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Tuesday 2 July 2019

Deputy Catherine Murphy
Dáil Eireann,
Leinster House,
Kildare Street,
Dublin 2

RE: PQ Ref: 25090/19 – To ask the Minister for Health if there are age restrictions or otherwise for persons wishing to avail of treatment in view of the fact that spinraza treatment has been approved; if so, the rationale for imposing a barrier to the treatment; and if he will make a statement on the matter.

Dear Deputy Murphy

The Health Service Executive (HSE) has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted to the Minister for response.

As you will be aware, on the 11th June 2019 the HSE Leadership Team approved access for the drug Nusinersen (Spinraza) for children with Spinal Muscular Atrophy (SMA) Type I, II or III on an exceptional and individualised basis.

The decision to approve access for children with genetically confirmed SMA Type I, II or III is in accordance with the controlled access criteria recommended by the Rare Diseases Technology Review Committee. The rare diseases committee recommendation was targeted at the youngest and most severely affected SMA patients, and this group is the clear priority for the HSE. While access to Spinraza for adults is not provided for under this programme, the actual patient assessment and approval process will be the means for determining access on an individual case by case basis to avoid difficulties for children transitioning into early adulthood.

It remains open to the applicant company to bring forward an application for reimbursement in respect of an adult cohort of patients, supported by clinical and economic evidence and which the HSE would of course consider.

I trust the above information is of assistance to you.

Yours sincerely,

John Hennessy

John Hennessy
National Director
Acute Strategy & Planning