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Deputy Fergus O'Dowd
Dáil Éireann
Leinster House
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9th June 2023

PQ24754/23- Deputy Fergus O'Dowd- To ask the Minister for Health if a national strategy for haemochromatosis is currently under consideration, where everyone has equal access to testing, diagnosis, treatment and quality of care, regardless of where they live in Ireland or their financial circumstances; if consideration has been given to the development of a population screening programme for haemochromatosis in primary and hospital care settings; and if he will make a statement on the matter.

Dear Deputy O'Dowd,

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 'Hereditary Haemochromatosis Model of Care' developed by the Hereditary Haemochromatosis Working Group and the Irish College of General Practitioners' 'Hereditary Haemochromatosis- Diagnosis and Management from a GP Perspective' guidance document, and at this point a national strategy isn't under consideration.

The current service delivery for diagnosis at present varies depending on the symptoms which cause the patient to present. However, central to the diagnosis of HH is the patients' GP given the symptoms which the patient may present with. Typically, a patient with a known family history of HH may be diagnosed via their GP as families are advised to screen children when they reach the age of 16. Raised iron studies may be picked up via routine blood monitoring. Patients diagnosed with liver disease are typically screened for haemochromatosis on specific blood monitoring for liver conditions. A population screening programme for Haemochromatosis doesn't exist, this would require a policy decision by the National Screening Advisory Committee (NSAC).

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

Yours sincerely

Sharon Hayden
General Manager
Office of the Chief Clinical Officer