



Spina Bifida Hydrocephalus Ireland (SBHI) prepares for an unprecedented Awareness Week during COVID-19

Spina Bifida Hydrocephalus Ireland (SBHI) will be celebrating their annual Awareness Week from 25th – 31st October.

From the 25th – 31st October, Spina Bifida Hydrocephalus Ireland (SBHI) will be celebrating the thousands of people living with spina bifida and/or hydrocephalus in Ireland as part of their annual Spina bifida and Hydrocephalus Awareness Week.

Due to the restrictions imposed by COVID-19, the charity will be celebrating the week as an online campaign.

Spina bifida is the most common neural tube defect (NTD) which causes incomplete development of the spinal cord. The condition causes significant mobility issues, continence problems, pressure sores, and social challenges. Around 40 babies are born with spina bifida each year in Ireland, one of the highest incidence rates in the world.

Hydrocephalus is a condition where too much cerebrospinal fluid builds pressure in the brain, which is usually relieved by a shunt. Common issues arising from hydrocephalus include intellectual difficulties, behavioural problems, memory issues, and cognitive processing challenges. 1 in 1,000 pregnancies are affected by hydrocephalus each year.

Speaking on the significance of the week, SBHI CEO Tom Scott explains, 'Every October we share stories that challenge us to raise more awareness and support around those living with spina bifida and/or hydrocephalus. As an organisation we achieve this by telling people more about the conditions, spina bifida and hydrocephalus. We talk about how the conditions impact our services users and/or their families.'

'As a community, we ask everyone to learn more about spina bifida and hydrocephalus, and for us all to raise awareness in our own circles or to the larger networks that we are part of. During these challenging times those living with SB/H

are more vulnerable than ever, we are working to ensure that even with the reality of COVID-19, our service users and members are still able to reach their full potential.'

In September, the charity launched their Political Brief campaign which outlined the actions that elected representatives could take to support those living with spina bifida and hydrocephalus in Ireland. The emerging themes included ensuring equal rights, a right to adequate health services, a life in the community, accessibility, education, and employment.

The campaign also featured a video series where SBHI services users highlighted the issues challenging their fundamental rights. Commenting on the issue of access to adequate housing for people living with disabilities, SBHI Adult Advocacy Group Chairperson, Marcus Ward, mentioned that finding suitable accommodation was a long and arduous process, exacerbated by living with a disability.

'Under the United Nations Convention on the Rights of Persons with Disabilities, as ratified by Ireland in 2018, the Government must provide accessible and adequate housing for people with disabilities. This is not the case in Ireland today, and I call on the Government to do something about this. People with disabilities have the same rights and desires to live independently, and to have somewhere to call home.'

Watch the video series here: www.equalitynow.ie/politicalbrief2020

Speaking on the current state of Governmental supports for people living with a disability, the Disability Federation of Ireland (DFI) CEO John Dolan notes, 'Government, in its Programme for Government, accepts that it has a lot more to do during this COVID-19 and Brexit period. People with disabilities experience life through poverty and exclusion. This Spina bifida and Hydrocephalus Awareness Week is about changing this around so that people with disabilities can live fully and equally in the community.

Spina Bifida and Hydrocephalus Awareness Week will take place from the 25th – 31st October, beginning on World Spina Bifida and Hydrocephalus Day. The week will see the publication of a Charter of Rights, a new video series from SBHI service users, and a series of informational videos.

The issues that individuals living with spina bifida and/or hydrocephalus are experiencing are a matter of urgency, and we call on the Government to prioritise and act immediately. We ask for nothing less than 'Equality Now!' - Spina Bifida Hydrocephalus Ireland (SBHI)

To keep up with Awareness Week or find out more about SBHI, please visit: www.equalitynow.ie