

# Introducing Owen!

**Handle on Hemophilia - A Day in the life of this busy 2-year old**

*As told by his incredible parents, Stacie and Kyle*



**Owen is just like any other 2-year old boy.** He loves to explore, play, and watch construction equipment and airplanes. He also knows how to push his sister Abby's buttons—but is quick to hug her when he makes her cry. There is one thing, or lack thereof, that separates Owen from the rest of his peers. Owen was diagnosed with Severe Hemophilia A shortly after birth, a bleeding disorder that prevents his blood from clotting. Owen's body is missing blood clotting factor therefore prolonging both internal and external bleeding from an injury. Additionally, there are times for no reason at all, his body will spontaneously bleed causing muscle and joint pain.

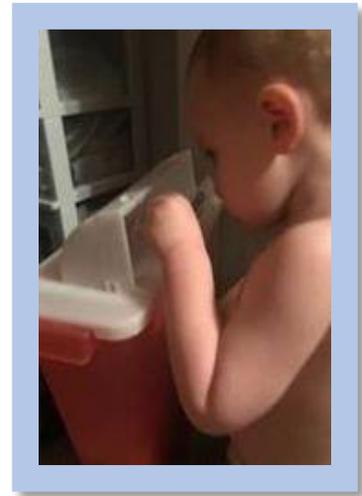
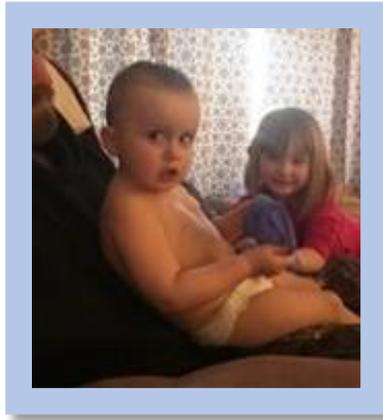
**Owen was six months old when he had his "first bleed."** He wouldn't extend his little arm and screamed as I attempted to put it through his pajama sleeve. I rushed to call my sister, Jessica, to get her advice. She was quick to calm me down, and soon we were at the hospital, where he received his first infused dose of factor. It was my job to hold him down for the technician to scope out a viable vein – only to watch the vein collapse. We then had to start the process all over again with fingers crossed that the new vein would be strong enough to administer his medication. After a few attempts, the factor was finally in his bloodstream.

**I picked him up and held him tight and cried the whole way home.** So many thoughts went through my head: Will he blame me for "giving" him Hemophilia? Will he think he is different? What if he asks me why I had another baby knowing that I carried the gene? I realized that as a family we were going to educate ourselves and become his biggest advocates; being strong is our only option.

**After many trips to the ER due to spontaneous bleeds,** his hematologist determined that a port would be easier on Owen. Having a port would mean we don't have to look for a "good" vein and take the risk of having his veins collapse and weaken from overuse. Today Owen has a port located on the right side of his chest that Kyle and I access to carry out infusions at home. Owen has had his port for a little over a year and is going strong!

**Our most recent trip to the Hematologist for blood work showed** Owen was using his medication up faster than normal. Meaning that his medication, which is supposed to last up to 48 hours, was running out after only 26 hours; making him prone to more bleeds and not allowing previous bleeds to heal. Given that his body absorbs it faster, we now give Owen his infusions every other day versus twice a week.

**During our infusions, Owen and Abby love to help!** Abby is a very good nurse and often sings to Owen; while helping set up wearing her oversized gloves. All said and done and assuming we are able to hit his port on the first attempt, a normal infusion can take 10-15 minutes.



**We start by informing Owen that we are going to be doing a “poke”** and letting him help get the supplies ready. Once Owen is sitting on Kyle’s lap we get started. We first need to clean his port and the surrounding area with ChloroPrep. While that is drying, I place my sterile gloves on, get the needle hooked up to his first saline flush and insert the needle into his port, flushing his port to make sure it is not clogged. I then clamp the needle, undo his saline and hook up his medication, once his medication has been pushed through, we repeat with the second saline. The final step is injecting heparin (a blood thinner of all things) through his line, so it will not become clogged. After his needle has been removed and safely covered, Owen walks it to the sharps container for which he receives a well-deserved round of applause. We make sure to also give Abby kudos by telling her what a wonderful helper she was!

**With having any foreign object in the body, there are always risks involved,** namely infection. Any time Owen has a fever of 100 degrees or higher we have to take him into the ER for blood cultures and IV antibiotics. Should his port and ultimately his bloodstream become infected, his body could go into shock with potentially fatal results. We are hopeful that a cure or long-lasting medication will be found in his lifetime and Owen and all those who suffer from bleeding disorders will not have to endure another “poke!”