



Welcome to the Spring Newsletter 2010

In this issue:

- Annual General Meeting - Saturday, May 29th 2010
- Haemochromatosis Awareness Day -Thursday, June 3rd 2010
- Flora Women's Mini Marathon Monday, June 7th 2010
- Ploughing Championship - Tuesday Sept 21st – Thursday September 23rd 2010

FEATURES

- Interview with Professor Suzanne Norris
- Address to the British Haemochromatosis Society by Professor Stephen Shalet
- Interview with DJ Robin Galloway from Scotland
- Dolphins and Haemochromatosis



ANNUAL GENERAL MEETING

This year's AGM will take place at the Irish Blood Transfusion Service in St. James's Hospital, James's Street, Dublin 8 on Saturday May 29th 2010. Coffee will be available from 10.15am. A brief business meeting beginning at 11am will be followed by guest speakers. Details are on the enclosed official AGM announcement. The talks will be followed by a question and answer 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) 8735911

We would like to thank the IBTS and the Medical Director, Dr. Murphy for once again making the centre available to us and for generously sponsoring morning coffee and lunch. Family and friends are welcome.

HAEMOCHROMATOSIS AWARENESS DAY, THURSDAY JUNE 3rd, 2010

A working group was set up by Minister Mary Harney in March, 2006 to examine the nature and extent of Haemochromatosis in Ireland. One of the recommendations was that there should be a major Government-funded awareness campaign.

A key part of this would be a Haemochromatosis Awareness Week. This has not happened.

The European Federation of Associations of Patients with Haemochromatosis (EFAPH) decided at the AGM in Portugal last June that the member associations should have a Haemochromatosis Awareness Day, during the first week in June 2010. In line with this, the IHA will be holding an event on Thursday, June 3rd. It is hoped to organise Information Stands in different venues throughout the country. If possible we would like to include Dublin, Cork, Limerick, Galway, Sligo, Roscommon, Waterford, Tralee, Kilkenny and Wexford. Please let us know if you can help to organise a stand in your area or if you have contacts with the local media. All relevant information will be on the website.

ELECTION OF DIRECTORS

The Directors are responsible for the day to day running of the organisation for the members. Nominations for appointment to the Board of Directors should be in writing and signed by at least two members of the Association. Such nominations should be sent to the Secretary at least ten days before the AGM. Address of the Secretary, Ann Campbell is:
7 Ashleigh Green, Castleknock, Dublin 15.

FLORA WOMEN'S MINI MARATHON MONDAY JUNE 7th 2010

Enter online at www.florawomensminimarathon.ie, or on entry forms available in the Evening Herald every Wednesday and Saturday from the March 3rd, 2010. All participants who enter as Runners or Fast Joggers must wear a Timing Tag. Sponsorship cards and T shirts are available from margaretmullett@ireland.com or by phoning (01) 873 5911. Closing Date for entries is April 27th, 2010.

VOLUNTEERS

We need your help. The IHA is run by volunteers and we are looking for more members to help both with the running of the Association and in the organisation of the upcoming Haemochromatosis Awareness Day. Any assistance that you can give would be greatly appreciated. Phone (01) 8735911 or email margaretmullett@ireland.com.

MESSAGE FROM THE TREASURER

Thanks to the many members who have renewed their membership fees. The membership fees and the money raised through the marathon are at present our main source of income. Sincerest thanks to Britt Miller who last October, ran the Dublin City Marathon for the IHA in record time! A special thanks also to Gerard Cox who last year, very generously donated €550 to the IHA from the proceeds of his Art Sale.

DOLPHINS HAVE BEEN FOUND TO HAVE HAEMOCHROMATOSIS



Dolphins can have a condition strikingly similar to type-2 diabetes in humans.

At a recent meeting of the American Association for the Advancement of Science, researchers in San Diego suggested that the best non-human model for type 2 diabetes is not a rat or even a primate. It's a dolphin! Apparently, these marine mammals regularly shift their blood chemistry in a way that can cause problems

strikingly similar to those associated with diabetes in humans, such as insulin resistance, Haemochromatosis, and kidney stones.

In 2007, scientists at the University of California, San Diego, School of Medicine who had reviewed 7 years of routine blood samples from 52 bottlenose dolphins, found that the blood chemistry after fasting resembled that of people with diabetes with characteristics such as higher levels of glucose and other molecules, whereas the blood after

a meal was like that of healthy people. This allows the dolphins to maintain adequate glucose levels while eating a high-protein diet. Dolphins appear to turn on and off a diabetes-like state as needed. This "switch" mechanism is likely driven by dolphins' high protein and low carbohydrate fish diet.

Veterinary epidemiologist, Stephanie Venn-Watson proposed that dolphins could be the most realistic model for studying diabetes. Although significantly different to us, there are more similarities than expected - not least their exceptionally large brains! Last year, the group described signs of disease complications associated with diabetes and some dolphins were found to have Haemochromatosis. This information is taken from ScienceNow which is published by the American Association for the Advancement of Science

Credit: Brian Balmer, Sarasota Dolphin Research Program

INTERVIEW WITH PROFESSOR SUZANNE NORRIS

This is a summary of Derek Mooney's excellent interview with Professor Suzanne Norris on January 12th, 2010. It was perhaps one of the most comprehensive radio discussions of HH in recent years.

Dr Norris began by describing the familiar features of Haemochromatosis (HH), what causes it and how it manifests itself. She emphasised the importance of early diagnosis and the problems to do with suspecting that it might be the cause of a patient's rather vague symptoms, predominantly fatigue and mild joint pains. In this regard she praised the IHA for its role in building awareness of the condition among the medical and allied professions, the result being that her clinic is now seeing people in their 30s and 40s as opposed to their 70s and 80s. Early treatment by venesection of this younger group can prevent later onset of serious conditions such as diabetes, cirrhosis and so on. With regard to the transfusion of blood removed from HH patients, for use by the Irish Blood Transfusion Service, Dr Norris is hopeful that the scheme already begun in Stillorgan will soon be rolled out across the country to regional branches.

In reply to a question from a listener she explained that not everyone who



has the two genes for HH actually develops the disease. Most of the research indicates that only 50% of people who have the two genes will actually develop the condition itself, so they have the fingerprint or the susceptibility to it but may never actually develop iron overload. There is obviously another trigger factor but as yet it is not known.

Derek Mooney asked whether it was possible to avoid getting HH, to which Dr Norris replied that if one has inherited the two genes from one's parents then, as she said 'naturally it's going to follow down the line.

There is nothing you can do about it. You have it.' She emphasised the importance of notifying the siblings of anyone recently diagnosed with HH.

On the subject of diet Dr Norris said that moderation was the key,

and that one should not be overly concerned about cutting out various items. She noted the importance of avoiding Vitamin C in tablet form and advised patients to drink tea, as tannin prevents the absorption of iron.

Dr Norris concluded by calling for a National Screening Programme to find those who have not yet been diagnosed with HH or are unaware that they have the condition. She referred to the Working Party that was convened by the Minister of Health in 2006 and which reported within six months with a list of 20 recommendations. That working party was chaired by Senator Maurice Manning. One of the recommendations suggested a National Policy endorsing a framework for management of Haemochromatosis. Another recommendation was that there should be a HH Screening Programme. Unfortunately the funding has never been made available.

The interview ended with Derek Mooney commenting that, in the long term, early detection of HH is cost-effective, and prevents very costly treatment which would be required if the condition were not diagnosed in time.

ADDRESS TO THE BRITISH HAEMOCHROMATOSIS SOCIETY (NORTH WEST GROUP) ON SEPTEMBER 19TH, 2009 BY PROFESSOR STEPHEN SHALET, ENDOCRINOLOGIST, UNIVERSITY OF MANCHESTER

This summary by Howard Don is not intended to be a verbatim account of Professor Shalet's talk, it is a precise of what was said and discussed at the meeting. Howard is a member of the British Haemochromatosis Association and is a patient of Prof Shalet. He has offered to talk with any members of the IHA, who may be experiencing similar problems and feel they might benefit from discussing their concerns with him. He can be contacted at 0044 1695 423344

Endocrinology can be defined as the study of disorders of the ductless glands. Examples of these are the pancreas, pituitary gland, adrenal glands, and gonads which are the testes in men and the ovaries in women.

Some examples of the type of patients who present to an endocrinologist could be those with diabetes mellitus, osteoporosis and reproductive disorders such as infertility and thyroid diseases.

Haemochromatosis is an iron overload condition resulting in excessive iron deposition and damage to many parts of the body including the endocrine glands. Failure of the gonads, or hypogonadism, can occur in both men and women. In men the testes have two functions: the production of testosterone and the production of sperm. The testes are driven by the front part (anterior) of the pituitary gland, which is about the size of a thumbnail and is situated in the brain. It produces six hormones, two of which are Gonadotrophins i.e. related to the gonads. These are called Follicle Stimulating Hormone (FSH), which controls sperm production, and Luteinising Hormone (LH), which controls testosterone production. The hypothalamus, also situated in the brain, in turn drives the pituitary. The hypothalamus

produces a hormone called GnRH (gonadotrophin releasing hormone) which passes directly into the bloodstream and which stimulates the pituitary to work and hence stimulates the gonads to function. There is a pulse of GnRH secretion approximately every 90 minutes.

If a man is testosterone deficient, the endocrinologist will perform tests to determine the site of damage, ranging from the testes to the pituitary gland to the hypothalamus. The outcome of this testing will determine the nature of the treatment. The most common cause of testosterone deficiency associated with iron overload is a lack of the hormones FSH and LH caused by a malfunction of the pituitary gland. FSH and LH deficiency can lead to the following:

In men

- Infertility and testosterone deficiency because the testes are not being hormonally driven.
- Change in the composition of the body.
 - Loss of muscle.
 - Increase in fat
- Loss of interest in sex (low libido)
- Impotence or inability to maintain an erection sufficient to have sex.
- Voice changes
- Skin changes

In women

- Low libido
- Menstrual periods cease
- Infertility because ovulation stops

Both genders

- Increased risk of osteoporosis due to lack of the hormones testosterone in men and oestrogen in women.
- Loss of body hair.
- Fatigue

It would appear that Gonadotrophin deficiency has been reported in 10% to 25% of patients with haemochromatosis. However if the haemochromatosis is diagnosed in its early stages this figure is reduced to approximately 6%. The risk of developing Gonadotrophin deficiency is also dependent on the severity of the haemochromatosis. Gonadotrophin deficiency may, in some cases, be reversible if diagnosed early enough and treated with venesection. However, if the condition does not reverse then the following treatment options are available:

- 1) If the patient (male) wishes to recover sexual potency, but is not concerned with fertility i.e. sperm production, then treatment by testosterone replacement will often be effective. This can be done via intra muscular injection, subcutaneous implants or the daily application of a gel to the skin.
- 2) If the patient wishes to have children, and therefore recover both potency and fertility then regular injections (two or three times per week) of a hormone HCG similar to LH, usually with the addition of FSH injections, can be successful in stimulating the testes to produce sperm once more. It should be noted that this process could take up to two years before fertility is restored.

It is important to note that most endocrinological diseases are eminently treatable and most of these treatments are relatively inexpensive.

The IHA would like to thank the British Haemochromatosis Society for permitting us to include this article in the newsletter.

INTERVIEW WITH ROBIN GALLOWAY IN THE SCOTTISH SUNDAY, FEBRUARY 20th 2010



Robin Galloway is a forty-eight year old Scottish radio broadcaster and the current presenter of the Real Breakfast Show on Real Radio Scotland.

Robin was recently interviewed by his colleague Yvonne Bolouri. "Just four years ago, aged 44, Robin was so tired that he struggled to make it in to the studio for his 6am on-air start. No one listening to his lively wake up call-could ever have guessed how he was feeling. Robin hadn't been feeling great for some time but he pushed himself, cycling to work, watching his diet and keeping fit. He and his family put his tiredness down to his hectic schedule. Robin said that when the joints

in his fingers started to get sore, he thought it was the start of arthritis. He went to see his GP and it was a huge shock to him when blood tests showed that he had Haemochromatosis."

Robin vividly describes his reaction to this news.

"I had 29g of iron in my body when the level should have been less than 1g. The 'tan' that I'd always thought was natural, was because of the iron. It's like rust. Over time, iron gradually builds up in the body tissues and gets into internal organs. If it's not treated, it leads to arthritis, cardiovascular disease, liver cirrhosis and cancer. You have to get rid of this iron overload and the only way to do it is by having blood taken." Robin had to attend Gartnavel Hospital in Glasgow twice a week for venesection. He had two units drained off every week for five months. Because he was so fit he could be in and out in about 15 minutes, but he found it very debilitating.

"I'd be presenting my show at full-pelt but afterwards I just wanted to rest. It's emotionally stressful too. Everything takes its toll. It's not just your body that's affected, it hits the brain too so you're not quite as sharp as you should be, and you can feel it. I'm not good with needles and I always dreaded it - still do. But I felt very humble because I was treated at the Beatson Oncology Unit with people who were ill with cancer. While I was shaking in my shoes, frightened over needles, they were laughing and joking. They

were the bravest people I have ever met, and they gave me tremendous support."

Eventually Robin's iron levels were reduced to a safe figure and now he only has to give blood four times a year.

He said: "I'm feeling pretty good now. I am much less irritable than I used to be. My blood levels have to be kept very low, almost to the point of anaemia. And because of the liver damage, I have to be careful not to drink too much - a couple of glasses of wine at the weekend is about it. But once it's diagnosed, it can be controlled and that's why I think it is so important to raise awareness. Robin would like to see a screening programme introduced in Scotland and feels that the heel-prick tests in babies should include Haemochromatosis."



BLOOD MOBILE

Attention: The Bloodmobile will be visiting St James's Hospital once a month for the next year. Only patients already attending St. James hospital for venesection are eligible to donate. For more information please contact Nurse Liz Ellis on 01 416 2329

EMAIL ALERT

If you have not received an email from us recently, we probably do not have your correct email address. To help us rectify this please send Catherine Geoghegan, kategeog@gmail.com an email with your full name and using the word *Haemochromatosis* as the subject. Catherine is one of our hard working Directors!

NATIONAL PLOUGHING CHAMPIONSHIP (NPC) 2010

The NPC will take place at the same venue as last year, Cardenton, Athy, Co Kildare from Tuesday 21st to Thursday 23rd September. In 2009 it was estimated that 189,000 people visited the site.

The IHA will have a stand again this year and would greatly appreciate your help in manning the stand.

