



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 Roisin Shortall,
Dáil Eireann,
Leinster House,
Kildare Street,
Dublin 2.

PQ 17630/21

“To ask the Minister for Health the steps he has taken to ensure that all adults have access to a multidisciplinary team in the treatment of spina bifida and hydrocephalus; his plans to remedy the lack of coordinated care for persons with spina bifida and hydrocephalus that are transitioning from adolescence to adulthood; if provision is being made to provide complex needs nurse specialists and administration staff to coordinate care across disciplines; and if he will make a statement on the matter”.

Dear Deputy Shortall,

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

Currently all newborn babies in Ireland who are diagnosed with spina bifida are transferred to CHI at Temple Street soon after birth for neurosurgery and input from the spina bifida team during their in-patient stay.

After discharge home they are linked with local medical, therapy and Nursing services and followed-up with the spina bifida multidisciplinary team (MDT). The spina bifida MDT meeting in CHI Temple Street is held every month with the following clinicians: Physiotherapy, Neuropsychology, Medical Social Work and Clinical Nurse Specialist.

The clinic is based around a child-focused enablement approach to disability. Patients see the clinicians on the same day allowing for a shared and collaborative approach to care.

The majority of children under 16 years of age with spina bifida attend CHI at Temple Street.

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.

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There are sufficient patients on CHI at Temple Street caseload to operate more frequent clinics as is our goal but this is not possible at this time due to limited resources and this had had an impact on waiting times between appointments.

Ideally children should be seen annually, however, the current waiting times for follow-up appointments is 25 months and the waiting time for a new referral is 6 months. New referrals are rare as the majority of children are born into the service. When they do occur they are triaged and accepted or declined following review of the speciality services already available to the child and in discussion with the clinical leads.

Surgical services in CHI at Crumlin are delivered in separate surgical clinics. They deliver care to children known there since birth – children born before the Neurosurgical services were established in 2008.

All children in Ireland with Spina Bifida will access the MDT in the new children's hospital when it opens as part of the new paediatric model of healthcare services across Ireland.

Yours sincerely,

Joe Gannon
Chief Operations Officer
Children's Health Ireland
Email: joe.gannon@nchg.ie