



Príomhoifigeach Cliniciúil
Oifig an Phríomhoifigigh Cliniciúil

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BY EMAIL ONLY

Deputy Denis Naughten
Dáil Éireann
Leinster House
Kildare Street
Dublin 2

9th June 2023

PQ24809/23- Deputy Denis Naughten- To ask the Minister for Health his plans to establish a clinical lead for haemochromatosis; and if he will make a statement on the matter.

Dear Deputy Naughten,

Thank you for your representation.

Hereditary Haemochromatosis (HH) is a common autosomal recessive disease resulting in over absorption of iron from the gastrointestinal tract. Over time, excess iron accumulates in cell of organs including the liver, pancreas, heart causing damage. It is more common in those of Celtic or northern European origin and thus, is the most common genetic disease here in Ireland. It is estimated that 1 in 83 people are genetically predisposed to develop HH.

The diagnosis, treatment and management of patients living with HH is guided by the HSE's *Hereditary Haemochromatosis Model of Care (2016)*¹ developed by the Hereditary Haemochromatosis Working Group and Irish College of General Practitioner's (ICGP) *Hereditary Haemochromatosis - Diagnosis and Management from a GP Perspective guidance* document.

The current HSE National Clinical Programme for Gastroenterology and Hepatology (NCP G&H) is led by a Clinical Lead, who reports to the National Clinical Advisor and Group Lead for Acute Operations, HSE. Multidisciplinary working groups deliver the work of the programme. This work is overseen by a Clinical Advisory Group set up by the Royal College of Physicians of Ireland. There are currently no plans to develop a Clinical Lead post specifically for Haemochromatosis.

The HSE are due to meet the Irish Haemochromatosis Association in the coming weeks.



Yours sincerely

A handwritten signature in black ink, appearing to read 'Sharon Hayden'.

Sharon Hayden
General Manager
Office of the Chief Clinical Officer

Reference:

1. <https://www.hse.ie/eng/about/who/cspd/ncps/gastroenterology-and-hepatology/model-of-care-for-hereditary-haemochromatosis.pdf>
2. <https://www.hse.ie/eng/about/who/cspd/ncps/gastroenterology-and-hepatology/model-of-care-for-therapeutic-phlebotomy-for-patients-with-hereditary-haemochromatosis.pdf>