

'Every day I wait for a miracle' - mom of toddler with rare disease fights for a cure

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St. Mary's County, MD -- "Every day I wait for a miracle," says Ashley Miller. Her son, Jameson Miller is an adorable toddler living with an ultra-rare and deadly condition called PKAN, that attacks his body while leaving the mind intact.

Jameson, who just turned two on August 3, is believed to be the youngest person in the world to be diagnosed with this disease. Children who show symptoms at earlier age (typically around age 3-4 years old) usually decline at a rapid rate.

According to his mom, Ashley, "He is such a happy soul. His life is hard. Normal human things like eating, breathing, and gross motor functions are incredibly difficult for him, and yet, every day he wakes up and is happy. He literally falls down and gets right back up; all day, every day. His smile is infectious, his determination is inspiring."

As you can see from these images from his mother's Instagram page, despite PKAN, Jameson is doing his best to live life to the fullest.

Jameson is the youngest sibling in a family made up of parents Chris and Ashley Miller and older sisters Sophia (6) and Evelyn (4).

His mom says he experienced problems with 'normal baby things' starting at birth. "He couldn't work his mouth, he cried all the time, he wasn't able to breathe well, he was burning more calories than he was consuming, he wasn't gaining weight, etc..."

Despite mouth surgery and feeding therapy, his condition didn't improve and he was dependent on feeding too as well as having breathing issues.

His mother says the hospital continued to send him home saying that "he will snap out of it" answer. Problem was, Jameson was not "snapping out of it".

He continued to lost weight, aspirate food, struggle to breathe, and sleep more than he should. Doctors tested him for many serious conditions but didn't get an answer until he was nearly five months old.

Jameson has a degenerative brain disease called Pantothenate Kinase-Associated Neurodegeneration (PKAN), which is a type of NBIA disorder.

While there's currently no cure or treatment for PKAN, researchers at Oregon Health & Science University (OHSU) are working on a treatment that is getting close to clinical trials.

A non-profit organization called The Spoonbill Foundation, has been established by the OHSU team in hopes of making the clinical trial available to all families at the lowest cost possible.

An event is planned at the St. Mary's County Fairgrounds to raise money for The Spoonbill Foundation, in hopes of helping Jameson and others living with PKAN.

Ashley Miller says it's been difficult for the family to share their story, "I want people to know that all of this is not just about Jameson. We used to be an incredibly private family. Learning about PKAN, and how rare it is, changed that quite a bit. In order to make a difference, we had to share, we had to step out of our comfort zones."

Miller says all money raised is going to fund research organizations. "This is more than just raising awareness for Jameson. It is for all of our PKAN family," she says. "Since receiving the PKAN diagnosis we have met and interacted with so many inspirational and amazing families battling NBIA disorders. There isn't a single day that goes by that I don't think of them. My heart breaks when we hear of another child passing because of PKAN. We are all hopeful and waiting every day to have a cure, and I am doing all I can to help make that happen."

Jameson's Jamboree will be held at St. Mary's County Fairgrounds on Saturday, August 24 from 10 a.m. to 4 p.m. Admission is \$5.(Cash only)

Activities include live music, a bounce house, story time, touch-a-truck, games, vendor booths, raffles, silent auction, face painting, special appearances by foundations 4 Heroes, and so much more! (Games, bounce house, and face painting require extra tickets). The first 100 attendees receive a swag bag.

All proceeds go to raise money for The Spoonbill Foundation.

The Fairgrounds are located at 42455 Fairgrounds Rd in Leonardtown.

You can learn more about the event and about Jameson's fight against PKAN at the *Jameson Greater Than PKAN* Facebook page at this link: <https://www.facebook.com/JamesonGreaterThanPKAN/>