

# HI, MY NAME IS SIMON

Age: 7

Motto: "Try again!"

Diagnosis: Sanfilippo Syndrome

Dream Team: Bonner Carrington (Stuart Shaw)



Simon's parents first noticed developmental delays when he was a child. After seeing multiple doctors and specialists, they discovered that Simon lacks a single enzyme responsible for ridding the brain of a toxic storage material. This toxic buildup causes extensive damage that leads to something like Alzheimer's in children, and has a 100% fatality rate since there is no FDA-approved treatment or cure. Simon is expected to slowly degenerate in his mental and physical abilities over time.

Simon joined a clinical trial in 2019, which helped slow his condition significantly along with a combination of continuous therapies. Still, there are daily signs of developmental plateaus and possible regression in his abilities. Simon's parents work hard every day to prevent this by helping him keep up with his current skills, along with searching for a viable treatment path for his condition.

Simon is a sweet, happy little boy with a bright light and warm smile. He enjoys shooting basketball hoops, playing on playgrounds, building with blocks, listening to stories, putting together large floor puzzles, playing disc golf with Dada, listening and dancing to music, and learning sign language. Simon is motivated by verbal praise, engaging eyes, and a big smile.