

Newborn Screening

By Carolyn Clifford
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With a just a few drops of blood, babies can now be screened for nearly 60 genetic disorders, but Michigan checks newborns for fewer than a dozen conditions. Now, one mother is fighting to change that.

Shelley Grabow, who grew up in Macomb County, has a special wish this Mother's Day. She wants Michigan to expand its newborn screenings so babies don't die soon after they're born.

Shelly Grabow's first son, Caleb, lived for only 14 days.

"A day and a half later he passed away in my arms," she now remembers. "It was that quick and we didn't know why."

Shelly's third son, Noah, made it to four months.

"And he knew that Mommy and Daddy loved him. We gave him the best time we could for the short time he was here on Earth," she says.

Only her middle son, Caden, was spared the inherited disorder called TFP. In TFP, he body can't break down certain fatty acids. The boys' hearts gave out.

Since Noah's death a year ago, Shelly has turned her grief into action.

"I want every state to screen every child that is born in the United States for all the current disorders that are available for screening, which is 50 plus," Shelly explains.

Newborn screening programs differ from state to state. Last year, Michigan tested for only 8 hereditary conditions. It has now expanded to 11.

Dr. Gerald Feldman of the Metabolic Clinic at Children's Hospital of Michigan hopes the screenings will soon grow to 29 disorders.

"We are optimistic it will happen and we're making the effort to be ready for it when it does happen," Dr. Feldman says.

Expansion will take money, a change by the state, and greater awareness. Geneticists say people are starting to realize that while these conditions are rare, with expanded screening, many lives can be saved.

Dr. Roderick Hume with the DMC Hutzel Hospital explains, "There's more emphasis not just for Moms who have been affected, but from Obstetricians and pediatricians say, 'Geez, why don't we look for this?' because it's hard to figure it out and too late if some one's passed away."

In some disorders, such as PKU, a child can be helped simply by changing their diet. Sadly, there were no treatments for Shelly's sons. While expanded testing wouldn't have saved them, Shelly wants to be sure the tests will be there for other mothers.

"At least you have a fighting chance instead of sitting there and watch your child die and not knowing why," she explains.

The March of Dimes is pushing for all states to screen newborns for at least 29 metabolic diseases. This year, instead of going door to door for donations to help make that happen, the March of Dimes has teamed up with Hutzel Women's Hospital for the country's first "Virtual Canister Campaign." It just takes a simple mouse click to give, at [the DMC's March of Dimes website](#).