



Children's Health Ireland

Sláinte Leanaí Éireann (SLÉ), Herberton, Siúlán San Séamas, Rialto, D08 HP97, Éire  
Children's Health Ireland (CHI), Herberton, St James's Walk, Rialto, D08 HP97, Ireland

29th April 2021

Deputy Alan Kelly,  
Dáil Eireann,  
Leinster House,  
Kildare Street,  
Dublin 2

**PQ 16765/21**

"To ask the Minister for Health if he will take measures to ensure that all adults have access to a multidisciplinary team in the treatment of spina bifida and hydrocephalus; if he will remedy the lack of coordinated care for persons with these conditions that are transitioning from adolescence to adulthood by providing complex needs nurse specialists and administration staff to coordinate care across disciplines; and if he will make a statement on the matter".

Dear Deputy Kelly,

I refer to the part of your parliamentary question above to which I have been asked to provide a response on behalf of Children's Health Ireland (CHI).

CHI is fully supportive of measures to ensure that all adults with spina bifida and hydrocephalus have access to a specialist multidisciplinary team.

The lack of a counterpart multi-disciplinary service for adults with spina bifida upon reaching 16+ means that there is no natural setting to which the paediatric services can transition children with spina bifida. This deficiency is a significant concern in terms of the multiple co-morbidities over the spina bifida lifespan that benefit from a co-ordinated approach.

It is challenging to source appropriately-trained surgical counterparts of the paediatric surgeons who meet their often complex surgical needs in childhood/early adolescence. In the rare cases that it does happen, it is undisciplined in nature.

There is no adult counterpart of the paediatrician in neurodisability. While there are a few Rehabilitation Medicine specialists, with transferrable skills, their resources are dedicated to acquired as opposed to congenital disability, which means that the needs of our patients are not met in this respect.

Mission – To promote and provide child-centered, research-led and learning informed healthcare, to the highest standards of safety and excellence. We do this in partnership with each other, with children, young people and their families through a network of children's services in Ireland.

CRA Registered Charity Number (RCN): 20202295 Revenue Charitable Status CHY: 22235

Board Members: Prof James Browne (Chairman), Prof Niamh Brennan, Mr Con Cronin, Ms Mary Cryan, Mr Liam Dowdall, Prof Martin Elliott, Ms Catherine Guy, Dr Anne Kilgallen, Dr Gavin Lavery, Ms Brigid McManus, Mr Turlough O'Sullivan, Mr Sean Sheehan



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In summary, plans to resource and develop an integrated service for adults with spina bifida hydrocephalus need to be prioritized. This would ideally be led by an adult in rehabilitation medicine, supported by nurse specialists, with input from surgeons who have specific expertise in the condition.

Yours sincerely,

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