THE ELLA JEWELL FOUNDATION

“ TOGETHER, WE CAN MAKE A DIFFERENCE”

SUMMER 2012

LONG RACE 4TATE

THE LONG RACE 4 TATE

By Gretchen Long

In August 2011, when our son, Tate Long, was 17 months old, we found out that he was neutropenic. This explanation for this chronic illness felt like we finished the race, but the race was really just beginning.

Within days of finding out our son had this incurable disease, we knew that we would not be satisfied giving him a shot every day and hoping that someone would tell us one day there was a cure. We wanted to be part of finding a cure. We were thrilled to quickly find the McGuinness family. Knowing there was another family out there who immediately decided to take action and had already started a non-profit dedicated to research gave us something very positive to focus on, even though we were grappling to understanding Tate’s condition. All we needed to do was figure out how to help the cause.

It didn’t take long to come up with a plan: The Long Race 4 Tate. Tate’s dad, Thad, started distance running soon after Tate was born. We decided that any race he runs would be dedicated to Tate and the Ella Jewell Foundation mission. Now all we had to do was ask our family and friends to “sponsor” Thad in his upcoming races by donating to the Ella Jewell Foundation.

www.longrace4tate.com was born! We are amazed by the support we have received. Not only have our friends and family donated, they were quick to dedicate their races to Tate too. and the network of donators grew exceptionally. To date we have raised $17,352 dollars.

The Long Race 4 Tate is not a single event, it’s not a pledge per mile. “Team Tate” has raced 50K’s, 5K’s, full & half marathons, rough terrain races and a dedicated climbing trip in Alaska. The races have taken place in Canton, OH; Pittsburgh: Portland, OR; Baton Rouge, LA; Charlotte, NC. The list keeps growing.

Not a single dollar goes towards Tate’s medical expenses. Every penny we raise goes to The Ella Jewell Foundation, and all funds raised by the EJF go towards research.

The biggest honor is that the McGuinness family is joining our fundraising efforts. “Team Ella Jewell” will be running their first race on August 12th.

Now all we need is you!

To dedicate your race to the neutropenic in your life and help raise funds for a cure contact Gretchen Long at gretchenwlong@yahoo.com. Whether you walk, run, cycle, or bike; it’s easy to join this effort.

To donate, pick a race at www.longrace4tate.com

2012 ELLA JEWELL FOUNDATION EVENT

“ Team Ella Jewell”

The Ella Jewell Foundation 2012 event is much different than past events. This year we are joining forces with The Long Race 4 Tate. We will be running a 5K race. On Sunday August 12, 2012. “Team Ella Jewell” will be running the Runyon 5K at Yankee Stadium. Your Challenge: Sponsor us and help us to reach our team goal, join our team or run a race of your own in honor of Ella Jewell.

Please log on to www.longrace4tate.com today and look for Team Ella Jewell. All funds raised benefit childhood bone marrow failure disorders research. Running towards a cure!!!

The McGuinness Family

Katie and Kara Loader

THE LOADER FAMILY PITCHES IN!

BY: TAMMY LOADER

After attending the 2011 National Neutropenia Network Family Conference, Katie, age 10 and Kara, age 7 set a goal to raise funds to find a cure. At the closing session of the conference, Katie heard Kristin McGuinness share information about the Ella Jewell Foundation. Katie, who has watched her sister live with Neutropenia called to action. Kara jumped on board as well. The entire five hour trip home from Michigan consisted of idea after idea of ways to raise money and awareness for the cause. Katie's hope is to help raise enough funds to find a cure and to ensure that " even kids in Third World countries" can have access to the cure.

With the support of their parents, Bill and Tammy, the girls shared their plans with their small church, Christ Evangelical Lutheran Church, in Cambridge Ohio. The children of the congregation chose to take up collections during Sunday School to help the girls. The ladies of the congregation held a purse party and a collection was taken at the annual Easter Breakfast. As a result their efforts and the support of their community, they raised over $1600.00 for the Ella Jewell Foundation. The girls are pleased with their start and the family is working very hard on their next fundraising opportunity which will take place in the fall " Harvest A Cure For Neutropenia." They will donate all sales of their pumpkins to the EJF.

THANK YOU TO NEWLYWEDS JAMIE & DAVID COLONNA

Above: Mr. and Mrs. Colona with Ring Bearer: Christian Lakis

Thank you and Congratulations to Newlyweds Jamie and David.

Jamie and David Colonna were married on May 11, 2012 at Woodbury Country Club in Woodbury, New York. In Lieu of a traditional wedding favor the couple made a generous donation to The Ella Jewell Foundation in honor of their nephew Christian Lakis and sister Jennifer Lakis. Jennifer and Christian are both diagnosed with Severe Congenital Neutropenia. The Colonna and Lakis family are joining forces with EFJ and dedicated to do all that they can to help raise funds for research. They will be hosting their first fundraiser event in the winter of 2012. THANK YOU for believing in our mission and being a part of our team.

MIA'S BIRTHDAY WISH

Left: Mia Morakis

Mia Morakis is Ella Jewell's cousin. She lives in Singapore. Mia learned all about Ella's condition and The Ella Jewell Foundation. She wanted to help raise funds and awareness.!!! With the help of her parents Dianne and Todd they came up with a fabulous idea. Mia turned 5 years old on December 5th 2011 and in lieu of traditional birthday presents, Mia asked her friends and family to donate in her honor to her cousin's foundation. She also helped her parents to educate their guests about neutropenia. This was a very big girl decision. And, we were very grateful and proud of Mia. In honor of Mia over $1,000 dollars was donated to The Ella Jewell Foundation. Thank you to the Morakis family for being part of our mission. A special thank you to Mia from all families affected by Neutropenia .

Research Report

Progress in understanding severe congenital neutropenia

Our research team at the University of Washington remains very committed to understanding the causes, consequences and treatment for severe neutropenia.

Our studies of severe congenital neutropenia remain focused on understanding how mutations in the gene for neutrophil elastase cause neutropenia. We had identified more than 60 different mutations in a total group of about 225 patients. Some mutations appear to be associated with more severe disease and require higher doses of G-CSF/Neupogen, but others cause less severe disease and respond to just a little G-CSF. Some, but not all mutations, are associated with transformation to leukemia. We are now collaborating with basic researchers at the University of Washington and at Lund University in Sweden to understand these relationships and developed predictive models based on genetic analysis.

We are also engaged in several other studies which are very important for the future of patients with neutropenia. Two examples are:

1. We are studying a potential oral therapy; this work is still at the laboratory stage and we are seeking funding to accelerate this work. We are also asking patients and families to help us with obtaining fresh bone marrow samples to test in the laboratory. There are several promising new technologies for growing blood cells from the bone marrow that we believe will help us to accelerate this work.
2. We are starting to test a new blood cell counting device which can be used at home. The device is a miniature blood cell counter. It uses a tiny drop of blood from a finger prick, just the same as is used for monitoring blood sugar for people with diabetes. We hope to begin studies of home monitoring this summer. With this device we hope to be able to conveniently monitor blood counts and to diagnose cyclic versus congenital neutropenia more precisely than ever before.

Thank you so very much for your interest in neutropenia and for you support for neutropenia research.

David C. Dale, M.D.
Director, Severe Chronic Neutropenia
International Registry
Professor of Medicine
University of Washington
Seattle WA


Above: Ella Jewell having fun at home.

A Special Thank you to Mr. and Mrs. Carinci

Dana and Paul Carinci have been friends with The McGuinness Family for many years and have been a huge support and help with the foundation. In October, 2010 Dana and Paul were married. In lieu of a traditional wedding favor the couple made a generous donation to the Ella Jewell Foundation. THANK YOU very much for always being their for us and your generous donation!!

Thank you all, for your continuous love, prayers and support.

Additional Thank you to:

Our family, friends and the EJF committee for your commitment.

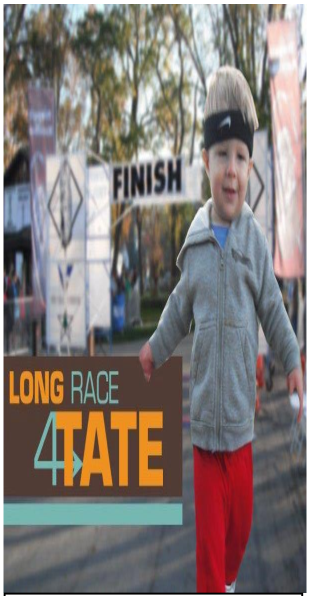
Erik Bodelson for our awesome EJF website.

Amy Balliett for the awesome Long Race 4 Tate website.

Gretchen Long, my teammate and friend! xo

Thank you for making this all possible.

Kristin McGuinness



Above: Tate Long running for a cure

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or

Make Check Payable to the
"Ella Jewell Foundation"
and mail to the address above.

to donate to Team Ella
Jewell or Team tate visit
www.longrace4tate.com

THE ELLA JEWELL FOUNDATION RECAP 2011 EVENT

BY: KRISTIN MCGUINNESS

2011 Wine Tasting Event

On October 21, 2011 the Ella Jewell Foundation held a Wine Tasting Event at the beautiful Shenorock Shore Club overlooking the Long Island Sound in Rye, NY. Over 150 guests enjoyed a large variety of wines from all over the world courtesy of Cai Palmer from Wine at Five in Rye. Guests were also treated to a fantastic food selection prepared by Chef Lenny Phillips of the Shenorock Shore Club.

In addition to the entrance fee, a portion of all wine purchased benefited the Foundation.

Guests also had the opportunity to bid on some fun and interesting items at the silent auction.

The evening was a huge success. The Ella Jewell Fondation rasied over $22,000 to benefit neutropenia research.

We greatly appreciate all that attended and donated. We felt humbled by the love and support. It was a night that we will never forget and one that brings our family so much hope. Thank you!!!

We are always looking for stories for future Newsletters. If you hold a Fundraising Event, send us the information . If you have a story about an experience with Neutropenia, let us know. We are also looking for photos of people showing support for the Neutropenic in their lives. All submissions can be e-mailed to **Admin@ellajewellfoundation.com**