

HB 5212

Sasha Zatyarka, West Suffield

I love my husband with every ounce of my being. I hate to see him in pain. Every day. I often tell people that hemophilia actually affects his day-to-day life more than HIV. To most people HIV seems so huge and hemophilia so unknown. But to Mark, hemophilia is what makes every bump and every far reach—every common movement—the potential for days and days of pain. He can cross his legs for too long and get a bleed in his ankle. He can lightly knock his elbow on the door as he walks by and inside the blood starts flooding into his elbow joint. As heart wrenching as it is to see these common movements lead too often to so much pain, its worse yet to see him deal with the chronic, never-ending pain he has from the complete deterioration of his shoulders from thirty years of bleeds. I can't imagine how it must feel but I can tell just by the way that he's standing and holding his arm or sitting and hugging a pillow to immobilize his shoulder and prevent the bone-on-bone friction that keeps him in constant pain. I want to take all the pain away. I honestly often wish I could truly feel it instead of him so he didn't have to feel it anymore. But obviously it is an empty wish. I do what I can to help ease the burden of course. But even more important than a wife's loving care is all that HB 5212 would protect.

HB 5212 is a beacon of hope for us. It helps us not be as afraid that the quality care and services that ease the burden of hemophilia will be threatened. My husband deserves choice in his care and access to all available options and not having that choice could drastically affect his quality life in concrete, real, painful ways as well as in logistical nightmares.

Mark's regular infusions of factor help restore some normalcy in his body, at least temporarily. But I am fully convinced that not all clotting medications are equal and do not all work the same for everyone. Mark has pretty much used the same product since before we met. However, he twice switched to another product, the same product both times, and both times he sustained serious, lengthy bleeds that caused even more pain than he normally bears. I hated it and still wish he never had to deal with it. But it was his choice. Without the passage of HB 5212, Mark could be forced to use that product or another one that won't work as well. His pain should not be measured in dollars and, without HB 5212, it very well could be. He and his doctor should be the only ones to have input into what factor he uses and he should have access to all available products, not just the ones deemed cost-effective.

Likewise, he deserves access to hemophilia treatment centers. I just recently accompanied Mark to a HTC appointment and it is incredible. Talk about easing the burden. This model of care serves the patient so fully. I felt such comfort as Mark's wife to witness him getting such due attention to every aspect of his condition and of our life affected by his condition. These specialists demonstrate a level of expertise and commitment that is so refreshing in the face of the reality of managing hemophilia, a reality that HB 5212 will greatly improve.

I try to share in that reality as fully as I can with Mark so he doesn't have to do it alone. Very soon after we met, I started to learn how to infuse him as one tangible way to "walk" with him. It is quite a process, let me tell you. There are so many steps and so much skill and so many ancillaries like the alcohol pads and the gauze pads and the butterfly needle and the syringe. We have to have access to all these items and I can only imagine if we had to gather them from here and there and everywhere. We are fortunate that our homecare pharmacy provides all we need to be able to infuse. It would be daunting otherwise. We recently had the experience of trying to buy butterfly needles while on a trip in DC and it was impossible, literally. There is so much else to worry about connected to hemophilia; ancillaries should certainly be the least of them but yet again there is the risk of it coming down to money. We need HB 5212 to provide assurance that this seemingly minute aspect of hemophilia management is not in question.