



The Campaign to change the Emergency Medication Protocols in every State!

Let me introduce myself, Darlene Shelton, the driving force to this campaign but also the grandmother to a precious little boy, **DANNY**, who is the heart behind my desire to prevent morbidity and mortality for a certain population of people with Bleeding Disorders and a few other rare diseases which require individuals to carry their own rare medications.

The Shelton Family journey with Hemophilia started in 2011 when our precious grandson, **DANNY**, had his first “bleed” at 10 months old. After a week of ER visits and testing, the diagnosis of “severe” was determined and our lives changed forever.

With no previous family history, we dove into researching medications, treatments, and answers for a safe way of life for our little man and soon felt as secure as possible that we had medication, plans and procedures to protect him as much as possible for a long, happy, basically normal life.

But, in April of 2014, one of those safety plans was torn apart! We were informed that although we had Medic Alert on his car-seat with his Factor pack attached to it with medical orders & dosing, the Paramedics or E.R. Doctors were not allowed to give it. This is based on protocols which prohibit administering any medications not in their possession.

We were completely shocked and doubted the accuracy. However, with research, we sadly realized it is true which started the spark of discontent. After a Ladies’ Retreat in June hearing the actual horror stories of experience and even one family’s loss of a father/husband, I knew we had to TAKE ACTION and not just in Missouri but across the entire United States.

With our research, we determined the following:

- A. most states only have 1 to 4 cities where factor is available
- B. most ER doctors & Paramedics do not have training in bleeding disorders and will not administer the medications in the patient’s possession because they are unsure of the purity/safety and due to liability
- C. waiting for a transfer of the injured person to or the “safe” meds from the HTC results in a delay in treatment
- D. many in our community and their hematologist have no idea that these protocols exists and believe they are protected

The DANNY’S DOSE campaign has 3 main goals:

1. To amend the protocols to allow paramedics to administer our life-saving medications in an emergency situation when the person or caregiver is unable to do so to prevent a delay in treatment
2. To assist in creating training programs for Paramedics and ER Doctors for Bleeding Disorders and the medications
3. To assist in training our consumers in having a complete overall Emergency Plan and procedures to ensure that a good treatment plan is in place for any emergency

We started “at home”, at the top, with our MO government, with nothing but dead ends. At a loss, I tried a several different avenues to no avail. I prayed even harder about the desire God had placed on my heart and soon a friend was elected as our District Representative, one message to her in January opened the door and she started working. Things were moving slowly until March 2nd when our local News aired the story which ended up going nationwide. Since that time, we have been working hard to inform our Legislators, Department of Health, EMS Bureau and our fellow community members and work together to find a solution in this gap in coverage while our family has also been putting together a “Plan of Action” for other states as well as working on Emergency Plan education for families.

At this point, our Missouri government has created a Task Force to look into this gap in protection as well as other areas and the necessary changes are being worked on. Also, in conjunction with one of our hospitals, we are having the first CEU Credit training for Paramedics in Bleeding Disorders. Things are happening now and each of us will be better protected.

We have learned that standing up with a strong voice, does make change happen and those changes may even end up protecting more people than you originally thought about. Each one of us can make a difference when we work hard, however, **when a group joins together working toward a common goal, the work is easier and the results happen more quickly.**

You may visit the website for more information: www.dannysdose.com and follow our facebook page or if you want to discuss making changes in your state, you may call me personally. (573-820-2819)

MANY VOICES HAVE MUCH MORE POWER THAN ONE!