Irish Haemochromatosis Association

Carmichael Centre, North Brunswick Street, Dublin 7

WELCOME TO THE SPRING NEWSLETTER 2019

In this issue:

SURVEY ON AGEING AND HAEMOCHROMATOSIS

Professor David Melzer from the University of Exeter

Dr Luke Pilling, of the University of Exeter Medical School

Recent research, led by Professor David Melzer and a team from the University of Exeter showed that haemochromatosis, which was previously thought to only rarely cause health problems, is actually linked to more serious disease and disability than previously thought.

Professor Melzer said "The long story of the research survey, which was recently published in the British Medical Journal, probably starts with my wife's grandfather, Owen Tracy. He was a submariner in the First World War and was fit enough to climb into a modern Royal Navy submarine on his 100th birthday. I am a medical epidemiologist, and this set off in me an enduring fascination with why some people are still active at 100 years old, while most people develop serious disease in their sixties or seventies"

The UK Biobank study of 500,000 volunteers provided the University of Exeter with a world leading opportunity to study ageing. Linking volunteers' anonymised genetic data to NHS hospital records provided a gold mine for health research.
The survey showed that UK Biobank volunteers who had two copies of the Haemochromatosis C282Y mutation had much more disease than expected. Some clinicians thought of people with the mutations as being safe if they didn't develop disease by the age of 60. One of the surprises in the research study was finding a higher incidence of disease in 60 to 70 year olds in the Biobank follow-up.
Studies have revealed that haemochromatosis, previously thought to be a low-level health risk, actually quadruples the risk of liver disease and doubles the risk of arthritis and frailty in older age groups. It also causes higher risk of diabetes and chronic pain.
The research, funded by the UK Medical Research Council, suggests that routine screening may be needed for people at risk of haemochromatosis.
Symptoms can include feeling tired all the time, muscle weakness and joint pains, meaning it's often misdiagnosed as the signs of ageing. The researchers found that in men, 1.6% of all the hip replacements and 5.8% of all liver cancers occurred in those with the two haemochromatosis gene mutations.
The team analysed data from 2,890 people with the two genetic mutations nearly ten times more than in the previous largest study. Having two copies defines most diagnoses of haemochromatosis. Of that group, one in five men and one in 10 women with the mutations developed additional diseases, compared to those without mutations.

Owen Tracy was a submariner in the First World War and was fit enough to climb into a modern Royal Navy submarine on his 100th birthday

The average age of those studied was 63, and the data suggested that even more disease developed at older ages. The team found that both the men and women with the mutations aged 65 to 70 were much more likely to suffer from frailty and chronic pain, and had lower muscle strength.

Dr Luke Pilling, of the University of Exeter Medical School, first author of the BMJ paper, said that diagnosis of haemochromatosis is often delayed or missed. That's not surprising as symptoms such as joint pains and tiredness are frequently mistaken as signs of ageing. Yet it is likely that these potentially deadly health risks could be treated and avoided, transforming lives, especially at older ages.

Professor David Melzer and Dr Luke Pilling, University of Exeter Medical School.

LIMERICK FARMER'S STORY

Jim Jackson and Bobby O'Connell at Clonmel show

Farmer and retired quarry owner, Bobby O'Connell from Clarina in County Limerick was diagnosed with haemochromatosis (HH) 15 years ago when he was 47.

Bobby had been feeling very tired and experiencing pain in his hands for several years prior to diagnosis. He had cramps in his hands and in the backs of his legs as well as pains in his shoulders. For a long time the doctors thought that he had brucellosis.

When Bobby was finally tested for HH in 2003 his ferritin level was nearly 3,000ug/l. It should be under 300ug/l. Bobby had blood taken every week for the first six months and then regularly afterwards.

All his siblings were tested and it turned out that two of his brothers and two of his sisters also had Haemochromatosis. One brother died young, so he was never tested, but Bobby feels that he could have had it as well. Before diagnosis one sister was told to give up drinking alcohol, as her liver was affected, but in actual fact she didn't drink at all.! The damage was probably caused by iron overload.

Bobby feels well when his ferritin levels stays under 80 ug/l. From experience, he knows when he needs to have blood taken off.
"My wrists get sore every time, and my fingers start cramping. I know that if I give blood within a week I'll feel all right".

Bobby had several heart attacks and a stroke in 2012 and 2013. He doesn't know if being undiagnosed with HH for so long contributed to his heart problems. Years before he was diagnosed with HH, he had an angiogram to try and find the cause of ongoing chest pains.

Bobby believes he is lucky that he wasn't too badly affected by HH. "Some people died and didn't even know they had it." Bobby now has venesection every three months at a local medical centre. He advises anyone newly diagnosed with HH to contact the Irish Haemochromatosis Association for support and information. Thanks to Bobby for sharing his very interesting story.

This article which was originally featured in the Farmers Journal.

RED BLOOD CELLS THE KEY FOR EARLY DETECTION OF HAEMOCHROMATOSIS

The current blood tests which most frequently lead to suspicion of iron overload, measure serum ferritin and transferrin saturation. They are not routinely ordered as part of a general medical examination.
A recent research paper, Detection of HFE Haemochromatosis in the clinic and community using standard erythrocyte tests, showed that two test results from a very common blood test often performed as part of a routine medical examination can be a reliable indicator that a patient may have the genetic risk of iron overload from haemochromatosis.

The paper showed a strong correlation between elevated 'MCV' and 'MCH' values and the risk of haemochromatosis. MCV (mean corpuscular volume) measures the average size of your red blood cells.

MCH (mean corpuscular haemoglobin) is the average amount of haemoglobin in your red blood cells.
These results are commonly used to highlight vitamin B12 and folate deficiencies, anaemia and thalassaemia.

These two values measure the average size and haemoglobin content of the red blood cells (erythrocytes). The research team studied results from 144 patients with identified hereditary haemochromatosis, 1,844 control patients from the general population and 700 chronic disease subjects. They found that the results were always higher for the haemochromatosis subjects than the other groups, regardless of whether the haemochromatosis patients were displaying symptoms.

The results do not eliminate the need for subsequent iron studies and genetic testing for the HFE gene. They do offer a new tool for GPs to detect the risk of haemochromatosis in their clinical practice.

IRISH BLOOD TRANSFUSION SERVICE (IBTS)

Certain eligible Haemochromatosis patients can now give blood at all whole blood clinics.

The Haemochromatosis programme enabling certain eligible Hereditary Haemochromatosis (HH) patients to become regular blood donors has now been rolled out to all whole blood donation clinics.

Potential donors must meet the Haemochromatosis criteria below AND standard blood donation criteria, to be able to attend clinics to give blood which can then be used to save lives throughout the country. You will not need a prescription from your doctor to donate. When attending their local clinic, members of the public who have Hereditary Haemochromatosis (HH) will have their eligibility to donate assessed by completing a Health and Lifestyle Questionnaire (HLQ). There is a new question on the HLQ asking about a diagnosis of or treatment for HH, please answer yes if this applies to you.

You may be accepted to donate if:

- You do not suffer from complications as a result of HH e.g. cardiac, liver
- You don't require and have never required venesection

OR

You may be Accepted to donate if:

- You do not suffer from complications as a result of HH e.g. cardiac, liver
- You require maintenance venesections of no more than 8 per year (you can only attend an IBTS clinic 4 times per year with a minimum of 90 days between phlebotomies)
- You must have had at least 1 therapeutic venesection without complication
- You have not had a venesection in the last two weeks
- You have completed iron depletion therapy

Following an interview with IBTS staff:

- If you fulfil all other IBTS criteria to donate, we will measure your haemoglobin level using a finger prick test. If the result is within range we will collect a donation of blood along with samples for testing.
- If you are temporarily deferred from donating, we will measure your haemoglobin level using a finger prick test and venesect you into a dry pack (i.e. not for patient use in a hospital) on the day you attend. We will collect samples with the venesection and carry out our standard tests. We will inform you of the length of time the deferral will apply and you may attend the clinic for a therapeutic venesection (i.e. not for patient use in a hospital), while the deferral is in place.
- **Exception:** If you are not feeling well on the day you attend (e.g. flu or chest infection), we will not venesect you.
- If you are permanently excluded from donating, the IBTS will not collect any blood or blood samples from you on a whole blood clinic.

The IBTS will NOT monitor your Ferritin levels; you must continue to attend your treating physician for the management of your HH.

Phlebotomies will be at a maximum frequency of 4 per year with a minimum of 90 days between phlebotomies.

The IBTS is very anxious that all eligible patients avail of the service. Please check your eligibility.

You can check for standard blood donation criteria which you must meet to be a blood donor, and you can check for upcoming clinics on www.giveblood.ie or postmaster@ibts.ie http://www.giveblood.ie

- Call 1850731137 if you have any further queries –

Irish Blood Transfusion Service
Seirbhís Fuilaistriúcháin na hÉireann

The inheritance of Haemochromatosis is similar to the inheritance of red hair and blue eyes. You have to get a gene from both parents .

INFORMATION MEETING GALWAY APRIL 9TH

The Galway meeting on Tuesday April 9th takes place at the Connacht Hotel, Old Galway Road, Galway at 7.30 pm. Professor John Lee, Consultant Endocrinologis, University Hospital Galway, is the principal speaker. Dr Conchúr O' Brolchain will speak from the patient's perspective.

INFORMATION MEETING CORK APRIL 17TH

The Cork meeting on Wednesday April 17th takes place at the Clayton Hotel, Lapp's Quay at 7.30 pm. The speaker is Dr James Ryan, Consultant Endocrinologist, Mater Private Hospital Cork and Bon Secours Hospital, Tralee. Tea and coffee will be available from 6.30 pm.

MINI MARATHON: SUNDAY JUNE 2ND 2019

The VHI Women's Mini Marathon will held in Dublin on Sunday June 2nd. Start time 2pm.

If you would like to walk, jog or run in aid of the IHA, please contact the IHA for sponsorship cards and T shirts. Phone 01 8735911 or email info@haemochromatosis-ir.com
It is always a great day and raises badly needed money for charity.
To enter sign up at www.vhiwomensminimarathon.ie or entry forms will be available in The Herald. The cost of entry is €25. For general questions, phone:
01 2930 984 or email: info@womensminimarathon.ie.

AWARENESS DAY: THURSDAY JUNE 6TH 2019

Awareness Day is Thursday June 6th. This will coincide with the World Awareness Week for Haemochromatosis (WAW) which this year is June 3rd to June 9th .
If any of you have media contacts, please let us know as we need your help to raise awareness of both the Awareness Day and the World Awareness Week. There will be information stands in several shopping centres throughout the country on June 6th. Volunteers are urgently needed to man the stands as without your help the awareness day would not be possible. If you can assist please phone 01 8735911 or email margaretmmullett@gmail.com

A list of the proposed venues will be posted on the web-site: www.haemochromatosis-ir.com

INFORMATION MEETING ROSCOMMON MAY 14TH

The Roscommon meeting will take place in Roscommon County Council Building, Roscommon town on Wednesday May 14th at 7.30 pm. Tea and coffee will be served from 7pm. The speakers from Roscommon University Hospital are, Dr Gerard O' Mara, Consultant Geriatrician, Nurse Margaret Kelly, Advanced Practitioner in Diabetes and Haemochromatosis Specialist Nurse, Olive Arnold.

ANNUAL GENERAL MEETING: SATURDAY MAY 25th

The meeting will take place at the Irish Blood transfusion Service (IBTS) St James's Hospital, James's Street, Dublin 8.

St James's Hospital is near Heuston station and is served by the Luas. Parking is available adjacent to the IBTS headquarters.

The IHA would like to thank the IBTS and the Chief Executive Officer, Mr Andy Kelly, for once again making the centre available to us for the AGM and for generously sponsoring coffee and lunch.

Coffee will be available from 10.30 am. A brief business meeting beginning at 11am will be followed by guest speakers. Details are on the enclosed sheet.

The talks will be followed by a Q and A session. The meeting will conclude with lunch. For catering purposes please let us know asap if you will be attending by returning the reply strip posted out with the official AGM announcement or by phoning 018735911

KILLINEY GOLF CLUB

A special thanks to Mrs. Kay Hamilton who organised a bridge morning in aid of the IHA in Killiney Golf Club on March 1st. A record sum of over €5,000 was raised and the120 people who attended were experts on Haemochromatosis as well as bridge by the end of the day !

RENEWAL OF MEMBERSHIP

Sincerest thanks to everyone who renewed their membership and to those who made donations to the IHA in addition to the annual fee. Your on-going support is greatly appreciated and is one of the main sources of income for the Association. The address where you send your membership is:

Brendan Keenan
66 Harold's Cross Cottages
Harold's Cross
Dublin DO6WF72

Should you no longer wish to be a member of the IHA, please let us know by emailing info@haemochromatosis-ir.com or alternatively leave a message on the voicemail 01 8735911.