



Sarah

LIVING WITH ZTTK (ZHU-TOKITA-TAKENOUCHI-KIM) SYNDROME

ZTTK Syndrome affects Sarah from her head to her toes.

“Sarah has been through so much in her short 5 years. She is our princess warrior and her smile and laugh lights up the room.”

Sarah is 5 years old. We believe she is the only case of ZTTK (Zhu-Tokita-Takenouchi-Kim) Syndrome in Ireland. We think there might be 3 cases in England and near 200 worldwide.

Sarah was delivered at 37 weeks. She was only 4 pounds when she was born. She failed to thrive from the start.

Feeding Sarah was extremely difficult.

At 5 months old we discovered she had a large hole in her heart which required open heart surgery. She recovered really well but it didn't resolve her feeding issues.

At 6 months old we discovered that Sarah had 3 healed fractures and so the testing started. We received the diagnosis of ZTTK Syndrome a year and a half ago, after a 3 year wait. ZTTK Syndrome affects Sarah from her head to her

toes. She has a brain malformation called bilateral polymicrogyria. This affects the signals in the brain and can cause seizures. Sarah has issues with her eyesight, feeding, poor muscle tone and hypermobility, and epilepsy. Sarah is nonverbal and unable to walk at the moment. She also has osteopena.

Sarah has been through so much in her short 5 years. She is our princess warrior and her smile and laugh lights up the room. Everyone who knows her absolutely adores her.

We are so proud of her and her big brother, James....