



Our angel Keira, born February 18, 2008, was diagnosed with Rett Syndrome at 30 months of age. Rett Syndrome can present with a wide range of disability ranging from mild to severe. Rett Syndrome causes problems in brain function that are responsible for cognitive, sensory, emotional, motor and autonomic function. These can include learning, speech, sensory sensations, mood, movement, breathing,

cardiac function, and even chewing, swallow-

ing, and digestion. Rett Syndrome is two to three times more likely to appear in girls than phenylketoneuria (PKU), yet all newborns in the USA are tested for PKU and not for Rett Syndrome. Rett Syndrome strikes all racial and ethnic groups, and continued research on Rett Syndrome is considered a "Rosetta Stone" in helping scientists understand multiple developmental neurological disorders. In 2007, using laboratory mouse models, a study demonstrated disease reversibility.

We are blessed that, currently, Keira has maintained her ability to walk, has had no recorded seizure activity and has had a normal EKG. Unfortunately Keira has not regained any verbal skills and her purposeful hand use has continued to decline, making it difficult for her to feed herself and perform most other independent self help skills. We continue to strengthen and maintain the abilities Keira has through Physical, Occupational and Communications Therapies, as well as indoor swimming, each week. We have struggled to manage her irregular sleep patterns, her variable breathing patterns, and her overall health with daily medicines, diet adjustments and many doctor appointments. Through all of this, Keira has proven her unwavering determination and has not lost her loving disposition.

Keira is not able to speak, so please be her voice. It is now our mission to advocate and educate people about Rett Syndrome and we hope you will join us in educating others.

#### **Because of Keira...**

We are more informed;  
We are more passionate;  
We are more compassionate;  
We are more loving;  
We are more hopeful;  
We are more driven to find a cure.



We need YOU more than ever to join in this fight! Follow my story by searching for Keira Bathie on Facebook! To learn more about Rett Syndrome please visit [www.rettssyndrome.org](http://www.rettssyndrome.org).

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