WELCOME TO THE SPRING NEWSLETTER 2018

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MY STORY: CONCHÚR Ó BROLCHÁIN

My own personal haemochromatosis journey has been an interesting one. My father was diagnosed with Haemochromatosis in 2002 after bouts of severe fatigue that actually culminated in him being diagnosed with terminal cancer. His passing was extremely sad and traumatic for us all, but it did provide a catalyst for close family members to be tested for iron overload. In the months following his death all of his brothers were found to be haemochromatosis sufferers, a rarity apparently, that has led us all on a journey of comparing and contrasting phlebotomies and iron ferritin levels for the best part of 15 years.

In my efforts to be more informed about the disorder I have taken a great interest in my iron ferritin levels from phlebotomy to phlebotomy. I have worked out that giving a unit of blood seems to reduce my iron ferritin level by around 50-60 points each time. The last text I received from my local medical centre stated that my ferritin levels were 77, the text message before that stated 124 and the one before that was around 180. This isn’t an exact science however and all sufferers of haemochromatosis know that there can be many different variables that affect ferritin levels. That said, and in light of the sheer amount of phlebotomies that I have had over the past 15 years, I feel like I have developed the capacity to make an educated guesstimate.

Despite the minor inconvenience of frequent phlebotomies and the occasional anxiety about symptoms that may affect me in later life, I believe wholeheartedly that having haemochromatosis has helped me to develop a deeper consciousness about health, wellbeing and diet. My most recent wellbeing adventure has culminated in a decision to become vegan. If it was the diagnosis of haemochromatosis that sparked my search for a healthy lifestyle and diet, it was various Netflix animal welfare and environmental documentaries that have pushed me over the edge into a plant based eating lifestyle.

Not only has my cholesterol dropped to 4 but in light of the Irish Haemochromatosis Association’s information booklet, detailing the difference between haem and non-haem food sources along with a thorough description of inhibitor foods, it appears to be a positive health decision for me. Although I will need to continue to stay informed about the Celtic curse and also to have iron ferritin levels monitored regularly, I can say with hand on heart that having ‘the bloods’ under control, keeping alcohol consumption to a minimum (except when the Galway hurlers won the all-Ireland) and eating healthily has lead me to a place where I feel happy, energetic and healthy.

Sincerest thanks to Conchúr for sharing a very interesting story.

Conchúr O’ Brolcháin, his wife Niamh and children Aoibhe and Cillín
KILKENNY MEETING: MONDAY NOVEMBER 13th

Dr Barry Kelleher, Consultant Gastroenterologist, Mater Hospital, Dublin gave an excellent presentation in the Mount Errigal Hotel. Despite snow and treacherous weather conditions there was a great turnout. It was well worth the effort as Dr Kelleher answered all the questions that are most frequently asked, as well as specific questions from the audience.

Barry explained that the majority of cases of Haemochromatosis are caused by mutations in the HFE gene which is located on chromosome 6. This disorder is termed type 1 or HFE associated HH. There are other rare forms of haemochromatosis not related to the HFE gene. The four main forms are caused by mutations in the genes: hemojuvelin, hepcidin, transferrin receptor 2 (TfR2 ferroportin) and ferroportin.

Ferroportin disease, also known as hemochromatosis type 4, is a rare genetic disorder characterised by the abnormal accumulation of iron in the body. Ferroportin disease is caused by mutations of the SLC40A1 gene. The specific symptoms associated with ferroportin disease can vary greatly from one person to another. Classical ferroportin disease is characterised by hyperferritinemia (high iron), normal transferrin saturation, and iron overload in macrophages. Macrophages are a type of white cell and can be found in all tissues.

Juvenile (JH) or type 2 haemochromatosis although very rare is a more severe form of haemochromatosis with an earlier age of onset than HFE-HH.

Take Home message:

In Ireland HH is relatively common, the prognosis is excellent and treatment is relatively straightforward. New ‘molecular’ discoveries and ongoing research will help. It is important to enjoy life, eat a balanced diet and avoid exclusionary iron-free diets, keep to a moderate alcohol intake and avoid Iron and Vitamin C supplements.

LETTERKENNY MEETING: SATURDAY DECEMBER 9TH

Dr Barry Kelleher

Letterkenny Ladies who braved the weather to attend the meeting

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KILKENNY MEETING: MONDAY NOVEMBER 13th

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Dr Gary Courtney, Consultant Gastroenterologist, Clinical Nurse Specialists Noreen Maher, Pauline Carroll, Angela Buggy and Nurse Linda Kirwan, Community Infusion & Venesection Unit (CIVU).

Sincerest thanks to the staff of the Hepatology Unit at St Luke’s Hospital, Kilkenny for their excellent presentations at the recent meeting. The speakers were Professor Gary Courtney, Consultant Gastroenterologist, Clinical Nurse Specialists Noreen Maher, Pauline Carroll, Angela Buggy and Nurse Linda Kirwan, Community Infusion & Venesection Unit (CIVU).

More than 70 people were at this very enjoyable meeting, including Ann Dooley who was home on holiday from Brussels. Ann gave an interesting account of her early diagnosis, in Brussels, more than 20 years ago.

The Hepatology Nurses explained the protocol in St Luke’s Hospital and mentioned that part of their role was to advise screening of family, spouse/partner where applicable and to act as patient advocate. They ensure continuity in care, particularly after the initial treatment is finished and also ensure compliance in follow up care.

Dr Courtney gave a very clear and comprehensive overview of Haemochromatosis and was delighted that there was so much audience participation in the Q and A session.
always increased in patients with hemochromatosis.
- Later, serum ferritin levels increase, indicating the accumulation of iron in tissues.

**Treatment**
- Weekly phlebotomy
- 1 unit venesected = 200-250mg of iron
- Target Ferritin less than 50ng/ml
- Maintenance phlebotomy every few months

**Hepcidin**
Hepcidin is now considered to be the principal hormone involved in iron regulation. Since its discovery in 2000, hepcidin has been a focal point of the iron research field, as it appears to be the master regulator of body iron levels, controlling how much iron is absorbed from the diet and how much is released from the body’s cells. People with haemochromatosis have low hepcidin levels; this is believed to be what causes them to accumulate more iron than is healthy.

Scientists believe that by finding a way to increase hepcidin levels or activity, they will be able to restore normal iron control to haemochromatosis patients.

**In Summary**
Be reassured: Organ damage due to haemochromatosis is unusual today, due to earlier and more accurate diagnosis. Disease progresses in only a minority of untreated patients.

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The AGM of the European Association of Patients with Haemochromatosis (EAPFH) took place in Zurich University on February 11th. The IHA was represented by board members Ann McGrath and Margaret Mullett. Margaret gave a brief presentation on behalf of the IHA.

Representatives were at the meeting from France, Germany, Portugal, Spain, United Kingdom, Norway, Denmark, Austria, Hungary and Italy. Potential new members include Sweden, the Netherlands and Romania.

The meeting was run in conjunction with the European Iron Club (EIC) and EAPFH members were invited to attend oral and poster presentations given by delegates from the EIC. The presentations covered iron deficiency as well as iron overload.

Dr John Ryan from Dublin is a Clinical Lecturer in Gastroenterology at Oxford University. John was one of the speakers at the EIC meeting in Zurich. He described promising results from current work exploring the effect of phlebotomy on the faecal iron and gut microbiota in HH patients.
MALARIA AND IRON DEFICIENCY IN AFRICAN CHILDREN

John Muriuki is a Medical Researcher with the Welcome Trust Research Programme. He presented the following interesting information at the European Iron Club meeting in Zurich and very kindly gave us permission to include a synopsis in the newsletter.

Malaria and iron deficiency are common causes of ill-health in African children. In 2016 alone, there were 194 million cases of malaria and 407,000 deaths due to malaria in sub-Saharan Africa. Up to 50% of individuals carry malaria parasites without symptoms and therefore don’t seek medical care. Iron deficiency is common, affecting one in three children and it has been associated with poor brain development. Iron deficiency has been reported to worsen over a malaria season and improve after malaria transmission is interrupted, thus suggesting that malaria may cause iron deficiency. The research team studied whether malaria causes iron deficiency in 3950 children from Kenya, Uganda, South Africa, Burkina Faso and The Gambia. The preliminary findings suggest that malaria may be causing iron deficiency, probably by reducing iron absorption. Therefore, malaria elimination strategies might have an added advantage of addressing iron deficiency. However, giving iron supplements might not be effective in managing iron deficiency as children in malaria endemic areas absorb iron poorly.

MINI MARATHON: SUNDAY JUNE 3RD 2018

The VHI Women’s Mini Marathon is to be held in Dublin on Sunday June 3rd. All participants must enter either on the official Entry Form which will appear in The Herald every Wednesday and Saturday or online from 7th March 2018 at www.vhiwomensminimarathon.ie. The cost of entry is €23. Entries will close on the 18th May 2018 or when maximum number of entries is reached.

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: 01 873 5911 or email: margaretmmullett@gmail.com

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 renewal of membership is:

Brendan Keenan
66 Harold’s Cross Cottages.
Harold’s Cross
Dublin D06 WF72

Should you no longer wish to be a member, please let us know as the cost of posting and printing is very high. Also let us know if you would prefer to receive the newsletter by email. If your email address or phone number has changed, please contact Kate by emailing Kate.

www.haemochromatosis-ir.com

VOLUNTEERS REQUIRED

The IHA will participate in the World Awareness Week (June 4th to June 10th). We are working with the other European and International Associations and are asked to co-ordinate our efforts.

The IHA is a totally voluntary organisation. In particular help is required with awareness events, information meetings, fund-raising, administration and the Newsletter.

Please contact Margaret if you think you can assist. margaretmmullett@gmail.com

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ANNUAL GENERAL MEETING: SATURDAY MAY 26TH

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. Family and friends are welcome. 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&A session. The meeting will conclude with lunch. For catering purposes, please let us know as soon as possible if you will be attending by returning the reply slip posted out with the official AGM announcement or by phoning 01 873 5911.

The IHA would like to thank the IBTS headquarters.

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