Maureen’s Story

The mother of Andres explains how her son was diagnosed with hemophilia and offers advice to parents of newly diagnosed children.

This is not your typical story of a hemophilia diagnosis.

While many infants with an inherited bleeding disorder are diagnosed immediately at birth, little Andres was not.

At about 6 months of age, Andres had an egg-sized hematoma on his chest which Maureen guessed happened when Andres rolled over on his pacifier. She took him to the pediatrician — not the usual doctor they had seen — but the one who was available.

“I remember the pediatrician asking specifically, if anyone in our family had a bleeding disorder and I answered no. Neither my husband, nor me, had any indication or any memory of anyone ever having some kind of bleeding disorder.”

This led to a few more questions from the doctor.

By the time the doctor visit was over, and based on the injury and the lack of any family history of hemophilia, the pediatrician felt Andres might be in danger. (Something doctors are required to report to authorities.) Because Maureen was a stay-at-home mother, Child Protective Services (CPS) was called and a case officially opened. It's not
something Maureen ever expected when she walked into the doctor’s office that day.

“We felt lost, confused, angry and sad all at the same time.” Maureen said.

About a month later, once testing proved Andres had hemophilia, the CPS case was dismissed.

We asked her how Andres’ diagnosis had affected her and her extended family.

“My family is older and has an old school mentality when it comes to kids. If they fall and they aren't bleeding ... they are fine! But unfortunately with Andres everything has changed because he can't really fall and just get up and dust off. I think my family and others see me as the paranoid mom who is constantly following her kid telling him not to jump off the stairs and not to run! I am a stay at home mom and since we got the diagnosis I became the worry momster.”

Andres, now three and a half years old, has severe hemophilia and is infused twice a day — every 12 hours. That’s more often than many others with hemophilia will need. That’s because Andres has what’s called an inhibitor which makes his body reject the medicine they give him. For that reason, Maureen has to give Andres infusions more often along with another medication to help prevent rejection.

Maureen and her husband also have a daughter who is three years older than Andres.

Her advice for parents, especially those whose children are newly diagnosed, is to reach out and network with other families who can provide needed support.

“I have found that meeting other moms and parents of children with hemophilia makes me feel less of a weirdo! When we attended our first bleeding disorder conference in 2013 and we met all the other parents and caregivers of bleeder babies I almost felt relieved that we weren't the only ones! To hear others people's stories makes us feel normal of what we go thru on a day to day basis.”

The Nevada Chapter of the National Hemophilia Foundation offers a number of support groups, including groups for families of newly diagnosed children. For additional information on support groups or any other services and benefits provided by NHF Nevada, please call (702) 564-4368 or email Anne at amcguire@hemophilia.org