



Danny

LIVING WITH SWAN - "SYNDROME WITHOUT A NAME"

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Danny is 7 years old and was born with a number of rare conditions - a heart defect called truncus arteriosus with an interrupted aortic arch, microcephaly and autoinflammatory disease. He has an intellectual disability and is nonverbal.

Danny's overall diagnosis is still not known so he is referred to as a SWAN "syndrome without a name". Danny has spent his whole life in and out of hospital with a number of open-heart surgeries, cath lab procedures, feeding tubes, and PICC lines to treat infections.

The most challenging part of Danny's life has been the misdiagnosis of syndromes. The journey to get diagnosed with a autoinflammatory disease took 7 years. While which type of autoinflammatory disease is still unknown it can be managed very well on the right medication which has greatly improved his quality of life. We are hopeful that one day Danny will receive a named diagnosis. I feel like getting a diagnosis is really important. While I understand it wouldn't change anything it

could give us a glimpse to what the future may hold as right now we are walking through it blindfolded not knowing what may lie ahead for Danny. Maybe we could even connect with other families as it can feel quite isolating.

While life has been extremely challenging it has also been extremely rewarding to care for him. Danny has taught us more about life than we could have ever imagined, and it's been fascinating to watch him learn and grow in a different way than most.

Danny is nonverbal but can use 'lamh', sound gestures and pictures to communicate and more recently a communication device. Danny is a very happy little boy who loves his little sister Willow and his family. He loves music and dancing and watching movies. He is full of life and energy and is very mischievous; there's not a day that goes by that he doesn't have us laughing, he really is the light of our lives.