

15 February 2024

The Honorable Pamela Beidle
Chair, Senate Finance Committee
3 East Miller, Senate Office Building
Annapolis, MD 21401

Subject – SB0117- Health - Newborn Screening Program - Krabbe Leukodystrophy

My name is Brian Stone and I am the uncle of Lillian Grace Smith. You will read and hear testimonies from families impacted by Krabbe and how not being screened at time of birth has impacted their child's and the entire family's lives and the importance to pass this newborn screening bill for Krabbe. What I wanted to walk each of you thru is what a typical day is like for Lily, age 12, diagnosed at 6 months, transplanted at 7 months.

7:00 am – nebulizer treatment, shaky vest, cough assist, 2nd nebulizer treatment, trachea care followed by medications and flush – lasts about 45 minutes

9:00 am – food, medications and flush, bath, change of clothes, physical therapy for 1.5 - 2 hours

11:00 am – food and flush, back to bed for side laying, position change

12:00 pm – occupational therapy and/or speech therapy

1:00 pm – food, medications and flush

3:00 pm – food, medications and flush, change of clothes, positional change to lay on couch, medications

5:00 pm – food and flush, positional change

7:00 pm – food, medications and flush, nebulizer treatment, shaky vest, cough assist, 2nd nebulizer treatment, trachea care

9:00 pm – food, medications, and flush, get ready for bed.

REPEAT. Day after day. 7 days a week. 52 weeks a year.

Note - Every hour someone needs to change Lily's positions to avoid bed sores.

A schedule of other therapies IF its during the school year, IF therapists/teacher are available and IF Lily and therapist/teacher are not sick

Monday – Physical therapy for 45 minutes for head control

Tuesday – home teacher for 1 hour

Wednesday – School for occupational therapy and physical therapy

Thursday – Private Occupational therapy

Friday – virtual speech therapy

All of that care is needed in a typical day, yet Lily is the bravest and strongest person I know and is one of Krabbe's biggest transplant success stories. Most of this could have been prevented if the state of

Maryland had screened Lily for Krabbe at child birth. Lily would have been diagnosed early on, received a successful transplant and had a very normal day to day life as a 12 year old. If costs are concerned, let me assure you that the cost to care for Lily and other Krabbe children in the state of Maryland FAR exceeds any costs to acquire an additional testing unit and around the clock coverage to man perform screening. That's not including the emotional toll it takes on a Krabbe baby's family, friends and community. Give Maryland families the knowledge of what their child faces and give them the opportunity to make a decision on what is best for their family immediately after child birth. Thank you for your time and looking forward to helping pass this important bill along with you.

Sincerely,

Brian Stone
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