



NAME: Lillie

LOCATION: Atlanta, Ga. USA

AGE: 7

This is Lillie, a very special 7 year old little girl. She is globally developmentally delayed, has severe sensory issues to sound, light, and motion, and has struggled with gross motor and fine motor skills since infancy. Lillie has been in therapy since she was 10 months old, and through lots of hard work and determination, was finally able to walk at age 3. She receives physical, occupational, and speech therapy. She loves music (Disney songs and classic rock!), Disney movies, playing outside, and going for long walks. She adores her brother Jacob and he loves and adores her. Although non-verbal, she is working toward communicating with the use of a device and is very expressive in other ways. Lillie has an infectious smile and, although her severe sensory issues can cause a lot of anxiety, she is a very happy little girl. Her bravery to navigate through this world with all her difficulties inspires us every day!

Please join us on our journey to learn more about HRNRPH2 variations, to help support each other, spread awareness, and raise funds to further research into possible treatments and/or a cure! There is so much to learn, and knowledge is power!

