in the conference cost: soft drink and light snack at the meet and greet on Friday afternoon, Morning tea and lunch on Saturday at the Venue.
- Kids program costs are included with registration
- Conference pack will include some written information and details on joining the international registry

Kids Program: The kids program will run only on Saturday from 8:45am - 12pm and after lunch from 1:30 - 5pm

[Click here to register.](#)

Question? Contact [Kath Henry](#).

Shop & Support the NNN!

You care about our cause, and we care about YOU! That's why we've teamed up with Giving Assistant to make it easier to donate.

Simply sign up, select our cause, and shop at over 3,000+ online stores. You'll save money and earn cash back on your everyday purchases, all while making a difference.

Shop by clicking on the 'Giving Assistant' Logo! Happy Shopping!



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.

Give Today

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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