

## Mackenzie Plick's Story



Mackenzie was born on December 19, 2012. She was a beautiful, happy and seemingly healthy baby. Her first year of life was marked by the enjoyments of hitting all of the expected milestones. We as her parents could not have been happier.

When Mackenzie was 1.5 years old she began losing skills that had previously been easy for her. She no longer was able to pull to stand or walk. As time went on she slowly began to lose her fine motor skills as well. Mackenzie started physical, occupational and developmental therapies through early intervention. Even with all of these therapies Mackenzie was not regaining her skills. The doctors ran numerous tests, and (incorrectly) diagnosed Mackenzie with mitochondrial disease.

After meeting with many specialists, her diagnosis started to be questioned. After much more testing and evaluations Mackenzie was finally diagnosed with Tay-Sachs disease. Tay-Sachs disease is a rare genetic neurodegenerative disorder that has no treatment or cure.

After her diagnosis, we traveled to Minnesota to speak with more specialists who are trying an experimental drug treatment. They are hoping this experimental medication will slow the progression of the disease. In the meantime, we are hoping for a more effective treatment to help children with this disease live a healthier, longer life.

Although Mackenzie suffers from seizures, feeding difficulties and movement issues she continues to be the light of our life. She does not speak but shows love with lots smiles and snuggles. She has taught us all so much about love, perspective and hope. We hope for a cure for her and all the children affected by this disease. Our sweet Mackenzie turned 3 this past December. We feel incredibly grateful for every day we get to have with her. Turning 3 is not a milestone all children with Tay-Sachs get to experience. We ask you to please keep our daughter Mackenzie in your thoughts and thank the Shannon Daley Memorial Fund for helping our family and for helping us spread awareness about Tay-Sachs Disease.

To learn more about Tay-Sachs, please visit [www.curetay-sachs.org](http://www.curetay-sachs.org).

