

## Lily (written by Lily's mother, Sarah)

Lily was born on April 7, 2003, a seemingly healthy and beautiful baby girl. She was the first grandchild, so she received plenty of attention and love. I was so excited for the journey ahead of being her Mother. We were stunned when the morning of the week before her first birthday, she got up to crawl and fell face-first into her crib. She was rushed to the hospital and upon arrival and review, the Doctor's admitted her for dehydration. Later in the day, she suffered a seizure. When we were later able to transfer her to Children's Hospital, the doctor's there ran tests and confirmed that Lily had Glutaric Acidemia Type I. It was then that we learned that Lily would probably have a disability for the rest of her life. She would need a g-tube to eat, and medicines to regulate her condition and high muscle tone. From there on, she has been unable to eat on her own, or to talk and walk. For most of her life, she has struggled with unending illness and the recurring hospitalizations, and several surgeries. Nonetheless, time has healed our hearts, and God remains faithful in showing us Lily's amazing strengths and enduring spirit.

Lily started conductive education classes in October with the help of three sets of donors. We are already seeing results that have made a difference in Lily's daily life. She is SO happy to go to classes and "talks" the entire drive home after class. She wiggles and moves more than we're used to which makes bathing her and dressing her somewhat funny— she just moves and laughs, almost like a game she's playing with us. That is wonderful initiative from her! She can also roll from her back to front when she's on the floor! When I tell people this, I can hardly believe the words coming out of my mouth – and they're surprised to hear it! Lily has not gone to the hospital in over a year, and I feel that some of this is due in part to Lily being out of her chair and learning to move and support herself at conductive education!

