

Carsen

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHOSE CHILD
HAS GLUTARIC ACIDEMIA TYPE II (GA-II).

Pure joy arrived in the Richards' home on June 9, 2003, at 4:44 P.M. in the form of a bouncing bundle named Carsen Phillip Alan Richards, the newest member of the Richards clan.

Because big brother Caden was diagnosed with GAI, Carsen was screened at birth using MS/MS technology. The first newborn screening card indicated a problem. However, Carsen was showing no signs of GAI and was doing very well except for an abundance of spitting up causing the need to switch him to a Lactose Free formula. Carsen hasn't had any problems since starting the new formula.



"He is the best baby. Carsen never cries, eats well, has great muscle tone, and the re-test was normal," brags Krystena.

However, for safety's sake, his parents arranged for additional, in-depth tests. "I am naturally a bit unconvinced [that Carsen is not affected] since Caden's real problems didn't exaggerate until he was about 8 or 9 months old, and his labs have been normal at times and abnormal at others. For now, we are just enjoying being new parents all over again."

But this enjoyment was short lived. Before we were able to bring you this story we received word from Krystena that test results confirmed that her baby does have GAI.

"Carsen is affected and we are devastated. He seems to be doing so well. It all started with a phone call about the skin biopsy results..."

And so it begins...

The rush to see the metabolic team, waking Carsen every 2 ½ to 3 hours to be fed, the supplementation of Carnitor and Riboflavin, the pre-ordered IV should Carsen look the slightest bit sick, and the universal call that goes hand-in-hand with a metabolic disorder: "But he doesn't look sick – he seems so healthy."

Carsen is one of the few lucky enough to be diagnosed before crisis sets in, placing the odds in his favor. Even with these odds the family waits... waits for more information from the doctors, waits to see how well Carsen will do with his disorder, waits for the first 'virus season', waits hopefully that all will be well with their

smallest angel...

Mike & Krystena Richards

Parents to:

Carsen Richards DOB: 6/9/03 GAI/MADD

Caden Richards DOB: 7/13/98 GAI/MADD - Diagnosed: 6/18/02

Warren Prater - half sibling/7 yrs unaffected

Jaime Richards - half sibling/10 yrs unaffected

Info supplied February 2004 by Krystena Richards