

30 January 2019

Victoria Kuhn

Falmouth ME

Dear State Senators, Representatives and EMS Regulators:

I am writing about needed changes to current EMS protocols to assure all individuals with Special Medical Needs and Specialty Medications are protected. As a family personally affected by a bleeding disorder (severe Hemophilia A) that requires regular at-home, three-day-a-week prophylactic treatment, my 12-year old son needs his medication to be safe, healthy, and strong.

When my son was three, he was in a vehicular accident with his caregiver. At the time, three days a week, I worked 60-miles away from where we live. On that day through the grace of God, I was less than four miles from the accident and we infused him at home within 15 minutes of the accident and then took him to the hospital emergency room for a MRI of his brain. I live in a small town of 11,000 people. My family is the only family that has hemophilia in Falmouth. Police and EMS staff did not know anything accurate about hemophilia and the ambulance did not stock his factor medication. **Something that keeps me up at night is if my son is unable to self-infuse or if I cannot infuse him due to an emergency – what will happen to him, especially with life-saving factor medication in the car.**

When someone with a bleeding disorder has an emergency (especially with trauma to head, neck, and internal bleeding into the body core or organs), it is mandatory that he or she receive immediate treatment of factor medication dosed to 100% level. The medical protocol is to treat first with factor medication, then assess injuries. This is counter-intuitive to emergency medicine for nearly all traumas, I know, but it is necessary to stop or treat a bleed for someone with a bleeding disorder.

If Missouri laws do not permit trained emergency officials, such as Paramedics, to administer my son's medications (that we routinely keep in our car along with a travel letter from my son's hematologist), it will come at significant and potentially life-threatening costs to his health when we travel to your state. As I understand, today, the only option is for EMS to transport my son to either St. Louis or Kansas City hospital, which creates a major delay in care. This option is NOT acceptable and has the potential to be life threatening.

My son and I urge you to make the changes necessary so that people with hemophilia, other bleeding disorders and other rare diseases can be treated by Paramedics promptly. Please support SB452!

Best wishes,



Victoria Kuhn