

WATERFORD INFORMATION MEETING NOVEMBER 25TH



Professor Suzanne Norris gave an excellent presentation on Haemochromatosis at the Viking Ramada Hotel Waterford, on Friday November 25th. Professor Suzanne is a Hepatologist/Gastroenterologist

at St James's Hospital, Dublin and Associate Professor of Medicine at Trinity College Dublin. The meeting was well attended and the presentation was followed by a most interesting and informative Q and A session. Milo Walsh and Paddy Early helped organise the meeting. They are interested in starting a support group in Waterford. Please contact them if you would like to be involved.

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Phone: Milo 087 6239370

Sincerest thanks to Professor Suzanne for her excellent overview of Haemochromatosis and also for her invaluable help to the IHA over the past ten years.

MARATHON ACHIEVEMENTS



Thanks to Elaine Clancy who raised funds and awareness for Haemochromatosis by running the Cork Women's Mini Marathon on September 25th.

NATIONAL PLOUGHING CHAMPIONSHIP (NPC)



Sincerest thanks to Amgen who manned the stand on Thursday 22nd September. Left to right Amgen Staff, Odran Power. Willie Maher, Marie O'Connell, Liz Wickham, John Rafter, Roger Towey, Hilary King and Fionan King.

We would like to thank all our volunteers who manned the Haemochromatosis stand on Tuesday 22nd and Wednesday 23rd September at the National Ploughing Championships. This is the largest open air show in Europe and is a great way to target a huge cross section of the Irish public.



Gerry Murray ran the Dublin Marathon on October 30th in memory of his late brother Des, who died in May 2016. Sincerest thanks to Gerry and his family and friends who raised €550 for the IHA.

RENEWAL OF SUBSCRIPTION - CHANGE OF ADDRESS

Membership renewal forms are enclosed with this newsletter. Please complete and return to our treasurer Brendan Keenan. If you have recently sent in your subscription or pay by standing order, please ignore this reminder. Brendan is in the process of moving house. For the moment please send subscriptions to:

Brendan Keenan
c/o 41 Bushy Park Road,
Rathgar, Dublin 6

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 kategeog@gmail.com with Haemochromatosis in the subject line.

Your ongoing support through the annual subscription is greatly appreciated and is one of the main sources of income for the Association.

Sincerest thanks to each of you who have made donations to the IHA, in addition to the annual fee. Unfortunately we cannot thank each of you individually as the organisation has a large administrative burden.

BETTER TOGETHER VIDEO COMPETITION

The IHA entered a video for the Better Together Competition. One of our members, Sean Carter made an excellent video, featuring his horse Danny and himself. Many of you voted for the video.

To see the video just click on the link below www.bettertogether.ie

FUTURE MEETINGS

It is hoped that information meetings will be held in Kilkenny and Cork in the New Year. Details will be on the web-site and on facebook. Members of the IHA will be notified.

CHRISTMAS GREETINGS

We take this opportunity to wish you all the very best for Christmas and for the New Year.



WELCOME TO THE WINTER NEWSLETTER 2016

In this issue:

Interview with Larry Strain – Irish News November 23rd

Interview with Colm Kavanagh – Farmer’s Journal June 25th

The Iron Heart is a Fragile Heart - Professor Pierre Brissot

National Ploughing Championship - Stradbally

Cork Women’s Mini Marathon - September 25th

Dublin City Marathon- Sunday October 30th

Better Together Video competition

Waterford Meeting Friday November 25th

Future Meetings

Renewal of subscription - Change of address for Brendan



HAEMOCHROMATOSIS IS A ‘CELTIC CURSE’ WHICH SILENTLY ‘DESTROYS LIVES’

In an interview with the Irish News, Omagh GAA manager and Haemochromatosis sufferer **Larry Strain** tells **Gail Bell** about why it's important to get tested for this potentially life-threatening genetic disorder which causes an overload of iron in the body.

Larry, who manages Omagh St Enda’s senior football team, presented with typical non-specific symptoms of Haemochromatosis: fatigue and general malaise, which were initially dismissed by a GP who, on examination, could see “nothing wrong”.

“Then, when I felt really unwell, I visited the A&E department of the Tyrone County Hospital in Omagh and they discovered an irregular heart-beat,” Larry recalls.

“I was kept in for further tests and an echo-cardiogram revealed that my heart was only functioning at 25 per cent.

At that point they were talking about a transplant, which was when things got really scary. I had more tests at Belfast City Hospital and was suspected of having heart failure. The tests showed that my ferritin levels were through the roof. The level is supposed to be below 300 ug/l but mine was 6000 ug/l and the overload of iron deposits had been damaging my heart”.

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Larry Strain picture by Ann McManus

In fact, heart damage, along with liver damage, are two of the more serious consequences of untreated haemochromatosis – but, fortunately, in Larry’s case the damage was reversible.

“I was very fortunate and it was such a relief knowing what the problem actually was,” he says.

“Once, the correct diagnosis came, the treatment was straightforward – removal of blood from the body which is known as venesection. Initially, I had to give a unit of blood – which is just under a pint – for five days in a row, then a unit per week for

two years.

The only permanent effects I have been left with are pains in my hands which are eased by a daily anti-inflammatory tablet. I think I have definitely been one of the lucky ones, but my message to anyone worried about symptoms that don’t go away, is just go and get tested before it’s too late”.

Thanks to Gail and Larry for permitting us to share this very interesting article. Larry was very lucky to have been diagnosed and treated before more serious consequences ensued.

INTERVIEW WITH COLM KAVANAGH by Margaret Hawkins



Colm Kavanagh from Kiltulla, Athenry, is a part-time farmer who was diagnosed with Haemochromatosis in 2006. He was 59 at the time. For years he had been experiencing sudden bouts of tiredness and sore ankles. He put this down to general ageing.

"The tiredness used to hit me coming in from work or on my way home from work. When I was working in Ballinasloe, 20 miles away, I'd often feel so tired driving home that I'd have to pull over to rest" he says.

Colm used to think that he had a cold or flu coming on when this sudden fatigue hit. "I used to say to myself that if I lay down for a while I'd recover. When I'd feel better, I'd say I'd overcome that bout, whatever it was. That happened regularly".

Joint pain also affected Colm at the time. "My ankles would get quite sore for no reason and I couldn't understand it. It was like someone suddenly hit me with a stick or a hurley. For example, my leg would nearly go from under me when I was playing golf".

Colm had no idea that he had

Haemochromatosis – a condition which was once called bronze diabetes because patients, in latter stages, had bronze skin.

"I had worked overseas in jobs where medicals would have been very strict, but nothing was picked up until about ten years ago" he says. He regards his diagnosis as "almost accidental". "When I was going in for my usual yearly check up, my GP decided to do the ferritin test along with the routine ones. That's how it was found out. I didn't know that there was a test for haemochromatosis, as I had never heard of the condition. The test came back positive and I was told it was bad news but I wasn't too upset when the full story was explained to me. It certainly solved the mystery of the tiredness. My iron level was about 900 at the time so I had to give blood for six or seven weeks to bring the iron levels down".

Removing blood is the only method of removing excess iron from the body and is called venesection or phlebotomy therapy. Colm had never

donated blood so this was a whole new experience for him.

"I had hepatitis B years ago so I wasn't able to be a blood donor. I was a bit squeamish for the first few bouts but the staff at the clinic were excellent, so after five or six times I'd built up confidence about the process" There was no instant change in how he felt but over time the bouts of fatigue lessened. "After a while, I wasn't getting so tired as often".

The ankle pain disappeared. Colm's siblings and children were tested for Haemochromatosis after his diagnosis, but luckily none of them have the condition. Looking back though, Colm

suspected that some of his uncles may have had Haemochromatosis without knowing. "A lot of my ancestors died fairly young, mostly of heart attacks. Two grand uncles we used to talk about were reputed to be very lazy and sit by the fire all day, so it's possible they had haemochromatosis. They died aged 56 and 60.

"Knowing what I know now, they could have had haemochromatosis that was never diagnosed."

Colm helps out during the Irish Haemochromatosis Association (IHA) Awareness Days each year in Galway and at the National Ploughing Championships. He believes that people should be checked for Haemochromatosis routinely.

"I think people should be checked for iron overload even if they don't have the symptoms, given that haemochromatosis is so prevalent in Ireland," he says. "You'd only need it done once to know if you're positive or negative. Hopefully once you're found to be negative then that's it, the

Two grand uncles we used to talk about were reputed to be very lazy and sit by the fire all day, so it's possible they had haemochromatosis. They died aged 56 and 60.

test is done and dusted." He thinks doctors aren't really aware enough of the condition and the need for the test yet.

"I know of people who have tested positive but their siblings and children weren't automatically tested by their GP after their diagnosis. Doctors should immediately tell people to get all their family tested because they could have the same diagnosis as it's an inherited condition."

The IHA would like to thank Colm for sharing his story and also for the incredible help and support that he has given to the association over the years.

'THE IRON HEART IS A FRAGILE HEART' - Professor Pierre Brissot

"Haemochromatosis (HH) is known to cause chronic fatigue and skin pigmentation as well as other complications, including joint and bone damage (arthritis, osteoporosis), pancreas damage (diabetes) and liver damage (with the risk of cirrhosis and hepatic cancer).

The heart is another organ that may potentially be targeted. Indeed, when iron accumulates within this organ, it may be responsible for cardiomyopathy which can lead to rhythm disturbances and/or cardiac failure. This is why, once HH has been diagnosed from any non cardiac symptoms, it is part of the check-up to systematically explore the heart in two ways. On the one hand, cardiac iron deposition should ideally be assessed by MRI (magnetic resonance imaging) which has now replaced the invasive technique of cardiac biopsy. On the other hand, cardiac function must be explored by clinical examination, electrocardiography (ECG), and mostly echocardiography (ECHO). By combining the results of these two investigations, it is possible to evaluate the cardiac status of the patient and also to obtain predictive data on the possible risk of cardiac failure.



Professor Pierre Brissot

The main clinical problem is misdiagnosing the cause of the cardiac symptoms, especially when they are presenting symptoms and not associated with the other classical damage of the disease. Therefore, **it is of critical importance to think of the possibility of HH when facing unexplained cardiac symptoms.** This is all the more necessary so that HH cardiomyopathy can be treated in time. Besides the usual treatment for arrhythmia and cardiac failure, sustained venesection therapy must be applied, possibly associated with iron chelators. In conclusion, one should never forget the heart as a potential complication of Haemochromatosis"

The Irish Haemochromatosis Association would like to thank Professor Brissot for this informative article. Pierre, who is Emeritus Professor of Medicine at Rennes University is a world authority on Haemochromatosis and has for many years been a great friend and an incredible support to the IHA.

Note from the Irish Heart Foundation

Cardiac MRI is available in Ireland but it is expensive and time consuming so is not used as a first line investigation. Only a few specialist centres would be able to specifically assess iron overload at present. ECG and ECHO would be the first investigations of choice.

PRIORSWOOD and TALLAGHT TRAVELLERS

The IHA were pleased to be invited to meet members of the travelling community in Priorswood Community Centre on October 4th. Haemochromatosis is common in the community and they are aware that it is very important to alert relatives to the importance of early diagnosis.



Paddy Mc Donagh is a 46 year old traveller who has been diagnosed with Haemochromatosis. He presented to the GP with gout and the GP correctly

suspected that Paddy might have Haemochromatosis. Paddy also has diabetes and high blood pressure. He is very aware of the importance of venesection and attends the clinic in Beaumont Hospital. Paddy has three children who have not yet been tested. He greatly appreciates the care and attention given by Nurse Fiona Colclough in Beaumont.



Eileen Ward is interested in raising awareness of Haemochromatosis in the Travelling Community. She herself has been diagnosed with HH. She continually felt

very unwell with joint pain in fingers and ankles. She also suffered from chronic fatigue. Eileen has 6 children, 3 boys and 3 girls. One of the children has Haemochromatosis and thought that he was dying, he felt so badly before being diagnosed. One of Eileen's uncles and two aunts have also tested positive.



We also met John Maughan (34) in Priorswood. John is a Traveller Men's Health Worker and invited us to meet the Tallaght

Travellers in Fettercairn Community Centre on Tuesday 18th October. They were celebrating 15 years of the Primary Health Care for Travellers Project. John has been diagnosed with Haemochromatosis. His five brothers and one sister have refused to be tested, despite encouragement from John.