



## PROFILE

# Grace O'Malley

## LIVING WITH SPINAL MUSCULAR ATROPHY (SMA)

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**My name is Grace O'Malley, and I have SMA type II. When I was born, there was no indication of the disease and my parents excitedly took me home from hospital just like any other mother and father. However, it soon became apparent that all was not right. I started to miss key developmental milestones such as pulling myself up in the cot and taking my first steps.**

In the years that have followed, I have had many trips to hospital with chest infections and other complications such as scoliosis for which I require ongoing surgery every year.

My body continues to deteriorate, and this has accelerated as I grow in physical size. For example, as a younger child I could lift my arms to answer a question at school and could write without difficulty. I am now ten years of age and I am in 4th class at school, and already I have lost these abilities.

My parents have been fantastic as I require help with everything, washing, brushing my teeth, dressing and even toileting. That being said, I count myself as one of the lucky ones. Many with more severe forms of the disease have to be suctioned, ventilated and even peg fed.

I have a great electric wheelchair which I am just about able to drive myself. This gives me some independence and makes a big difference. I try not to worry about the future and enjoy the most out of every day.

### RARE DISEASE

#### About Spinal Muscular Atrophy:

SMA is a rare genetically inherited neuromuscular condition affecting circa 1 in 10,000 worldwide. The SMA gene mutation causes extreme weakness and lifelong muscle wasting, affecting the arms and legs, but also breathing, swallowing and head control. People with SMA are grouped into one of four types based on severity. Historically, 95% of children born with type I SMA have died before their second birthday.

SMA Ireland represents the 25 children and 30 adults living with the condition in Ireland. In May 2017, "Spinraza" was the first drug to receive EMA approval for the treatment of SMA. The HSE have approved this drug for under 18's on a case-by-case basis. Research towards ever more effective treatments continues.