



Health: Purple Day To Raise Epilepsy Awareness

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PHILADELPHIA (CBS) — There is new hope for a recently discovered form of epilepsy that strikes only girls. It's often misdiagnosed and difficult to treat. Thursday March 26th is designated as Purple Day to raise awareness about epilepsy.

There are many forms of epilepsy, it kills more people every year than breast cancer. Most of the time it can be controlled with medications, but not always.

This Purple Day has special meaning for one Delaware County family. Four year old Kayla Taylor loves to ride her bike, even in the house on cold rainy days. She has a rare condition that appeared out of nowhere two years ago, when she started having seizures. For weeks doctors couldn't figure out what was wrong. They thought maybe she had meningitis or rabies. Kayla was in a medically induced coma and put on toxic, high doses of three anti-seizure medicines that caused trembling, that can sometimes look like seizures. Kayla's mom Susan says, "It was heart breaking.

Kayla was finally diagnosed with PCDH19 female-limited epilepsy. It's a genetic condition that strikes only girls that's marked by cluster seizures and can sometimes come with developmental or cognitive issues. Kayla has a twin brother and older sister who are fine.

PCDH19 was only recently discovered in 2008, many young girls are often misdiagnosed. "These girls are suffering, their families are suffering," says Julie Walters with the PCDH19 Alliance. She says

Purple Day is an important way to help raise awareness. “We talk to neurologist and they haven’t heard of the condition they don’t know what it is and not testing for it,” says Walters.

PCDH19 is often drug resistant. Kayla got lucky, they finally found a medication that works. Her mom Susan says, “Sharing Kayla’s story I hope will enlighten someone else also experiencing something or needs some answers.”

There is a new experimental drug that looks promising for the treatment of PCDH19.

www.pcdh19info.org