The Kansas City Channel (KMBC-TV); September 30, 2003
Mother Urges Parents To Have Infants Tested For MCAD
http://www.thekansascitychannel.com/health/2521554/detail.html

Mother Urges Parents To Have Infants Tested For MCAD Disease Characterized By Enzyme Deficiency

KANSAS CITY, Mo. -- It's hard to imagine anything more painful to a parent than the death of a child and then finding out a simple test at birth could have prevented it.

"She was active in gym, loved to go out and play with her friends, ride her bike -- very active. No problems, no health problems whatsoever," said Kelly Peters, whose daughter, Alexis Knapton, died in March.

Without warning, the 8-year-old was found unresponsive in her bedroom. Doctors were unable to save her.

But her parents now know a simple screening test at birth could have prevented her death. She had Medium Chain Acyl-CoA Dehydrogenase (MCAD), which is a genetic disorder that causes an enzyme deficiency.

Missouri and Kansas hospitals do not routinely screen for MCAD and Alexis showed no symptoms until it was too late.

"By the time they come in, in that shape, even if we can revive them, they end up with significant brain damage," Dr. Majed Dasovki said.

Expanded newborn screening would likely have caught the disease right after Alexis was born and could have been treated, KMBC's Kelly Eckerman reported. For less than $25, Peters could have requested those tests and she wants other parents to know what she did not.

Peters has set up a Web site to honor Alexis and to educate other parents about the expanded newborn testing that is available. The website can be found at www.mcadangel.com.

"Carriers don't have signs, so unless you get screened, you're not going to know if it's going to be passed on. We had no idea," Peters said.