

HB 5212

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Hello, My name is Denise Mackey and I live in Windsor CT with my husband Dennis and our son, Sean(14) who has Severe Hemophilia Factor VIII. Thank you for this opportunity to speak on behalf of the bleeding disorders community.

My father had Hemophilia and he died at the age of 56 due to an intracranial bleed. His joints were ravaged by the many bleeds he had throughout his life. The medicine that was available back then was nowhere near as effective as the medicines of today.

Our treatment of Sean's Hemophilia began at birth as he had a slight bleed from childbirth. Ever since then we have had to advocate for our son. We need to have the option to get his medicine from a qualified specialty homecare pharmacy and we also need to have the ability to get the brand of factor that works best for Sean. We feel that Sean responds best to a certain product so we can't risk changing that. Children with hemophilia need to feel comfortable with their support system as they are self infusing at such an early age now. They, and us as parents, rely on the support from our HTC's and also our specialty homecare companies. Because of this specialized treatment, Sean has no joint damage today, unlike my father. Having to use a large mail order pharmacy that does not specialize in Hemophilia care would NOT fit into the security we need to ensure Sean lives a long productive life.

Also, when Sean was about 8 years old he hit his 1 million dollar cap at the job I was at. That is a real scary time for families with Hemophilia. All we want is to get that medicine for our kids! I had to get another job and thank God I don't have a cap now, but so many other families are struggling with this issue.

As you can see, Sean is doing great these days and this is so much due to the support we have received from our HTC and especially our homecare company. Thank you!