



Welcome to the Winter Newsletter 2008

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UPCOMING EVENTS

Tralee Meeting is at Fels Point Hotel on November 24th at 7.45pm. The speaker is Dr Jane English, Consultant Physician/ Gastroenterologist at the Bon Secours Hospital, Tralee.

DUBLIN MEETING

A Dublin Meeting will be held at the Catherine McAuley on Thursday 4th December - Education Centre, Nelson St (off Eccles Street) Dublin 7 at 8 pm. The speaker is Prof John Crowe and the Mater Haemochromatosis Team. All are welcome.

IT HAPPENED TO ME

Danny Morrison knew that something wasn't right for some time. Over several weeks he had had numerous tests but only after a battery of blood tests, was he diagnosed with Haemochromatosis.

"It was the last day of February 2007 when the phone call came. I went straight to the surgery. After a few pleasantries my GP asked me was I a heavy drinker.

Actually, I have done a fair bit of drinking in my day, but I told him that until just recently I had been off the drink for a year to lose weight. In recent years I had been increasingly crippled with arthritis and a few months earlier had had successful surgery for a right knee replacement. He then explained to me that my iron levels - whatever they were, I thought - were dangerously high, possibly as a result of alcohol abuse. With that eliminated he admitted to being in the dark and decided to send me to a specialist - a haematologist.

I knew that something hadn't been right for a while. After Christmas I was tired and irritable, my joints were swollen and aching more than ever. Over weeks I had had numerous tests but nothing was found.

However, one conscientious nurse at the practice decided to run a battery of blood tests for various things - even though the surgery, she said, didn't usually do this and couldn't afford such screening as a general rule.

The doctor had spoken about my 'ferritin levels' being astronomical and so, long before I arrived at Belfast City Hospital two months later, I had deduced from internet searches that what I had was probably Haemochromatosis.

My consultant talked me through my family history. My older sister, Geraldine, after many miserable years, was discovered to be suffering from coeliac disease, an auto-immune disorder caused by a reaction to gluten. My younger sister Susan died in 2001 from primary biliary cirrhosis, another

auto-immune disease which eventually destroyed her liver, heart and lungs.

He asked me did I ever experience any swelling along the second and third joints of my hand. I said I had for about five years but had attributed it initially to sports injuries on the squash court and had to stop playing when the hands became arthritic.

He said that was a classic sign of Haemochromatosis and added that the only treatment was regular bloodletting or venesections. I asked to start the venesections right away and was sent to the Bridgewater Suite where I have been for weekly treatment ever since. In 50 sessions they had taken the equivalent of five gallons of blood from me.

Most people absorb from their dietary intake about 10 per cent of the iron that they need for making red blood cells. But people with Haemochromatosis absorb up to 50 per cent or more of iron from their food. The body doesn't know what to do with the extra iron and so stores it in the liver, pancreas, heart, bone marrow and joints where it is toxic and begins destroying cells and can induce liver cancer or a heart attack.

The normal range of serum ferritin in a male is 12-300ng/ml (nanograms per millilitre). Mine was at 5,200 last August, even after 13 venesections, but has come down gradually.

I am now enjoying a six-week break before the treatment is resumed. A genetic test confirmed that the disease I had was hereditary Haemochromatosis, HH, as a result of mutant gene C282Y inherited from each parent. My sons were tested and were clear but my brother's results showed an iron overload of 1,500 and he too is now being regularly bled. The disease goes undetected - often until it is too late and organ damage has occurred. This is because the symptoms are often mild or mimic many other ailments and because many GPs are completely unaware of its prevalence, despite the fact that it

is the most common hereditary disease among those of Northern European ancestry, in particular those of Irish descent and has even been referred to as the Celtic disease.

Earlier this year the Downpatrick-born, London Independent satirist, Miles Kington, died from pancreatic cancer as a result of the disease. Others reckoned to have succumbed include Beethoven and Ernest Hemingway's father 'Doc Ed'.

A few months ago I had a biopsy after certain liver enzymes were elevated. The results revealed that I had fibrosis of the liver, short of cirrhosis, and was advised to stop drinking or certainly keep within recommended government guidelines.

The disease has made me more conscious of my mortality. At the hospital I see many faces I recognise (the suite also deals with patients on

chemo), and though there is a lot of sadness and suffering, there is a great feeling of solidarity and friendship among the patients and staff.

My routine is to go in early, get a bed, get a blood test to check that my haemoglobin is okay (to ensure the opposite - anaemia - hasn't occurred) and establish my ferritin level, then have the venesection and rest for a while. Some people watch television, I prefer to read, though I have to be careful not to laugh too loudly at my hero Rumpole sitting in Pommeroy's wine bar, contemplating the tail end of a bottle of Château Fleet Street and putting off the moment when he has to return home to 'She Who Must Be Obeyed'!

The needles used for the venesection are large and my veins are quite small, which often means a couple of attempts in my pincushion arms before

they strike oil. A few hours later I sometimes feel tired and need to lie down again.

I am due to have my left knee replaced in September and regularly the arthritis flares up in my feet, hands and wrists, most likely initiated by the Haemochromatosis.

In a medical book last year, *Survival of the Sickest*, Dr Sharon Moalem explained that during the pandemic Black Death in 14th century Europe, which killed perhaps 50 per cent of all healthy men and women, people with Haemochromatosis had better resistance and survived.

Every cloud, it appears, certainly does have a silver lining."

Danny Morrison is an author and former director of publicity with Sinn Féin

Published in The Irish Times Health Supplement, Tuesday, July 29 2008

EFAPH MEETING IN ST GALLEN (SWITZERLAND) ON SATURDAY SEPTEMBER 20TH

Fran Mullaney and Margaret Mullett represented the IHA. Other countries represented were France, Spain, Portugal, Norway, Belgium, Germany and the Netherlands. The representative from each country gave an account of the management and treatment of HH in their country and discussed the recommendations they would like to see implemented in their country. It is hoped in due course to organize a European Haemochromatosis Day. The French Association already has a HH day on the first Saturday in June.

Jean Riolland will stay on as President of the Association until the next General Assembly Meeting which takes place on 12th June 2009, in Porto, Portugal.

Ketil Toska from Norway agreed to join the board and Dr Barbara Butzeck and Dr Françoise COURTOIS Courtois agreed to stay on as board members. As yet, the Association does not have the financial support to pay a permanent secretary or rent an office. All work is done on a voluntary basis. EFAPH members agreed to encourage the EU countries that are not already members, to join EFAPH. A workshop is planned for November 2008 for Bucharest. EFAPH will be represented by Dr Barbara Butzeck.

EFAPH will be represented by Ketil Toska at a European Patient Forum in Vilnius - Lithuania on 27 November this year.

AFTERNOON SHOW RTE1 MONDAY, 10 NOVEMBER '08

Dr Philip McMahon, who is a GP in Dublin and Meath Footballer David Beggy featured on the Afternoon Show on Monday, 10 November. David who is a great help to the IHA explained that for years he had attended various doctors for a variety of complaints including stomach and chest pains. He was continually tired and would have to go for a rest before and after training sessions. He felt that he was a hypochondriac! Fortunately, two years ago, at the age of 39, David was required to

have a medical examination at work. David's ferritin was very high and a diagnosis of HH was confirmed. Over the past two years he has had weekly venesections and is now a 'new man' and is full of energy. Dr McMahon explained the effects of iron overload on the system and recommended that people who suffered from any of the symptoms and complications of HH should ask their doctor to organise a simple blood test for ferritin and transferrin saturation. A genetic test would confirm if they suffered from Haemochromatosis.

THE MINI MARATHON IN JUNE RAISED OVER €8,000.

Thanks to all the wonderful women who participated on behalf of the IHA and to the many people who supported them and contributed so generously. The Mini Marathon is the main source of revenue for the Association.

DISTRIBUTION OF INFORMATION TO THE GP'S

This year the IHA have again sent posters, brochures and a booklet to every GP practice in the country. The Transition Year pupils of St Mc Cartans School in Monaghan assisted the IHA by physically packing the 2,200 envelopes and organising the distribution and postage of the materials. Sincerest thanks to our Director, Brendan Gallagher, and to the pupils and transition year teacher for their great work.

BRIDGE EVENING IN KILLINEY CASTLE

The IHA would like to thank Eamonn De Loughry and members of the Killiney Bridge Club who organised a bridge evening, on behalf of the IHA on Monday 10th November in Killiney Castle Hotel. Thanks to the generosity of the members a phenomenal total of €2,500 was raised for the Association.

THE PLOUGHING CHAMPIONSHIP



Phillipa Moran and Brenda Flannery helped at the stand during this years Ploughing Championship

The Ploughing Championship was held this year in Farnley, Cuffesgrange, Co Kilkenny on 23rd - 25th of September '08.

The IHA would like to thank Michael Campbell of Europlan Health and Safety who very generously sponsored a stand for the IHA. The stand was manned by four members of the IHA each day.

This was a great success and we were lucky that the weather was so perfect. We were delighted to meet many members of the IHA, as well as people who had friends with

Haemochromatosis. An interesting survey of 1,444 people was carried out. Of the people interviewed 806 had never heard of HH! There were 446 who said that they had heard the word but knew very little about it. In total 127 had family members who had been diagnosed with HH. Another 65 knew of someone with the condition. These results show that there is still a lot of work required to raise awareness of Haemochromatosis. Please help in any way you can. Contact the Association if you require posters or brochures for distribution.



Majella O'Neill, Denise McAuliffe and Leonora Mullett

SOME FRUITFUL ADVICE



The following information was published recently in the Australian Financial Review: That well - worn phrase about 'an apple a day' needs updating. A new study has just shown that by eating at least two apples a day, men can protect themselves against iron overload disease.

Conducted at the Western Australian Institute for Medical Research, the study is the first to identify a dietary factor that reduces body iron stores in men. It showed that by consuming two non- citrus fruits each day, men can reduce their iron levels by 20 per cent.

While the mechanism is not fully understood, it is thought that the chemicals in the fruit interfere with the absorption of iron in the gut. They do this either by binding with the iron to stop it being absorbed or by disrupting activity along the specific pathway through which iron is absorbed into the gut lining. The authors of the study, John Olynx and David Ravine, both Professors at the Institute, say the fruit may also help to protect cells against oxidation and reduce inflammation, easing the pressure on internal organs that iron overload can cause.

Published in Mayo Clinic Proceedings, the study found that egg yolk, coffee and tea also inhibited iron uptake. While potatoes, other cooked vegetables and salads had no effect, red meat increased iron levels. Olynyk says that as most of our iron is absorbed from non - meat sources, following a vegetarian diet is no guarantee against overload. Exercise interferes with iron absorption too. He says elite athletes, such as footballers, eat well and are healthy, but have lowered iron stores.

MEETING IN CASTLEBAR, CO. MAYO ON THURSDAY OCT 16TH



Staff Nurse Jean Walsh and Dr. Luke O'Donnell

An excellent meeting attended by 110 people was held in the Mayo General Hospital on Thursday Oct 16th. Sincerest thanks to Staff Nurse Jean Walsh, who oversees Haemochromatosis care at Mayo General and to the Haemochromatosis team. Their hard work and commitment ensured the success of this meeting. The very informative and interesting talk, given by Dr. Luke O'Donnell MD, FRCPI was followed by a lively question and answer session. People who attended the meeting were glad to meet with other people also diagnosed with Haemochromatosis. The IHA were represented at the meeting by Ann Mc Grath and Margaret Mullett.

MEETING IN CLONMEL, CO TIPPERARY, ON THURSDAY 6TH NOVEMBER

Another very successful Information Meeting was held at South Tipperary, General Hospital on Thursday 6th November. The Haemochromatosis team included Dr Paud O'Reagan, Dr Sam Kingston, the HH nurses and Dietician Sareen Walsh. Dr Paud O'Reagan mentioned that

nowadays people are being diagnosed much earlier, before organ damage has occurred. Sareen stressed the importance of a balanced diet. After the talks, all three specialists, who gave so generously of their time and expertise, answered the many interesting and relevant questions.



Dr Sam Kingston, Sareen Walsh and Dr. Paul O'Regan

HEALTH OR LIFE INSURANCE

Any members who have issues with their Health or Life Insurance should contact Frank Falvey or Paul Holohan of the Irish Insurance Federation at ph: 01 676 1914 for advice and information. They will investigate any complaints and will advise you of your rights. Brendan Gallagher at ph: 047 772802 is a Director of the IHA and he will also be very happy to help you with insurance issues.

RENEWAL OF SUBSCRIPTION

Please complete and return the renewal forms to Brendan Gallagher. Your subscription is essential for the running of the IHA as unfortunately the HSE/DoHC have not contributed to the IHA, despite the Working Party Report of June 2006.

If any of the members would like to write an article or a personal story for the newsletter, please email it to margaretmullett@ireland.com