

HB 5212
Mandy McCullough

Hi my name is Mandy McCullough. I live in Simsbury, CT with my husband Mike, son Kyle age 7, Riley Jane age 4 and another little boy on his way any day now. Our son Kyle was diagnosed with Severe Hemophilia A at birth. With no family history this was devastating news to us as we knew nothing about Hemophilia, the treatment for it or what kind of life our son would live. All we knew was that our perfect little baby boy had a big challenge ahead of him. Thankfully, as of now, we live in a time where we have access to an amazing HTC, doctors and nurses and have the choice of product and Homecare Company to deliver that specialty product. I truly believe without having all of the above, Kyle and our family would not be where we are today. As you can see Kyle is a healthy happy child who is doing extremely well and that is because he has excellent care from the Hemophilia Treatment Center, we have had choice of product, and he receives an amazing service from our homecare company.

Since we do not have a family history there was so much to learn. We found a homecare company shortly after Kyle was born and they took care of everything for us and helped us become independent in managing our son's disease. They negotiated with our insurance company, worked with our HTC to ensure we were getting the right medication, dose, and delivered the specialty medicine within one day. They also provided a nurse to come to our house to infuse our son. When we were ready the wonderful nurses taught us how to do the infusions. All of these components are so important and needed in order to care for someone with hemophilia.

Over the past two decades so much progress has been made in the right direction: safer medication, choice of product, HTC care, homecare companies, and nursing to help with infusions. It would be devastating for us to regress back to how things were. History has shown us that there IS a need for the strict standards regarding products, product choice, having a homecare company and treatment center to care for these individuals. It is crucial that we continue to provide these wonderful services so that my son and many others can lead long healthy and productive lives!