



Angel Foundation®

Bridie's Story



September 2009: Angel of the Month
Written by Den Mother Laura

"The most wonderful thing about Bridie is her unbelievable sense of humor she is always happy and never down. She laughs about any thing. I think this is down to her fantastic mum and the hectic life they all lead." ~ Hazel, Bridie's amazing grandmother

Bridie Gutteridge is a beautiful 14 year old girl full of happiness and spunk. Those who know her say she is a wonderful, average teenage girl. She cannot sit, walk, or do many things for herself, but does so much more than doctors said she would be able to do. Bridie has overcome many challenges and her story is one of courage, determination and love.

Bridie was born on October 23, 2005. She was the third child, and was adored by her older siblings Mollie and Mikey as well as the rest of her family. She was a happy baby who grew and developed normally until she was about four months old, when Bridie's mother Michelle noticed that she couldn't hold her head up, had very low muscle tone and was unable to sit up without assistance.

Michelle took Bridie to the local children's hospital for an examination. The examining doctor felt that Bridie's slowed development was nothing to be concerned about. Michelle would not accept this answer, so she continued to take Bridie back to the hospital for more examinations and opinions. At the end of every visit she was always told that everything was fine. These visits continued until Bridie was about 12 months old, which is when she began to show symptoms that the doctors could not explain. The pediatrician finally decided it was a good idea to run some tests on Bridie to see what could possibly be going on.

After six months of testing that did not provide any answers about Bridie and her symptoms, Michelle, and Bridie's grandmother Hazel, took her to the London Research Institute. The doctor at the Institute told them that Bridie had something called Leukodystrophy. Leukodystrophy is a group of disorders characterized by the progressive degeneration of white matter of the brain (part of the central nervous system), which is caused by the imperfect growth or development of the myelin sheath: the fatty covering that acts as an insulator around nerve fibers. It is a result of a defect in a metabolism gene and there is no cure. The family was devastated.

The following day Michelle received a call from another pediatrician who apologized and said that Bridie had been wrongly diagnosed—she needed to be brought back to the hospital. This time they were told that Bridie did not have Leukodystrophy, but instead had Glutaric Aciduria Type 1. All of the doctors were baffled as very little was known about GA 1 in the United Kingdom at that time.

Even to this day, Newborn Screening and awareness for these disorders is not the same in the United Kingdom as it is here in the United States. Presently England only screens for Phenylketonuria (PKU), Congenital hydrothoidism (CH), Cystic Fibrosis (CF), Sickle cell disease (SCD) and Medium Chain acyl-CoA dehydrogenase deficiency (MCAD). Scotland and Wales test for PKU, CH, CF, and have MCAD under consideration to be added to their panel. Northern Ireland tests for PKU and CH, and also has MCAD under consideration. Upon review of the Newborn Screening Panel website for the United Kingdom, www.screening.nhs.uk/policies-newborn, I learned that many disorders, including GA 1 and other organic acidemias are NOT recommended to be added to their Newborn Screening panel of screened disorders.

Despite being placed on a very strict diet and enduring many hospital stays, Bridie still suffered a crisis when she was 18 months old. The six years that followed were very difficult for the family, with Bridie spending weeks at a time in the hospital. She has undergone several surgeries including have a hamstring stretch, two baclofen pump placements and rods placed in her spine. Deep brain stimulation has been offered as part of her treatment, but Bridie said "NO WAY!" to this. Reflecting on all that she has been through, her family cannot help but listen to her and will not be pursuing that as an option. Bridie's happiness is their utmost concern. Through it all, Bridie's amazing spirit and happiness has always shined brightly.

Bridie enjoys being around other people and going to school, where she looks after all the quieter, more shy girls. Always attentive, she never misses a thing!!

Bridie also loves spending time with her family, especially weekend visits with her grandmother Hazel. Spending time outside in the garden is something she really enjoys too.

She's incredibly kind, and is loved by everyone who knows her. When Bridie is sick, she will often apologize to her mom. She is always concerned about other people and their feelings, often asking how they are—a very determined young lady who never gives up on anything she wants to do. With her family's dedication and love, Bridie enjoys a life full of fun, surrounded by the people she loves.



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