

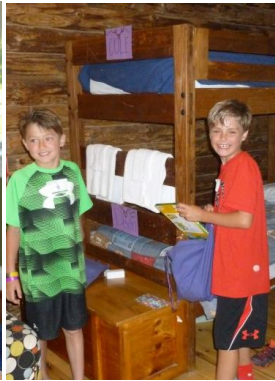
My name is Cole Hamstead and I have severe Hemophilia A. I need your help to make sure I continue to get the access to the care/medication I need to stay healthy.



Cole (age11) loves to play sports



Cole learning to find a vein and 'stick' himself for his infusion



Cole and his cousin Devin attend Hemophilia 'Sleep Away' Camp where they learn how to self infuse



Cole met with Senator Dinniman and Senator Killion this spring to discuss issues facing people with Hemophilia in PA



Cole got at chance to talk to Vice President Biden about having Hemophilia

Cole Hamstead is a happy and healthy 11 year old who loves playing baseball, tennis and golf. His favorite class in school is gym and he plays touch football and soccer with his friends at recess. Cole also has severe Hemophilia. The amazing medications that are available today allow Cole to live the active life he enjoys and not be defined by his illness.

Hemophilia A is a chronic lifelong illness where the blood is missing a critical protein (factor VIII) needed for the blood to create and maintain a clot. Individuals frequently experience spontaneous bleeding, most frequently into their joints, skin, and muscles. There are approximately 20,000 people in the US living with Hemophilia (1 in 5,000 male births). There is no cure yet for hemophilia A, but with the proper self-care care and treatment, kids and adults who have the disease can lead **normal, active lives**. The condition is mainly treated by increasing the level of factor VIII in the blood. This is done by an infusion (injection) of factor replacement therapy, also called factor VIII product. These medications are infused into a vein every other day.

Factor medications are very costly and the dosage is based on the weight of an individual. Cole receives factor medication every other day that is infused into a vein. Cole is 11 years old and his **factor treatments cost approx. \$70,000 a MONTH** (approx. \$4500.00 a dose) for preventative treatment and more when he has a bleed. If a cost-sharing structure of 25-50% was used for this medicine the cost to our family would be **\$17,500-\$35,000 each month**. This would be impossible for us to afford and Cole would no longer be able to have the healthy, active lifestyle he has today.

There are numerous factor products available—**no one factor product or dosage amount will work effectively for all Hemophilia patients**. The dosage, medication brand and treatment plans are customized for each individual since people with the same severity of Hemophilia can bleed very differently.

Cole visits his HTC (Hemophilia Treatment Center) at the Children's Hospital of Philadelphia three times each year and closely follows his treatment plan and to-date has healthy joints and is able to participate in many sports (golf, tennis and baseball).

One last comment. I live in Pennsylvania, but work in Delaware. I have family in Delaware. My parents live there. Cole and I were in the Senate Chamber in Delaware on the day a very similar bill (SB 35) was being voted on, three years ago. We came to support the families who would be positively impacted by this cost sharing cap bill.

I remember a man who spoke to the Senate just before the vote was taken. And I remember what he said. Bill Kirk, speaking on behalf of the Delaware insurers, made a public statement that the Delaware health insurers would not oppose the bill. That it seemed reasonable and would help the people of Delaware. The bill passed in the Delaware Senate and later that day in the House of Representatives. This cost sharing cap legislation became law in Delaware in January 2014. I hope Pennsylvania can do what Delaware did..... take action to protect its citizens from unreasonably high cost sharing for the medicines they need to live.

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