



Welcome to the Summer Newsletter 2014

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Michael and John Fennelly

FARMING BROTHERS, JOHN AND MICHAEL FENNELLY

Farming brothers John and Michael Fennelly, from Co Laois talked to Margaret Hawkins of the Farmers Journal about living with Haemochromatosis. John Fennelly was diagnosed with Haemochromatosis accidentally. A stay in hospital in 1998 because of a bad bout of jaundice led to the discovery. "John was 30 yrs old at this time and about to get married" he says. "Lots of tests were done

and one of the blood tests showed that my iron levels were very high and I had Haemochromatosis." After the jaundice cleared up, John was advised to begin treatment. "I had to have a unit of blood taken off once a month initially. I know now that it was good that the condition was diagnosed when I was younger because it gets more serious over time, as the iron levels build up in your system and can

cause organ damage." John now has a unit of blood taken off once every three or six months, depending on his iron levels. "At the start it meant a half day away from the farm, but now it doesn't take as long. I get the blood taken off in Portlaoise hospital now rather than in Dublin, so that's a lot handier." Overall, John is very positive about coping with Haemochromatosis.



2014 NATIONAL PLOUGHING CHAMPIONSHIPS SEPTEMBER 23RD, 24TH, 25TH SEPTEMBER

The NPC will take place at Ratheniska, Stradbally, Co Laois. If you are available to help man the IHA stand, please contact us by emailing: margaretmullett@gmail.com or call 01 873 5911

MICHAEL'S DIAGNOSIS

Michael Fennelly, John's brother, is also a farmer. He specialises in breeding Piedmontese cattle and sells the meat directly to customers. He had the test done for Haemochromatosis in 2000 on John's advice because siblings have a one in four chance of having the inherited condition. "I never had any health issues before that," Michael says. "My GP referred me to a specialist in Tullamore General who found that I had it too."

The treatment, as for his brother John, involved taking blood on a regular basis to bring his ferritin levels down. Within a year they had the levels back under 50, where they needed to be. He does notice that he has more energy about a week after blood is taken off.

The IHA would like to thank The Farmers Journal for alerting readers to the possibility that they may be suffering from iron overload.

UK SURVEY OF HAEMOCHROMATOSIS ARTHROPATHY

Dr Patrick Kiely: Rheumatologist at St George's Hospital presented the results of a Members Arthritis Survey at the AGM of the British Society in London on Saturday June 14th in the Royal Free Hospital.

A questionnaire was sent to members of the UK Haemochromatosis Society in December 2013. Questions assessed symptoms and their duration when the diagnosis of Haemochromatosis was made, the prevalence and distribution of affected joints, the range and effectiveness of treatments used, and the impact of Haemochromatosis and joint problems on employment and quality of life.

Questionnaires were returned by 470 people with Haemochromatosis. The diagnosis was made at a mean age of 56 years, following family member screening in 20%, routine health check in 23% and as result of symptoms in 57%. At diagnosis the

most frequent symptoms attributed to haemochromatosis were fatigue (300/462) and joint pain (270/462). The diagnosis was most frequently made by a GP (38%), Haematologist (24%), Gastroenterologist (21.5%) or Rheumatologist (7%).

88% of respondents reported joint pain, stiffness or swelling with pain on a daily basis reported as a little in 43%, quite a lot in 32% and a lot in 12%. 55% had been given a diagnosis for their joint problems: osteoarthritis in (74/252), and haemochromatosis arthropathy in (29/252). Joint symptoms preceded the diagnosis of haemochromatosis by more than 5 years in 47%, by more than 1 year in 78.5% and post dated the diagnosis in 14.5%. The most prevalent areas were hand or wrist, ankle or mid foot, and knee.

Venesection was reported to have helped joint symptoms in 5%, made

no impact in 20% and in 51% new joints had become affected following de ironing. Anti-inflammatory drugs, Paracetamol and Codeine based analgesics were most frequently used for joint symptoms, with the majority reporting them to be effective.

Amitriptylline and joint injections were less utilised but also reported to be effective. 23% of respondents had joint surgery, most frequently to the hip and knee.

The meeting was attended by Dr Willie Murphy and Staff Nurses Anna Capplis and Majella Jobling from Louth County Hospital. All three presented excellent papers.

Sincerest thanks to Dr Kiely and to Janet Furneau, Chairperson of the British Society for inviting us to the AGM and for allowing us to publish the results of their very extensive and informative survey

ANNUAL GENERAL MEETING MAY 24TH 2014

The AGM took place at the Irish Blood Transfusion Service in St James's Hospital, Dublin 8 on Saturday May 24th and was attended by 86 people. Margaret Mullett gave the Chairperson's report and the Treasurer's report was given by Brendan Keenan. The board of directors agreed to stay on for another year.

The IHA would like to thank the IBTS for once again making the centre available to us and for generously sponsoring morning coffee and lunch. We would also like to thank Professor Suzanne Norris, Dr Willie Murphy and Dr Maurice Manning for their excellent presentations.

DR MAURICE MANNING

Dr Maurice Manning is a board member of the IHA and spoke from the patients perspective.

" I was diagnosed with type 2 diabetes in 2001. The doctor wondered what caused this and did a few tests and discovered that my ferritin was extremely high. I was also suffering from joint pain, tiredness and crankiness. I was then diagnosed with Haemochromatosis.

My first reaction was one of fear. However, in hindsight I was very lucky to be diagnosed, hopefully in time to prevent a progression of problems. In 2006, I was asked by Mary Harney to chair a working group to report on the nature and extent of Haemochromatosis in Ireland and to advise her on the action necessary



Professor Suzanne Norris



Dr Maurice Manning, Chancellor of NUI

to address the problems caused by Haemochromatosis. In the space of six months we had a report for the government with 33 recommendations. Mary Harney was very encouraging but it has been very difficult to get the recommendations put in to action due to the high level of bureaucracy. All points raised by the working party are as valid today as they were in 2006. Unfortunately, there are people out there as yet undiagnosed. Political pressure is required to get a comprehensive screening programme underway. "

PROFESSOR SUZANNE NORRIS

Professor Suzanne Norris said that Haemochromatosis is an ideal condition to consider for population screening in Ireland. Funding must be prioritised to develop a HH screening programme. Information obtained from this programme will provide essential guidance to policy makers in structuring a countrywide programme for HH service development. The screening tests include:

Serum ferritin: is a measure of the amount of iron stored as ferritin in all the body tissues. For men the normal range is 30-350 mg/L and for women 20-250 mg/L

Transferrin saturation (%): indicates the amount of iron that is available to be moved from storage to utilisation. Normal range 10-45%
The Ferritin and Transferrin saturation tests together cost in the region of €8. If both Serum ferritin and transferrin saturation are raised then a genetic test is required to confirm the diagnosis.

In 2002, 100 people were referred to St James's Hospital to be genetically tested for Haemochromatosis, whereas in 2013 the number was 1,825.

Between 2005 and 2010, 18,592 people were treated for HH in Ireland. The numbers are increasing all the time but there are still 20,000 people yet to be diagnosed.

HAEMOCHROMATOSIS AWARENESS DAY, JUNE 5TH 2014

The Haemochromatosis Awareness day took place on Thursday June 5th 2014. There were over 36 information stands throughout the country. This would not have been possible without the incredible help and support from members of the Association and friends. Sincerest thanks to everyone who gave so generously of their time.

A special thanks to Ann Marie Walsh who helped organise the photo shoot and media coverage. This included articles in the *Irish Times*, *Evening Echo*, *The Star*, *Kerryman*, *Examiner*, *Limerick Chronicle*, *The Waterford news and Star*, *Medical Independent*, *Medical Times*, *Northside People* and *Irelands Own*.

Keelin Shanley interviewed Dr Willie Murphy and Dr Maurice Manning on Morning Edition (RTE). TV3 Ireland AM highlighted the Awareness day. There were several other radio interviews including News talk, Louth Meath FM, Kerry Radio Midland 103, Highland Radio and South East.



Sophie and Leah Mullett posed for photographs to support us on our awareness day



Nicholas Mulholland who helped man the stand in Portlaoise.



TV Presenter Lisa Cannon with Michael Fennelly



Phil and Sean Burke manning the stand in Blanchardstown



Arthur Lappin in Portlaoise

PRESENTATION BY DUNDALK NURSES: MAJELLA JOBLING AND ANNA CAPPALIS



Anna Cappalis and Majella Jobling

WOMEN'S MINI MARATHON, JUNE 2ND 2014

The IHA would like to thank all of the ladies who ran the Women's Mini Marathon in Dublin this year.



A big thank you to Amy Hughes who successfully completed this year's mini marathon in Dublin.

At the British AGM, Staff Nurses Majella Jobling and Anna Capplis gave an excellent presentation on the development of the Haemochromatosis clinic in Dundalk and its amalgamation with the clinic in Drogheda. They outlined the geographical areas and the numbers of patients attending the clinic. There has been a phenomenal increase since they first started in 2001 (26 patients to 850 currently). They spoke about their role in the expansion and the governance of the clinic under Dr. Sengupta and Dr. Keohane with an agreed standard operational procedure. They discussed the development of direct access to the venesection clinic (referrals are sent directly to venesection clinic for consultant opinion). Previously patients attended the medical outpatients department for assessment by the consultant which could lead to at least a 12 month delay in starting venesection. This initiative has decreased patient waiting times

in commencing venesection and on average patients are seen within three weeks of referral. Anna and Majella outlined the nurses' role in terms of assessment, planning, delivery and evaluation of care, and assessing quality of life issues. They promote a holistic approach into their daily practice. Verbal information is supplemented with a written booklet informing the patients of the treatment plan and target. In relation to the future, they mentioned the need for a national screening programme and a database.

They hope to establish a nursing forum on Haemochromatosis. If any other 'Haemochromatosis Nurses' are interested in joining they could contact Majella at majella.jobling@hse.ie

Sincerest thanks on behalf of the IHA to Majella and Anna for their great work and incredible interest in raising awareness of all issues relating to Haemochromatosis.

FLY FISHING COMPETITION

Members and staff of Monaghan General accepted a cheque for €500 on behalf of the Irish Haemochromatosis Association from Albert Berry. The money was raised from a fishing competition sponsored by SEAT on Lough Cullin, Co Mayo, and was presented on National Haemochromatosis Day.



Included in the photo are (L-R) Irene Kearn, Haemochromatosis Nurse, Jacinta McAree-Murphy, Day Service Manager, Brian Carroll, Charlie Friel, Chairman, Monaghan Branch of Haemochromatosis, Albert Berry, Winnie Moore and Mary McMahan, Haemochromatosis nurse. ©Rory Geary/The Northern Standard

Disclaimer: The IHA believes the information in the newsletter is accurate, but little is known about many aspects of HH and research is progressively revealing new information on the subject. Accordingly, any person using this newsletter does so, on the condition that he or she thereby indemnifies and keeps indemnified the IHA against action or any claim of any nature whatsoever arising directly or indirectly from the use of information contained herein.