This is Robbie

She is one of the 15 cases of SPG47 in the world known at this time. The first 9 patients have progressed to loss of mobility in some or all extremities, and are severely intellectually challenged.

Cure SPG47 is a non-profit organization devoted to seeking funding & accelerating research for a cure or treatment to stop the progression of Hereditary Spastic Paraplegia type 47 (SPG47), an ultra-rare neurodegenerative disease.

Because of the extreme rarity of SPG47, very little research has been conducted to date, and there is no known cure.

Come join us to bring awareness and help fund research for Robbie and all the families.