DANNY'S DOSE
the VOICE
for those with
special medical needs

A campaign to change state & federal
Emergency Medical Protocols

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Senator Anderson, Chair
Senate Committee on Health Care

RE: Support of SB-452: EMS Treatment Protocols for people with complex medical conditions who carry life-saving personal use medications

Dear Chairwoman Anderson and Committee Members:

After my first grandson received a surprise diagnosis of Severe Hemophilia B due to a mouth bleed at 11 months which left a crib that looked like a murder scene, our family stepped into gear to assure he was protected at all times. His protection comes in the form of replacement clotting factor administered by IV prophylactically, twice weekly, at home by himself or his parents. This is the life of a person with a bleeding disorder. Their lives revolve around regular doses of life-saving medications which requires an immediate additional dose when any trauma happens, especially if it involves large muscles, organs or the brain.

For three years after his diagnosis, we thought we had every avenue covered to protect him. In the auto, we had emergency alert on his headrest, a marked bag with an emergency dose of factor attached to the carseat and Emergency Medical Orders from his specialist. We were sure if his parents weren't able to treat that EMS would be able to give his life-saving emergency dose of clotting factor. Imagine our surprise when we learned we were wrong! Due to old protocols across the U.S. that "PROHIBIT PARAMEDICS FROM ADMINISTERING MEDICATIONS NOT ON THEIR AMBULANCE".

We were in shock this could be true but our research proved it was. Our family realized that Danny, his sister Lily, and every single person who has a special medical need has a right to prompt and proper treatment in an emergency including usage of their own life-saving medications which they must carry because the rare meds are only available at Level 1 Trauma Centers. We each carry an Emergency Dose in the original packaging and should not suffer due to delays or refusal of treatment and the extra stresses of being transported to a Trauma Center miles away in hopes it's "In Time"! Furthermore, our highly trained paramedics have the education and experience necessary to follow Emergency Medical Orders carried by a patient which provides proper dosage instructions to merely mix a medication and administer via injection or IV. They simply need old protocols changed that will no longer PROHIBIT and NOT MANDATE their action but will <u>ALLOW</u> them to act.

Our family founded the Danny's Dose Alliance in March, 2015 and began working with our State EMS Association and MEMSA Board. Our Bill passed and was signed by the Governor in July, 2017 making Missouri the first state to pass legislation which protects not only over 265,000 affected individuals but our many EMS personnel and advisory physicians.

Prior to the Bill passing, of course there were many questions and concerns and even opposition due to the unknowns until our largest hospitals, emergency physicians, EMS Personnel, legislators and advocacy groups came together to for clarification and education. Before and since the Bill passed, EMS education is continuing, new protocols adopted and patient families are being educated. We also have many different success stories including a 60+ year old hemophiliac who was choking on his own blood from a throat bleed. He could not self-treat and his wife just could not hit a vein. Two paramedics arrived on the scene, one provided suctioning while the other administered his medication. Within minutes, the clotting factor took effect, they transported and he is fine today. They did not have to delay with a phone call for authorization to treat because Missouri had already prepared for that "rare instance" that the "rare disease" person is the patient.

Since July, 2017, we are working nationally with many rare disease organizations including NORD, Every Life Foundation and Global Genes. We are also working with HRSA, American Academy of Pediatrics, NAEMT (Nat'l Assoc of EMTs), NAEMSP (Nat'l Assoc of EMS Physicians), NASEMSO (Nat'l Assoc of State EMS Officials), and EMSC (EMS for Children). They are all in acknowledgement of the issues for this patient population and we are working toward good solutions, recommendations, template protocols and a national paramedic education campaign for rare disease. But we don't need states to wait till we have every single thing lined out, we need states to help be the leaders in being part of a good solution.

Missouri and Oregon are very similar in their regulatory make-up with no statewide protocols and each service has supervising physicians. They have a State EMS Association with a Medical Advisory Board with several committees. Missouri came together to pass the legislation and work on the solution which is our hope for Oregon too. This is much like other times new protocols have been established for example; procedures for heart attack, stroke and Epi-pen. It is new and it requires some work, but there is proof it can be done and lives prove it must be done.

The purpose of SB452 is for protocols to be established to protect the "Special Medical Needs' patient. For EMS, this Bill will allow for:

- Collaboration of the Health and EMS authorities. Of course it is understood that would include the EMS medical advisors.
- Establishing protocols will not usurp the authority of the local supervising physician but relieve them from the liability of establishing their own protocol or to make a split-second decision about treatment on conditions they have little or no training
- Adaptability for individual services based on resources
- The discretion of the paramedic and/or medical advisor based on the particular situation and circumstances
- Extra level of liability protection for the EMS personnel trying to do their job
- Oregon EMS to expand their current education by including more around special medical needs and rare disease
- Oregon to be the SECOND state to step up to address the issue and provide a solution. (MN currently has legislation. OH and NE are in discussions and started specialized education.)

For the over 270,000 affected Oregon residents and their families who live with diseases that include: Adrenal Insufficiency, Bleeding Disorders, Complex Diabetes, Hereditary Angio-Edema, Mastocytosis, MCADD, Pulmonary Hypertension, and Urea Cycle Disorder plus some cancer patients taking certain chemotherapy meds and others; it will allow for:

- Prompt and proper treatments which will reduce pain, suffering, irreversible damage and even save lives
- Peace of mind for the families who live in daily fear of not being close enough to ensure they can provide treatment themselves
- Money savings with decreased hospitalization from delayed treatment
- Money savings from air-flight to a Level 1 Trauma centers which is the current solution in most cases
- Raising awareness to medical specialist for the need to work more closely with the patient's local EMS Service
- Establishing relationships between families and their local EMS service
- Giving better protections at school and peace of mind to school personnel knowing treatments can be had

In short, SB452 provides support, clarification and protection for EMS and more than 270,000 affected individuals.
Thank you for your willingness to help. As an organization, we are willing to be part of the solution and welcome discussion and dialogue with all stakeholders to address proper emergency care for the specialized patient.

Sincerely,

Darlene Shelton, President