

Oral testimony presented by Ms. Kathy Stagni, Executive Director of the Organic Acidemia Association and parent of an adolescent with propionic acidemia, a metabolic disorder, to the Health and Human Services Policy Committee of the Minnesota House of Representatives on March 19, 2003

Good evening—

My name is Kathy Stagni. I live in Plymouth, Minnesota. I am the Executive Director of the Organic Acidemia Association, a non-profit support group for families and professionals dealing with inborn errors of metabolism. I am also a parent representative on the State's Newborn Screening Advisory Committee.

You are considering House File No. 904 that mandates the expanded screening of newborns for inherited metabolic disorders, along with fees and administrative rules for implementation. I join you tonight to tell you of my personal experiences as they relate to newborn screening and solicit your support for passage of the bill.

My daughter Melissa is 14 years old. She has an inherited metabolic disorder called Propionic Acidemia. When she was born, Propionic Acidemia was not included in the newborn screening program. Shortly after birth, she fell into a coma, near death at the University of Minnesota neonatal ICU. Thanks to the vigilant efforts of metabolic specialists, Dr. Mendel Tuchman and Dr. Susan Berry, who is here with me tonight and other staff at the University of Minnesota, Melissa survived – but today suffers mental retardation as a direct result of delayed diagnosis.

I have had the opportunity to meet and talk to many parents whose children suffer with these disorders about their challenges, frustrations and fears they have in dealing with children afflicted with these life-threatening diseases. In many cases, the severity of the disease can be minimized if detected early. When these parents learn that newborn screening may have prevented or reduced the severity of their child's handicap, they are OUTRAGED that they didn't know – or worse, that it wasn't a standard test given to all babies. In some cases, the parents have even sued the hospitals.

Minnesota has been a leader in expanded newborn screening. We acquired the technology and for nearly two years have conducted a successful pilot program. Other states are looking at us and modeling their newborn screening after ours. We should be proud! Minnesota has set the “standard of care” for newborns – WE CAN NOT GO BACK!

Citizens of Minnesota have come to expect that we take a leadership role in applying technology to improve the society in which we live. We are very fortunate to have some of the leading medical institutions in the country in our community – but they can not fix what they don't know about!

Please pass this bill thank you for your time.

*presented by Ms. Kathy Stagni
Executive Director of the Organic Acidemia Association
Parent of an adolescent with propionic acidemia*