OVER 20,000 PEOPLE IN IRELAND ARE LIVING WITH UNDIAGNOSED HAEMOCHROMATOSIS OR 'IRON OVERLOAD'

The Irish Haemochromatosis Association is raising awareness of Ireland's most common genetic disorder during World Haemochromatosis Awareness Week 1st – 7th June 2024

It is estimated that 20,000 people in Ireland are living with undiagnosed cases of haemochromatosis or 'iron overload'. Haemochromatosis is the nation's most common genetic condition yet still remains one of the lesser known amongst the population.

In Ireland, 1 in 5 people are carriers, equating to a massive 20% of the population, and 1 in 83 people are predisposed to develop it. Ireland has the highest rates of this genetic disorder in the world, giving it the nickname 'the Celtic Gene'. Recent research also shows that up to 1 in 10 people in Northern Ireland are at risk of having genetic Haemochromatosis.

Haemochromatosis is a genetic disorder where large amounts of iron are absorbed from the diet into vital organs, in other words 'iron overload'. Early diagnosis is vital and if left untreated, iron overload can lead to organ damage or even premature death.

To mark World Haemochromatosis Awareness Week 2024, which will take place from 1st – 7th June, the Irish Haemochromatosis Association aims to raise awareness of the condition and is urging people to 'Get Checked for Haemochromatosis' and understand the symptoms in order to save lives – symptoms that range from chronic tiredness and joint pain, to abdominal pain and irregular heartbeat.

This year will see several City and County Councils throughout the country supporting the campaign and joining the wider, international initiative to 'Light Up Red', lighting up several iconic public buildings during World Haemochromatosis Awareness Week. Buildings being illuminated in red will include the Dublin Convention Centre, Fingal Town Hall, Cork City Hall, Limerick Council Offices, Sligo City Hall, Donegal Public Services Centre and Kerry County Council Buildings, Tralee, Princes Quay and Ashe Memorial Hall Building, Tralee, Killarney Town Hall and Kenmare Courthouse Building, Kenmare, Co. Kerry.

Helping to launch this year's campaign is 19 year old Jessica Byrne, who was diagnosed with haemochromatosis just a couple of years ago. Jessica is a student nurse, currently studying in Trinity College Dublin.

"As a young person with haemochromatosis it is so important for everyone to be aware of what haemochromatosis is. It's so easy to overlook symptoms that can affect your studies and ability to enjoy life. My dad has haemochromatosis so I knew to get tested. Some of the symptoms include chronic fatigure, joint pain and diabetes. The positives are that I can now

bring my understanding of managing a life-long condition and living a full life to my future nursing career."

Speaking about the awareness drive for World Haemochromatosis Awareness Week, **Dr Maurice Manning, who lives with haemochromatosis and is current Chair of the Irish Haemochromatosis Association** says, *"Ireland has more cases than anywhere else in the world, that's why it is vital that no Irish person should go undiagnosed. Our aim is for everyone to understand what Haemochromatosis is and to be aware of its prevalence in Ireland. Haemochromatosis, once diagnosed can be successfully treated and patients go on to live their lives to the full, without any impact."*

If anyone seeing this campaign and recognises any of the symptoms seek medical advice. Simply make an appointment with your GP and take a blood test. It could make all the difference."

Dr John Ryan, Consultant in Hepatology and Gastroenterology at Beaumont Hospital, comments,
"*Haemochromatosis is a genetic condition, more common in Ireland than in the rest of the world. When an individual has the affected gene, iron can build up in the body, potentially damaging the liver, heart and other organs. If Haemochromatosis is identified at an early stage, it is easily treatable through venesection. Since 2019, many patients can also donate blood through the Irish Blood Transfusion Service, where their blood is desperately needed. So finding people with Haemochromatosis and allowing them to donate blood is a win-win situation."*

Professor Suzanne Norris, Consultant in Hepatology and Gastroenterology at St. James's Hospital says,

"Early diagnosis of haemochromatosis is vital, which is why serious complications as a result of haemochromatosis can be avoided if a patient is diagnosed as early as possible. The work of the Irish Haemochromatosis Association has helped to increase awareness of Ireland's most common genetic disorder and educate the public on identifying symptoms and seeking treatment."

The Irish Haemochromatosis Association was established over 25 years ago. Volunteers and Ambassadors such as David Beggy, GAA All Star, Mark Cagney, former RTE Presenter and Paul Harrington, musician, songwriter and former Eurovision songwriter winner, who all have Haemochromatosis, have promoted awareness of the disorder throughout recent years.

The public can support the vital work of the Irish Haemochromatosis Association, by making a donation to its work **on the charity's website** www.haemochromatosis.ie or by donating via the Text to Donate service, **Text 'IRON' to 50300 to donate €4.** Funds raised will be used to support the IHA Helpline and provide information and resources for patients and their families.

Alternatively, the IHA are also encouraging members of the Irish community to come together with friends and family and host a small coffee morning during World Haemochromatosis Week, in an effort to raise awareness and potentially, funds, to assist the charity in their work throughout the year.

Contact:
For media queries, interviews or imagery, please contact IHA@harrispr.ie. We have a number of Haemochromatosis patients available for interview, as well as a number of medical professionals who specialise in treating patients with haemochromatosis.

Photography:
Julien Behal has provided the press photography.

Website & Social
Visit www.haemochromatosis.ie for more information or support and follow the IHA on Twitter, Facebook or Instagram. Text 'IRON' to 50300 to donate €4.

Editor's Notes

About the IHA
The Irish Haemochromatosis Association (IHA) is a life-changing medical charity and support group for haemochromatosis patients and their families. Their mission is to raise awareness of haemochromatosis nationwide and promote early diagnosis and treatment of the disorder. The IHA is a registered charity, which has worked for over 25 years to raise awareness of Ireland's most common genetic disorder. During World Haemochromatosis Awareness Week, taking place from 1st to 7th June, the IHA aim to raise awareness of Haemochromatosis in Ireland and save lives. They encourage people who are suffering from symptoms such as chronic fatigue, joint pain, diabetes, irregular heartbeat and liver problems to consult their GP. A simple blood test to check a patient's iron levels can confirm or rule out iron overload, Once people are diagnosed, the treatment is simple with regular removal of blood, similar to donating blood. Early detection is vital to avoid organ damage and live a normal health life after treatment.

What is Haemochromatosis:
Haemochromatosis (where the body overloads too much iron) is a genetic disorder where large amounts of iron are absorbed from the diet into vital organs such as the liver, heart and lungs and body tissue, in other words 'iron overload'. It can be fatal if not detected early and is the most common genetic disorder in Ireland, where 1 in 5 people are carriers i.e. 20% of the population and 1 in 83 people are predisposed to develop it. Ireland has the highest rates of this genetic disorder in the world.

What are the symptoms:

- Unexplained weakness or fatigue
- Abdominal pain
- Diminished sex drive or impotence
- Arthritis particularly if it occurs in the first and second knuckles and/or the ankles
- Type 2 Diabetes
- Liver disorders
- Discolouration or bronzing of skin
- Mood swings and irritability
- Irregular heart beat

The early biochemical signs of haemochromatosis tend to be increased serum ferritin and transferrin saturation. Iron builds up slowly so symptoms may not appear until people reach their thirties or forties. Most individuals with Haemochromatosis will develop at least one or two of the above symptoms, although possibly in a mild form. When undetected and untreated, iron overload can result in severe organ damage and premature death.

Irish Haemochromatosis Association C.L.G. Iron Overload

Testing

Haemochromatosis can be diagnosed by a blood-based genetic test combined with an iron panel test to identify high levels of iron in the blood. This can be organised through your GP.

Treatment

The main treatment for Haemochromatosis is venesection. This is where a unit of blood is taken from the patient every week or two until their iron levels are brought down to between 50-100 µg/L. When iron levels are reduced, patients are said to be in maintenance and get blood taken approximately every three months.