



Príomhoifigeach Cliniciúil
Oifig an Phríomhoifigigh Cliniciúil

Ospidéal Dr Steevens, Lána Steevens
Baile Átha Cliath 8 , D08 W2A8

Chief Clinical Officer
Office of the Chief Clinical Officer

Dr Steevens Hospital, Steevens Lane
Dublin 8, D08 W2A8

www.hse.ie
[@hselive](https://twitter.com/hselive)

t 01 635 2000
e cco@hse.ie

BY EMAIL ONLY

Deputy Bernard J. Durkan
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

19th January 2023

PQ1644/23- Deputy Bernard J. Durkan- To ask the Minister for Health the services that are 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 for anyone affected; and if he will make a statement on the matter.

Dear Deputy Durkan,

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 black ink, appearing to read 'Sharon Hayden', written in a cursive style.

Sharon Hayden
General Manager
Office of the CCO