Community Spotlight: Jace Capovilla

Meet Jace.

Jace went into surgery at 18 months of age to remove his adenoids. After recovery and once home, Jace continued to bleed internally for the next 6 hours. We had no idea that he was still bleeding until it was quite visible. He underwent emergency surgery. The doctor was able to stop the bleeding and ultimately saved Jace's life. This was the moment that changed our lives forever.

The next day, a hematologist from California flew to Nevada to meet with us in the hospital. This meeting was quite emotional from not only what occurred the day before, but also to be learning that our son had a bleeding disorder. We did not know anything about bleeding disorders. **Will Jace be okay? What does this mean? What will this look like? What do we need to do now and in the future?** We had so many questions and as some were answered more questions arose. Each test provided another layer to the complex diagnosis of hemophilia.

For months and months, 2 year old Jace underwent a multitude of blood tests and doctor visits. Each time, it left us exhausted and disheartened. Having to wrestle and hold your baby down for what seemed like hours because they couldn't get any blood or not enough blood, and watching your child endure this treatment on a monthly basis was excruciating. All the while trying to convince yourself that your little boy has to go through this to get answers. Luckily, we had a wonderful hematologist that spent time educating us. <u>We were trying to learn all we could while still trying to comprehend that Jace had a bleeding disorder and that our lives would never be the same again.</u>

After all of the tests, we learned that Jace had Hemophilia A. It was quite shocking to learn that merely 400 babies are born with hemophilia each year in the United States. Most importantly, we learned what to do if Jace had an injury, which was quite common being that he was a two year old boy in preschool<u>. Although we learned what to do it never prepares you for when it happens, even if it happens a lot. You do panic! You do freak out!</u>

Jace is 10 years old now and the panic and freaking out has subsided. Fortunately, he doesn't get hurt as often. When he does our hearts will still race and adrenaline rushes through our bodies, but we feel prepared and ready for anything that may occur. This preparedness is only because of the Hemostasis and Thrombosis Center of Nevada (HTC) and the Nevada Chapter.

Our lives have changed, and we are so fortunate to have such a wonderful young boy! Jace is in the 4th grade now and participates in sports. His favorite is swimming and soccer. The HTC has taught us so much about living life with Hemophilia. They have taught us about physical activity, teacher and school preparedness, medication, factor infusions, and the disease in general. Through the Chapter, Jace has had the opportunity to meet peers with bleeding disorders and has made some lifelong friends.

I would recommend anyone newly diagnosed with a bleeding disorder to get information as soon as possible. Knowledge is power! Our knowledge grows with every event and meeting. We are very involved with the chapter. We have participated in almost all of the northern Nevada events as well as some of the southern Nevada events. These events include walks, dinners, information events, advocacy days as well as a summer camp for the kiddos. **The partnership that our family has formed with the HTC and the Chapter has afforded us empowerment to advocate for our son.** I truly believe that once you have found a support system that works for you and your family then your child will be encouraged and empowered as well.