Haemochromatosis and Irish people.

The “Celtic Disease”

REPORT SUMMARY

Haemochromatosis which is often referred to as the “celtic disease” is the most common inherited disease among Irish people. It is a genetic disorder causing iron overload which affects many organs in the body and can have serious and even fatal complications if not detected and treated early.

Many doctors and health professionals believe it to be a rare disorder and have had little training in detecting and managing the disease. Doctors may also believe it only occurs in men from middle to old age, thus neglecting the women who have the disorder.

What is the Celtic Disease? It is a genetic disorder and the medical term for it is Hereditary Haemochromatosis (HH). The name 'Celtic Disease' comes from the fact that it is most commonly found in Celtic Nations: Ireland, Scotland, Isle of Man, Wales, Cornwall and Brittany. It will develop only if your Mother and Father both carry the defective gene.

People of Irish heritage are more likely than any other ethnic group to carry the gene that leads to haemochromatosis. In Europe as a whole between 1 in 300 and 1 in 400 people have the potential to develop the condition. In Ireland, by contrast 1in 83 people have the two genes and are predisposed to develop haemochromatosis. One in 5 Irish people are carriers of the gene. Scientists are not sure why the gene is more prevalent among people with Irish heritage but it is thought that the gene mutated 50 generations ago, about 900 AD.

Haemochromatosis is a disorder which is characterised by iron overload. Iron is essential to all plants, animals and human life. Normally our body controls the amount we need to absorb to remain healthy and secretes the rest. If you have the HH gene your body may store too much iron which is deposited in other vital organs such as heart, liver and pancreas. This affects the ability of the organ to function effectively. This absorption and storage of iron happens over a number of years which can then be described as '**Iron Overload'.**

How do I know if I have iron overload or HH?
As this is a genetic disease you are born with it. The gene is passed down from two parents who are carriers of the gene. Carriers may not know that they have this gene as it does not directly affect them. The symptoms don't become apparent until middle age. It is therefore difficult to know without getting a test done. The symptoms can also be linked to many other causes which is why so few people get tested for or diagnosed with HH. The liver problems caused by haemochromatosis may be wrongly attributed to excessive alcohol consumption and treatment may not be offered. We have examples of Irish men in particular, not receiving treatment because the symptoms of haemochromatosis have been wrongly diagnosed as alcohol related.

The symptoms to look out for:-

- Low or no energy, feeling really tired
- Stomach/abdominal pains
- Heart problems
- Liver problems (cirrhosis or abnormal liver function tests)
- Skin colour change
- Arthritis (often in first finger), joint pains
- Mood swings, depression, and memory loss.
- Diabetes
- Low sex drive or impotence (erectile dysfunction).
- Shrinking testicles.
- Irregular menstruation.

As you can see from these symptoms it is difficult to link it directly to HH as there can be many different reasons you have the above symptoms. However if you do have one or more of these

symptoms and are of Celtic origin you should consider bringing this leaflet to your GP and discuss possible testing for HH.

What should you do if you are worried?
Haemochromatosis is difficult to diagnose but it is important that the condition is diagnosed early. If the condition is treated before excessive build-up of iron occurs life expectancy should not be affected. So it is important that if you are worried you should go and see your GP as soon as possible and explain the symptoms to them. It is likely you will then be referred to a heart or liver specialist. Haemochromatosis is usually diagnosed though blood tests.

If a member of your family is diagnosed with primary haemochromatosis, the genetic condition, it is likely that you will need to be tested too.

What is the Test?
A simple blood test for ferritin and transferrin can be carried out by your Doctor. Ferritin measures the iron in your blood and transferrin saturation measures the iron carried in your body. If these tests show above normal levels of iron then a genetic test should be carried out to determine if you have HH. A genetic test is a special type of blood test used to find out if you have mutated HFE genes. The two most common Haemochromatosis gene mutations are known as C282Y and H63D.

Can Hereditary Haemochromatosis be treated?
Yes it is treated by:-

- Reducing the amount of iron absorbed by the body - patients are advised to avoid iron-rich foods and alcohol.

- Removing excess iron from the body by removing blood from the body (venesection therapy or phlebotomy). Initially this may involve removing a unit of blood a week (sometimes for many months) until iron levels in the blood are normal. Then most people can be kept stable by removing a unit of blood every 2-3 months.

The aim of the treatment is simply to reduce the stored iron in your body tissue. The treatment is the same as giving a blood donation. You may have to attend weekly or twice weekly sessions with your GP or nurse where they take a certain amount of blood from your body. If the condition is detected early before any organ is damaged then you will have a normal life expectancy. However if there is damage to the organs then the treatment can prevent further damage. Your GP or nurse will also give you further advice relating to diet and exercise.

What happens if I don't get tested?
The continuous build up and storage of iron in the body can become toxic to your organs. If untreated it can cause serious health issues affecting vital organs such as your heart and liver and can cause diabetes and arthritis. However if detected early the symptoms described above can be alleviated and in some cases resolved.

Where to get help
Irish in Britain is not a medical centre and the information supplied to you on this leaflet has been collated from research and from various Haemochromatosis Associations in the UK and Ireland. For detailed information and medical references we recommend you visit the following web sites or call the help-lines .

The Haemochromatosis Society
http://haemochromatosis.org.uk/

Merseyside and North West Haemochromatosis Support Group
www.haemochromatosis-merseyside-nw.org.uk

Irish Haemochromatosis Association
http://www.haemochromatosis-ir.com/

The British Liver Trust
http://www.britishlivertrust.org.uk/home.aspx
Tel: 0800 652 7330

NHS Choices
http://www.nhs.uk/Pages/HomePage.aspx

BBC article about 'Celtic gene' behind Haemochromatosis
http://news.bbc.co.uk/1/hi/northern_ireland/4842700.stm

The Darkness in Our Genes

"In the year 2000, gripped by tiredness, lethargy and an intense pain that made normal life impossible, I knew I was in trouble. At 39 I was not old, so what was the strange wearing affliction that had taken over my life?

Not everyone experiences their first taste of Haemochromatosis quite like I have done. Some get off scot-free, others don't know they have it until it emerges late in life, others know nothing until it takes their life, and some have their lives blighted in different ways and never know why.

For four years I struggled in terrible darkness against uncertainty, pain and disability. I had no explanation until I heard the strange word Haemochromatosis for the first time, from a consultant, when I was accidentally diagnosed due to my relentless and sometimes bitter search for answers. Only then did I realise that I had a genetic disease. It was a shock and a relief at the same time but it did, at least, make sense of my previous four years pleading that it felt like it was in my blood.

Now, with more knowledge, I know that it is more accurate to think of Haemochromatosis being in my genes than in my blood. Blood flows through us and is, therefore, such a transient thing, Haemochromatosis is more fundamental than that. It is a deep, deep thing that exists within your core because of who you are.

With a diagnosis my family searched its past. Aunts and uncles scanned their memories, from the streets of Dublin to the bogs of Western Ireland. We found characters with yellowed skin, failed livers, cancer and heart disease, all possible symptoms or outcomes of Haemochromatosis. Of course, the distance of time makes it impossible for us to link those lost then with what we know now but maybe we should do.

We should link Haemochromatosis to its background for many reasons; to save all future sufferers from the negative outcomes that will result from ignorance about this illness and also to save future sufferers from discrimination and wrongly placed questions about their drinking habits and the sexual mingling of their ancestors, posed by those who should know better but often, sadly, don't.

My experience has taught me that Haemochromatosis is the curse of the Irish and many more besides. It is a curse that has far more significance for those with Irish roots than people give it credit for. Among people from Irish backgrounds more than 1 in 83 people are affected and as many as 1 in 5 are carriers of the defective gene. I believe that there are many people out there, now, suffering in little ways or dying slowly from Haemochromatosis who will never hear its name. That's wrong! Only voices that are raised are ever heard in this world so let's shout loudly about Haemochromatosis, and highlight this darkness in our genes".

Kieran Lynch, 2011

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