



Hemophilia of North Carolina

Since 1977, serving the people
of North Carolina
affected by bleeding disorders.

April 1, 2015

260 Town Hall Drive
Suite A
Morrisville, NC 27560

Dear Friends,

Toll free: 800-990-5557
Local: 919-319-0014
Fax: 919-319-0016

It is amazing how quickly life changes. In November 2010 Karl and I went to the hospital for a routine, scheduled C-section. Everything went well and we were so happy to welcome our second son Noah into the world. The following day he was taken for his circumcision, just as our other son Riley had 2 ½ years earlier. But time ticked by and he wasn't brought back to our room quickly like Riley had been. Some nurses came in to tell us he had prolonged bleeding, but nothing to be concerned about. Then the doctor came in and asked us if bleeding disorders were in our family histories, but we dismissed the questions since no one had any. They told us they were going to stitch Noah up, which should stop the bleeding. It didn't. More time ticked by. They tried cauterizing but he still bled. Eventually the bleeding slowed down enough that the medical staff felt Noah could be brought back to us. The doctors drew blood, and in the morning we found out that Noah has moderate hemophilia A. We were told about hemophilia, treatment using recombinant factor, and how treatment had changed in the past couple of decades. We did end up having to send Noah back to the NICU and he was treated, which luckily stopped the bleeding. After several days in the NICU, we were able to take Noah home, but then what?

www.hemophilia-nc.org
info@hemophilia-nc.org

Executive Director
Charlene Cowell

Board of Directors
2014-2015

Steven Peretti, PhD
President

Michael Hoernlein
Treasurer

Dylan Clark

Reid Coleman

Erica Cook

Steven Humes, MM, MPH

Matthew Igelman
Advocacy Chair

Warren Ingram

Maxine Locklear

Amy Shair Miller

Sharon Sebolt

Zack Strange

Leroy Taylor

Luke Waller

I remember the social worker at the hospital had given me the website for NHF and Hemophilia of North Carolina. I started learning about hemophilia. I found out how to join HNC and was also given the name of another mom in my area that I could meet. As I continued to learn, I felt like I needed to meet other people in the community. We attended our first Annual Meeting and met so many nice people who knew were in the same boat as us. I decided I wanted to get more involved with HNC, and I heard about a new program that was being developed called HOPE, meant for those who had a newly diagnosed child. I wanted to be involved and help in whatever way I could. Over time, the HOPE program has evolved into what is now a program to support and educate families with a young child diagnosed with a bleeding disorder. I happily became the Program Coordinator for HOPE. We have had several educational and social programs and are continuing to develop more programming to educate and support our families.

Karl, Riley, Noah, and I attended our first walk in 2012. We named our team Hulk Smash after Noah's mealtime antics where he would pound the table like The Hulk. What a great opportunity to start sharing and educating those around us about hemophilia. Friends and family were so willing to support us. I even got support from some of the young students that I taught. It is through this support and education that better treatments, even a cure, can be found.

A proud member of



COMMUNITY
HEALTH CHARITIES

From attending the many events put on by HNC including the NHF Walk, it is evident what a tight knit community we are! It is this community that has helped me to see all the possibilities that Noah will have in his future. I hope that you will support the community and the 2015 NHF Hemophilia Walks in North Carolina.

Sincerely,

Gillian Schultz
2015 Hemophilia Walk Chair

Hemophilia of North Carolina is a 501(c)3 non-profit organization. All donations are tax-deductible.