



Newborn Screening
Saves Babies
One Foot
at a Time

Serina

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHOSE CHILD HAS
3-METHYLCROTONYL-COA CARBOXYLASE DEFICIENCY (3MCC)

My 8-year-old daughter has 3MCC or 3 Methylcrotonylglycinuria. She also has brain damage. The 3MCC couldn't be prevented, but the brain damage could have been--through comprehensive newborn screening.

Because Serina's disorder was not detected at birth, and we were not given the information that we needed to react with urgency when she began vomiting, she suffered an acute metabolic crisis at age 4, which left her in a coma for 3 days. It took 10 more days for metabolic tests to come back; meantime she was being fed protein through an I.V.--she cannot break down protein. So she was being further injured as she was supposed to be recovering from diffuse cerebral edema; again, because her disorder wasn't detected at birth.

Serina suffered left-sided hemi paresis and cortical blindness. She has endured many therapies, OT, PT, vision therapy, and others. Her childhood has been stolen from her, and from our family.

Now she is integrated into a regular 2nd grade classroom, with a one-to-one aid and a great deal of support. We're not sure if she will be able to drive, or take care of herself independently, let alone raise a family. All this could have been prevented.

Give parents the choice. I would certainly have chosen to take every precaution with her life. Think of Serina's life for just a minute. All of our hopes and dreams... Please consider adding as many disorders to your newborn screening as is possible. Who would you want to leave out? Serina?

Thank you for your time.

Sincerely,
Jamie
Serina's Mom