



PROFILE

Sean O'Kelly

LIVING WITH SPINA BIFIDA

"...go reach your dreams because you will get there"

My name is Sean O'Kelly, I am a 27-year-old disability activist living with spina bifida and hydrocephalus. I am a wheelchair user.

With regards to how spina bifida and hydrocephalus has affected my life - over the past number of years, I have found it difficult to gain employment. I am currently still on the job hunt! I don't know if this has been impacted directly because I have spina bifida and hydrocephalus but being a wheelchair user is definitely a factor.

I became a disability activist in 2016 out of sheer frustration, particularly in the area of public transport having experienced being stranded at Clontarf DART (Dublin Area Rapid Transit) Station in Dublin. I have co-founded a group called 'Access for All'. This is to highlight the fact that lifts at both DART and train stations are consistently 'out of order'.

Outside of activism, I am a DJ on Dublin South FM. My show is once a week from 4-5pm. I enjoy this as it helps me get the message of disability out in the media which is always important.

My advice for people living with lifelong medical conditions; feel the fear and do it anyway - go reach your dreams because you will get there!

RARE DISEASE

About Spina Bifida

Spina bifida is the most common neural tube defect (NTD), which causes incomplete development of the spinal cord in the womb. Translated, it literally means 'split spine'. The spine is made up of separate bones called vertebrae which normally cover and protect the spinal cord. With spina bifida, one or more of these vertebrae are not completely formed. Instead, they are split, and the spinal cord and its coverings usually protrude through a sac-like bulge on the back, covered with a thin membrane.

There are three main types of spina bifida: occulta, meningocele and myelomeningocele.

Myelomeningocele is the most severe and occurs when the spinal cord/neural elements are exposed through the opening in the spine. Effects of spina bifida include hydrocephalus, varying degrees of paralysis, pressure sores, loss of sensation of the lower limbs, malformations, latex allergies, social and sexual issues, and bowel and bladder incontinence. Spina bifida affects about one in every 1,000 children born per year in Ireland. Ireland has one of the highest incidences of spina bifida births in the world.