



Príomhoifigeach Cliniciúil
Oifig an Phríomhoifigigh Cliniciúil

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BY EMAIL ONLY

Deputy John McGuinness
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

12th January 2023

PQ62408/22- Deputy John McGuinness- To ask the Minister for Health the services currently available to those diagnosed with foetal valproate spectrum disorder; the way that families can access these services within their communities following a diagnosis; if he will provide an update on discussions between the HSE and his Department to improve access to services; and if he will make a statement on the matter.

Dear Deputy McGuinness,

Thank you for your representation.

Once a child or young person receives a diagnosis of foetal valproate syndrome (FVS), the Consultant Geneticist at CHI at Crumlin will send correspondence with confirmation of the diagnosis to the Community Healthcare Organisation (CHO) Chief Officer in the area that the patient resides. This letter will indicate the community health services that are recommended to support the FVS patient.

As part of this process, a community FVS pathway is in place for patients diagnosed with FVS which is supported by community Liaison officers. Liaison Officers are appointed in each Community Healthcare Organisation to guide patients in accessing any recommended healthcare supports, and each patient is assessed and referred based on their clinical needs.

The community liaison officers continue to support patients to ensure that any community healthcare supports individual to patient needs are provided as required under this FVS pathway.

The team in community primarycare have been engaging with the patient advocacy group in relation to feedback received from families and are currently carrying out analysis around the community FVS pathway. A follow up engagement will take place with the advocacy group in the coming weeks.

The HSE provides feedback to the DoH on the pathways for foetal valproate syndrome together with an update on the numbers of patients diagnosed.



I hope this provides you with some assistance.

Yours sincerely

A handwritten signature in grey ink that reads "Sharon Hayden". The signature is written in a cursive style with a large loop at the end.

Sharon Hayden
General Manager
Office of the CCO