

Hi, I'm Dennis Mackey and I am the president of the Connecticut Hemophilia Society and also the father of a 20-year-old son that has severe factor 8 Hemophilia. This means his body produces <1% of the factor needed to form a blood clot. Sean doesn't bleed any faster than I do. He will simply bleed longer. Someone like Sean, with hemophilia has to worry about spontaneous bleeding into their joints or directly into their muscles. After years of bleeding into joints people suffer from arthritis, chronic pain and mobility issues. The only cure for someone with hemophilia at his time is a liver transplant.

My son Sean has been on a factor 8 replacement drug since the day he was born. My wife Denise was in labor for 24 hours before they decided to do a C-section. When Sean was born he had a extracranial hematoma and by the time they got the blood tests back Denise had already started nursing and bonding with our son when they had to take him to the NICU for his first dose of 250 units. He was even scheduled for surgery a month before his first birthday to have a port-a-Cath placed into his chest. Before they were going to take Sean to the operating room they had to make sure that his factor levels were up to 100%. The operation didn't happen that day, so the next time the hematologist wanted to try would be in a month on Sean's first birthday.

After the port was put in life was definitely easier. I still had to cover every corner in the house with foam and Sean learned to crawl and walk with a helmet and special pants that Denise had sewn padding into. We would give Sean 250 units of his factor 8 replacement every other day. After a year or so we didn't have to use numbing cream anymore because of the scar tissue that had formed on his upper left chest. After around 1200 sticks to his chest with a port needle it had to be replaced. Sean then had to have another one put in because as parents we weren't ready to do intravenous access on our 5-year-old son yet and our insurance only covered 3, that's right, 3 visits from a visiting nurse. Over the next year my wife and I learned to do his medicine intravenously.

At the beginning Sean would get 250 units every other day and around 5 he was at around 1200 units every other day. We always had insurance for our family and with a million-dollar cap on insurance Sean was going to use it up before he turned 7 years old. We started skipping at least one day a week trying to have it last as long as possible. After the inevitability of reaching his cap we had to put Sean on state aid and received our factor from the Red Cross.

The only way for Sean to get his insurance back was for one of us to get a new job. Then we had to wait another year because of a pre-existing condition. Today Sean takes 3000 units every other day with a yearly total costing around \$800,000. Before the ACA my family could have been responsible for over \$200,000. Right now the ACA has a cap on out of pocket expenses, but it still is almost \$13,000

Who can afford to pay out \$13,000 within the first few months of every year. We would have no other choice but to tell Sean we couldn't afford his medicine. I would pray every day he doesn't suffer the same outcome as his grandfather and die from a spontaneous head bleed just lying in bed.

In Connecticut our exchange programs are based on a 4 tier formula with up to a 40 % out of pocket expense. That is just not feasible. Do we really think it's right or okay to burden those of us who already have enough of an uphill battle dealing with a chronic illness?

Thank you for giving me this opportunity to share my story