

CC4C

HI, MY NAME IS ALEXIS

I was born in 2008... and have been diagnosed with TUBB3 E410K



High School Team
Placeholder team name

Champion Teammate
Placeholder teammate



CHEYANNA'S CHAMPIONS 4 CHILDREN

uplifting the rare
& undiagnosed

Alexis was born with a visual impairment, and facial weakness. We enrolled her in a study at Boston Children's Hospital when she was 3 months old. At the age of 7 she was diagnosed with CFEOM (congenital fibrosis of the extraocular muscles), now defined as TUBB3 E410K syndrome.

There are less than 30 known cases in the world. Doctors are still learning a great deal about this genetic condition, but they have linked it to cyclic vomiting syndrome (CVS), Kallman's syndrome, and peripheral neuropathy. In the last 1 ½ years, Alexis has unfortunately developed the symptoms of cyclic vomiting.

Currently there is no cure, or even great treatment options for CVS, and Alexis often requires IV fluids and meds when she has an episode. Despite all Alexis has been through, she has the most positive attitude and is a kind and caring person. We remain hopeful for more information on this condition and better treatment options, or a cure in the future.

Alexis' Motto:
"Never Stop Trying"