Welcoming New Leadership

Kate Bottiger and Mariel Lewis began a new chapter in January 2017 as the co-Executive Directors of the National Neutropenia Network following Lee Reeves’ retirement. Both had worked on the NNN Board for several years. Kate and Mariel are excited to collaborate with Mara Lim who will continue her work for the NNN as the Conference Coordinator.

Kate brings almost 25 years of experience working in non-profits, leading areas of growth within program services, public advocacy, and volunteer management. She is capable of motivating and developing employees, volunteers, board members, and donors from diverse backgrounds and experiences. Currently, Kate is also the Executive Director for Reach for Resources, Inc., an organization that supports children and adults with developmental disabilities and mental illness.

Personally, Kate has struggled with the uncertainty of Idiopathic Autoimmune Neutropenia for 28 years. While trying to maintain a healthy lifestyle, Kate has dealt with years of illness and a couple of hospitalizations that included sepsis and pneumonia. Kate lives with her husband and two teenagers in Minnesota.

Mariel has more than 10 years experience in marketing and advertising with a focus in graphic design and project management. She looks forward to fine-tuning the NNN’s brand and continuing to raise awareness for the neutropenic community. Currently, Mariel is also the Owner/Graphic Designer of Trapdoor Design, LLC, which provides print design work for numerous clients.

Mariel’s journey with Neutropenia began six years ago when her first-born son was diagnosed on the spectrum of Congenital and Cyclic Neutropenia. She lives with her husband and two sons in Indiana.

Kate and Mariel are thrilled to continue the work of the National Neutropenia Network. They hope to carry on the passion and mission that started it all—promote awareness, education, and provide a support system for individuals with neutropenia and their families. They look forward to working with you, and hope to see you at the 2018 conference in Ann Arbor, Michigan.
Our son Liam, who will be 12 years old this summer, was diagnosed with Severe Congenital Neutropenia when he was 1 month old. He responds well to his daily Neupogen dose, which we give full credit to allowing Liam to live a “normal” life. By the time Liam was 8 years old, he desperately wanted to meet “someone just like him.”

I can still remember the day we first discovered the Ella Jewell Foundation (EJF). We had just finished having a garage sale to raise money for the National Neutropenia Network (NNN)~Liam was so excited that we had raised $307! We grabbed the mail and there it was…a newsletter from the EJF! It brought tears to my eyes to see another little girl with neutropenia. They were promoting the first “Bowling 4 Neutrophils,” and naturally, Liam was all about bowling after that!

We planned bowling events for 2 years, and in our second year, we had a phenomenal turnout of over 300 bowlers! However, coordinating 300 bowlers was not an easy feat! We decided that the following year we would need to find a venue that would accommodate a larger crowd….Dave & Buster’s was the perfect place!

Dave & Buster’s has nearly 100 locations across the U.S. and Canada (www.daveandbusters.com). They have a couple of different options to choose from to help with raising funds for the EJF. The first option is to “Fun Raise” with the sale of Power Cards (arcade game cards) in which 50% of the proceeds benefit the EJF. Another option is to plan a “Custom Event”…a fundraising party to your liking. These custom events will vary from location to location based on size of the venue, your preferences and the individual management. Both options are coordinated with an event planner at your local participating Dave & Buster’s.

We are getting ready to start planning our 3rd custom event at Dave & Buster’s in Cincinnati, “Power Play 4 Neutropenia.” The first 2 years were absolutely awesome! We were blessed to have had well over 225 people in attendance both years and our combined fund raising efforts at Dave & Buster’s alone have netted over $15,000 for the Ella Jewell Foundation! 75% of these funds go to the Severe Chronic Neutropenia International Registry and 25% of these funds go to the NNN. A Dave & Buster’s event coordinator worked with us on all of the on-site details and the staff at the events has gone above and beyond to help support our cause.

Although it may seem overwhelming to plan such events, it really is not…it has been an honor to do so. Kristin and Bobby McGuinness (Ella Jewell’s parents) have been supportive from day one. This past year, Bobby helped to create an online site so that our guests could RSVP and pay for registration, Power Card and t-shirt purchases, as well as make a donation online. We have carefully chosen how to “customize” our event based on those who come out to support us. Our events include a buffet breakfast, basket raffles (donated by local companies, family and friends), split the pot raffles and of course arcade games! We have coordinated with our Dave & Buster’s to hold our event from 9am-noon on a Saturday; this allows us access to the facility 2 hours before they open to the public! We utilize one of their banquet rooms.
to accommodate, quite possibly, my favorite part of our event……while our guests enjoy their breakfast, Liam gets up on stage at the podium and talks. He talks about what neutropenia is, how it affects his life, how he wants to be a voice for kids like him with neutropenia, and he has had the honor to introduce his grandfather who has talked about the “grandparent perspective.” And if that isn’t awesome enough, he has had the privilege to introduce other friends, some local and some from hours away, that he has met with neutropenia and have been able to be a part of our events.

Liam’s simple request of wanting to meet “someone just like him” has truly been a blessing. The NNN and EJF have opened doors to our neutropenia world that we otherwise would not have searched for. We have been able to connect with local neutropenia families who we now hold near and dear to our hearts. Neutropenia friends from afar have given and continue to give Liam reassurances when he has needed it the most. He values the opportunities to meet kids with neutropenia and he gets excited when he knows that we will be seeing the kids at the NNN conferences or knowing that he will have a chance to share moments of a special bond at one of our events. Quite possibly the most priceless blessing of all is his pride…..he wears his “neutropenia badge” proudly. In his own words “my neutropenia has made me who I am today” and “I don’t want to be known necessarily for being able to get up and talk about my neutropenia, but for being able to make a difference”………hosting fundraising events has been one of the best neutropenia related decisions we could have made!

See page 4 for EJF’s Power Play 4 Neutropenia Promotion Details!
Have you been looking for a way to *emPOWER* your child while raising funds for Neutropenia research and peer support? Do you have a Dave & Buster’s in your community? You are in luck!

The Ella Jewell Foundation is promoting “*Power Play 4 Neutropenia*” month this **November**! Take this opportunity to help your child and family/friends bring awareness to Neutropenia, raise funds for research and join in on all of the Fun!

Dave & Buster’s ([www.daveandbusters.com](http://www.daveandbusters.com)) has nearly 100 locations across the U.S. and Canada and has a few options to help raise money for the Ella Jewell Foundation.

- **“FUN” RAISE with the sale of Power Cards**—50% of proceeds benefit EJF

  OR

- **Plan a CUSTOM EVENT**—Coordinate your special day with a Dave & Buster’s event planner….the sky is the limit!

  No matter which fundraising event you choose to plan, you and your child will have a blast and feel *emPOWERED* to be able to make a difference in the world of Neutropenia!!

*Tanya Lakhia (tlakhia@yahoo.com), a fellow Neutropenia mom, can help you get started planning your event! In order to ensure adequate time for planning your event, please allow at least 8 weeks for a customized event and 4 weeks for a Fun Raising Power Card Sale event. (Note: these events can be coordinated at any time throughout the year, at least 6 months apart at the same location. The EJF would like to make a **POWERful** impact by coordinating as many events at several locations during the month of **November**)*
ASK A DOCTOR
Answered By: Dr. Peter Newburger

During the diagnosis process, should patients with severe neutropenia continue to receive routine vaccinations; or should they be put on hold until the cause of neutropenia has been determined and treatment has begun?

Both during the diagnostic evaluation and after establishment of the diagnosis of severe neutropenia, patients should continue to receive all recommended immunizations, including live virus vaccines. Patients with neutropenia have otherwise normal immune systems, and thus can respond to the vaccines and have no increased risks. The only exception would be in the very rare individual suspected of having neutropenia on the basis of an underlying primary immune disorder, in which case the live vaccine (MMR) might be held, but all other vaccines would still be safe.

To submit a question, please email Mariel at mariel@neutropenianet.org

TIPS ON PARENTING A NEUTROPENIC CHILD
By: Gretchen Long, NNN Board Member

These are the words many of us use to describe our neutropenic children. We mean it with all our hearts.

These are the words many of us use to describe our role as a Neutropenic parent. We mean it with all our might.

These are the words I use to describe how we try to raise our Neutropenic child into a Neutropenic adult. This is what we focused on during the parenting session of the Family Conference last summer. Teaching your child not just to understand Neutropenia, but to own it so that they can take control of their health when you can no longer protect them. Be just as focused on making Neutropenia a normal part of their lives as having the “normal” life they deserve.

For the first few years, we also focused on trying to help a very young child understand his neutropenia – probably using words and concepts way above his level. When Tate, was four, we were out to lunch with his cousins and his aunt. When they asked if the kids wanted sprinkles on their ice cream, my sister said, “No. They are allergic to food dyes.” That night before bed, Tate told me he would rather be allergic to germs than food dye. That was that. Neutropenia means “allergic to germs.”

We lucked out with our son, Tate, because we didn’t have nightly, epic battles when it came to his shot. There were definitely tears and wincing, and some nights were worse than others, but it was manageable. A few weeks before Tate’s third birthday, my husband, Thad, stumbled onto a solution that added a layer of calm to shots for good. He asked him if he wanted to push the syringe down. From then on, Tate was in control of how fast his medicine went into his body, and the tears ended for good. It turns out, the training we got at the doctor’s office one time, wasn’t right for our son. He takes several seconds to slowly push the syringe down. From then on, Tate was in control of how fast his medicine went into his body, and the tears ended for good. It turns out, the training we got at the doctor’s office one time, wasn’t right for our son. He takes several seconds to slowly push the syringe down. We had pushed it as fast as it would go to “get it over with quick.”

Now that Tate is seven and finished with first grade, we’re trying to figure out how to increase Tate’s understanding, ownership and control of his life with neutropenia. We’ve started counting out all the “steps” of giving the shot (step 1: wipe with alcohol …). Tate now wipes sometimes and pulls the syringe out of his leg after he pushes the syringe down. He told a friend at school he was allergic to germs, and his friend responded that everyone is allergic to germs. So now we’re back to having conversations that are probably above his level, but I’m confident that something will click soon that will help him through the next phase.
SHARON’S STORY
By: Sharon White,
NNN Board Chair

A lifelong wish of mine has been to hike the Appalachian Trail. Someone mentioned it when I was a kid, and I’ve been curious ever since. But, adult life has given me a different trail to follow, that of searching for answers regarding my health. In the late eighties, I got sick and stayed sick for months. I assume because you are reading this newsletter that you can already guess that no one could figure out what was wrong with me. Finally, I was referred to an endocrinologist who knew it was a neutropenia situation. He immediately sent me to an oncologist for my first ever bone marrow biopsy (in his office with no anesthesia at all). He determined that I was allergic to the petroleum products in lipsticks and balms!!! Well, that was just silly, but at the time I was thrilled to have a diagnosis. I continued to believe it until I saw a doctor in London, England two years later who disagreed. His diagnosis was that I was lacking folic acid. So, onto the high Rx doses that he suggested. Again, it was no help. Many more bumpy trails later I ended up as a patient at Stanford University with an incredible doctor who was familiar with the neutropenia study. That is how I got into the SCN Registry, just over twenty years ago, and that’s where I’m staying! Neupogen has given me a quality of life I wouldn’t have otherwise had. Yes I get sick, but so do people with healthy immune systems. Luckily, most of my days are healthy and symptom free. Thank you AMGEN! Thank you SCN!!

If you are interested in sharing your story, please email Mariel at mariel@neutropenianet.org

New Product: At-home WBC Monitoring Device

Athelas is a portable blood diagnostic device for monitoring white blood counts at home from drop samples. They are looking for participants with neutropenia for a trial. For more information, see the attached flyer on page 7, and visit athelas.com/neutropenia.

The National Neutropenia Network is providing information about Athelas as a service and makes no representations, express or implied, about the effectiveness or safety of the product. The National Neutropenia Network encourages you to make an informed decision for yourself whether to use or participate in any trial, testing or use of the product.
A breakthrough software platform driven by Machine Learning.

Monitor drug response, track immune conditions, flag neutropenia, all in seconds from a single drop of blood at a patient's home.

More than 10,000 tests run to-date on devices. Has helped identify cases of Strep Throat, Infection, and even Leukemia (missed by doctors) in clinical settings.

Deep Learning for drop analysis and diagnostics.

- White Blood Cell count
- Neutropenia
- Inflammatory Markers
- Bacterial vs. Viral trends
- Differentials
- Parasites
- Morphology Reports

Advisors + Partners

Stanford  
UCSF  
USC  
SEQUOIA