

BLEEDING DISORDERS FOUNDATION OF NORTH CAROLINA



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Dear Friends,

I am often asked why the **Bleeding Disorders Foundation of North Carolina** is such a special organization and why to support the **Family Festival & Walk** fundraiser. I can tell you that I wouldn't be where I am today without the support and resources I received after my son was born. And he wouldn't have a community of other kids who understand what it's like to live with a bleeding disorder.

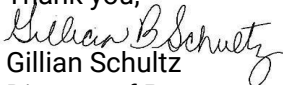
After the birth of my second son, Noah, my family's life changed. While we already had a healthy two-year-old at the time, we could not have anticipated what was to come. While Noah's birth went as planned, when he wasn't brought back to us quickly after his circumcision, we knew that something was wrong. The doctors started asking if there was a history of bleeding disorders in my husband's or my family because they couldn't get the bleeding to stop. It took hours of constant pressure, along with stitches and cauterization for the bleeding to finally slow. The next morning we received the diagnosis that we were entirely unprepared for – *moderate hemophilia A*. Noah spent a few days in the NICU, where he received his first factor infusion and then we took him home.

We knew that we had to learn all that we could about hemophilia. My husband and I both knew that hemophilia was a bleeding disorder and that in the past, people with hemophilia contracted HIV, though that didn't happen anymore. We did some research and found Hemophilia of North Carolina, now called the **Bleeding Disorders Foundation of North Carolina**, that provided support for people impacted by bleeding disorders. We quickly started attending as many events as we could so that we could learn more and meet other people living with bleeding disorders. We met many other families who have children with bleeding disorders. I learned from the men with bleeding disorders – Blood Brothers – about what it's like to grow up with hemophilia. The people who we have met and connected with over the years have become like a second family. We support each other through our ups and downs, and never have to feel isolated or alone because we always have someone to reach out to.

That was more than twelve years ago, and Noah is a typical kid! He plays soccer, rides his bike, hangs out with his friends, and spends entirely too much time playing video games and watching YouTube! And while he sometimes complains about having hemophilia, he hasn't let it stop him. Noah learned how to self-infuse his medicine when he was 8 years old because he saw another kid self-infuse. He looks forward to BDFNC events, where he can meet up with his friends with a bleeding disorder like him.

My family knew we needed to give back to the organization that helped us so much, so we started participating in the walks in 2012. Fundraising has provided us a great opportunity to share and educate those around us about hemophilia and bleeding disorders. Friends and family have always been so willing to support us. Noah and his brother have also started fundraising with a lemonade stand.

The Bleeding Disorders Foundation of North Carolina is an amazing organization and community! They provided my family *hope* and continue to provide services to individuals and families across North Carolina. Please support the **2023 Family Festivals & Walks** so that others can benefit from the same services that helped my family.

Thank you,

Gillian Schultz
Director of Programs