



Welcome to the Spring Newsletter...

In this issue:

FEATURES

- Annual General Meeting Saturday 24th May at IBTS
- Regional Meetings in Galway and Monaghan
- Midwestern Support Group
- Update from the Irish Blood Transfusion Service (IBTS)
- German Haemochromatosis Association
- Blood-letting in the Olden Days!
- Women's Mini Marathon Monday 2nd June 2008
- Donations and Fund-Raising

ANNUAL GENERAL MEETING SATURDAY 24TH MAY

The meeting will take place at the Irish Blood Transfusion Service (IBTS) St James's Hospital, James's Street Dublin 8. The IHA would like to thank the IBTS and the Medical Director Dr Murphy 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 11 am will be followed by guest speakers.

Details are on the enclosed sheet. 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.

Election of Directors

The Directors are responsible for the

day to day running of the organization 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.

The address of the secretary is:
Ann Cambell,
7 Ashleigh Green, Castleknock,
Dublin 15

REGIONAL MEETINGS IN GALWAY AND MONAGHAN

The Galway meeting on Thursday 23rd January at GMTI was attended by 120 members and friends. The four speakers included Dr John Lee, Nurse Angela Moore, Nurse Mary Bohan-Keane and Ms Ruth Kilcawley. Ruth is currently working in the Community Nutrition and Dietetic Service HSE West. She has a special interest in Haemochromatosis. The talks were followed by a very informative and interesting Question and Answer session.



Dr John Lee

The meeting in the Glencairn Hotel on 8th February was very well attended by over 50 members. Dr Muthalagu gave an excellent lecture and Nurse Geraldine Lennon and Dr Mary Flannagan participated in the lively Question and Answer session which followed. Brendan Gallagher from Monaghan is a Director of the IHA and can be contacted at 047 72802. It is hoped that the Monaghan branch will organise further meetings in the future. There are at least 200 people in the area who have been diagnosed with Haemochromatosis.



Dr Muthalagu

See inside for more photos.

MIDWESTERN SUPPORT GROUP

A meeting of the MWHSG took place in the community room at Raheen Church on Tuesday 23rd January 2008. Letters of notification were sent out to all members of the IHA in the Clare, Kerry, Limerick, and Tipperary North regions. A large number of Haemochromatosis patients attended the meeting. Many questions were raised from new members regarding the waiting times for admission to hospitals for venesection. A discussion followed with regard to establishing the number of HH sufferers that are in the Midwest Region. Members stated that each time they go for venesection they never seem to meet the same people. It was concluded that that the problem is more common than originally thought.

The next meeting will be held in April (date to be decided). Phone Denise at 0878298461.

Photo Gallery – Regional Meetings in Galway and Monaghan –



Top row from left:

Dr Mary Flannagan, Dr Muthalagu and Nurse Geraldine Lennon / George and Rosaline McCourt / Angela Moore

Middle row from left:

Prof. Dan O'Donovan and Limerick friends / Mary Bohan-Keane and Teresa McNamara

Bottom row from left:

Paddy McBride and Margaret Mullett / Ruth Kilcawley

UPDATE FROM THE IRISH BLOOD TRANSFUSION SERVICE

by Dr William Murphy IBTS National Medical Director

"The Haemochromatosis pilot scheme now has 160 donors on the books, mostly from St James's Hospital, but some from other hospitals also. We are opening a second clinic in D'Olier Street in the summer. We expect that ultimately 10 or 12 clinics will be able to cover the country, providing around 25,000 units of blood for hospitals; about one-sixth of the national need. The capacity for one clinic is about 600 donors with Haemochromatosis, that is the number of people one team including a Medical Officer and clerical support can manage comfortably. We will prepare a business plan for next year (2009) to set up clinics, each

We will prepare a business plan for next year (2009) to set up clinics, each catering for up to 600 people with Haemochromatosis, at one or more sites outside Dublin.

catering for up to 600 people with Haemochromatosis, at one or more sites outside Dublin. While funding will be needed for this, the project will save the acute system money in the long run. Because some additional resources will be required, we will have to explore funding routes - given that each clinic will provide up to 2,400 outpatient visits. Donors will come to us where otherwise the HSE would have had to provide the phlebotomy service. It should be possible to reach a reasonable agreement with the HSE to cover some of the additional costs. We are keen to provide the facility for Beaumont, and the service there is keen to get us involved too. There is a stumbling

block in that Beaumont charges every patient the €66 outpatient fee. They are the only hospital in Dublin to do this. The problem for us is that it introduces a theoretical financial imperative for Beaumont patients to switch to the IBTS clinics, and we believe it is very important to avoid any financial inducement for donors. The solution, and one we feel is really very easy, and only fair, is for Beaumont to drop the charge. However, in response Beaumont said it did not have any issue referring to the pilot scheme, it was just that the clinic's location was inconvenient for most of its patients. Further more the Hospital is required under health legislation to charge them as they are treated as day-case patients, as opposed to outpatients."

INTERVIEW WITH DR BARBARA BUTZECK

PRESIDENT OF THE HAEMOCHROMATOSE-VEREINIGUNG DEUTSCHLAND (HVD), THE GERMAN HAEMOCHROMATOSIS (HH) ASSOCIATION



- **How common is HH in Germany?**

The frequency of the homozygous mutation C282Y is about 1: 300. About 1:10 are heterozygous (carriers). It is estimated that about 150,000 persons in Germany are affected with symptoms and organ damage.

- **When was HVD founded?**

The first HH support group was started in Germany in 1997

in Cologne. The HVD as a non-profit association was founded in 2001. The office is in Cologne.

- **How many members do you have and how much is the subscription?**

At the end of 2007 we had 330 members and the annual subscription is €50 for each member.

- **How is your association organized?**

We have a board of five persons who are elected for three years. We have a president, a vice-president, a treasurer and two other members. The board meets every six weeks. In recent years some members have organized regional support groups in their area. Members act as contacts in nearly every federal county of Germany. They can be contacted by E-mail or a phone call. We provide a homepage www.haemochromatose.de which provides information and announcements.

- **How often do you have meetings?**

We have four meetings in Cologne, usually in February, June, August and November. The meeting in February is our AGM. Regional groups have additional meetings. In addition we organize one weekend a year for HH-Patients and their partners, in different venues each year. This has proved successful.

- **Do you send out a newsletter?**

We do not have a Newsletter. After each meeting I write the minutes of the meeting and the speakers give us a short summary of their presentation. This information is sent out to all members.

- **Is the blood taken in the Blood Banks?**

There is no standard procedure for venesection. In some federal counties of Germany the blood is taken in blood banks, but this is not usual. Usually the General Practitioner performs the venesection.

- **How much is the cost of treatment?**

The patients do not have to pay for the treatment, which is covered by health insurances. Since 2006 the doctors are not paid for each phlebotomy, but receive a quarterly fee for treating chronic patients. So, if more than one or two phlebotomies in three months are needed, it may not be profitable for the doctors and some of them refuse to give regular treatment. The HVD is in contact with the medical association to improve this situation.

- **Are ferritin and transferrin tests done routinely?**

When a person is first diagnosed, transferrin saturation is tested frequently. Later, during the treatment, it is rarely done. A test for ferritin is usually performed every three months.

- **Do you feel the medical profession in Germany needs more information / education about HH?**

Yes, absolutely. Although the number of people detected in the early stages of Haemochromatosis, has increased since 1995 (as a result of genetic testing becoming available), there are still patients with Haemochromatosis dying because of liver cancer. I know of two cases where HH was not detected until a liver transplant had been performed. This is incredible and unacceptable.

- **How and when were you diagnosed?**

I was diagnosed in 2000 in a clinic for rheumatology. Retrospectively the symptoms began before 1993. When my son was born he was tall (59 cm) and heavy 4500 gr (10lbs) and the doctors assumed that I might have diabetes. But the diagnosis of diabetes was not confirmed until 1999. In 1995 I had cardiac arrhythmia and the first operation for an affected joint, the left ankle. Because I used to play volleyball and soccer, nobody including myself considered any diagnosis other than arthritis, due to too much sport and exercise. Because of increasing fatigue, a decrease in energy level and pain all over my body, I stopped working in 2000 to be treated in a rheumatology department. There they tested ferritin for the first time – it was 5800 ng/dl – and a diagnosis of Haemochromatosis was confirmed by genetic testing. The liver, pancreas, heart and joints were affected. I started having four or five phlebotomies per month at the surgery of my general practitioner. I felt better and better. My liver enzymes normalized, the heart problems stopped and fatigue became less. I still have the diabetes and unfortunately the joint disorders have not improved.

- **How did you get interested in joining the association?**

I did not know anything about HH before I was diagnosed in 2000. I got in contact with a small HH-support Group in Cologne and they helped me a lot. When I got better two years later, they encouraged me to join the board of the recently founded HVD. Because of the subsequent dysfunction of several organs my life style has changed a lot. I want to ensure that this does not happen to other people in the future. Meanwhile I no longer quarrel with my fate because I have met so many friendly and highly motivated people from all over Europe who deal with this condition and help to educate the public and medical profession on Haemochromatosis.

Editor's Note: Barbara visited Ireland last summer with her son. That 59cm baby is now fifteen and well over 6 feet tall! He and Barbara enjoyed a game of golf in Connemara and a visit to the Galway races. Barbara works 20 hours a week as a Consultant Radiologist. As well as being President of HVD, she is very actively involved in the European Association and regularly attends meetings in Brussels. The IHA would like to thank Barbara and to congratulate her on all her great work.

BLOOD-LETTING IN THE OLDEN DAYS!

For six centuries the barbers of Europe practised surgery. This custom began with the papal decree of 1163 which forbade the clergy to shed blood. Monks were required to undergo blood-letting at regular intervals and some of them had been performing this task themselves along with minor surgery. After the papal decree these duties were turned over to the barbers.

The arrangement was satisfactory to the doctors of the era who considered that blood-letting was necessary but beneath their dignity. They were glad to relegate to the barbers other physical tasks as well, such as lancing of abscesses and treatment of wounds. The barbers of London were granted a charter as a trade guild in 1462. This guild was amalgamated with that of the surgeons in 1540 and members of the joint corporation were accorded the right to be addressed as Mr! British and Irish surgeons still prefix their names with Mr.

Blood-letting reached its peak in the eighteenth and nineteenth century. According to medical texts of the time, if you went to your doctor with a fever, hypertension or dropsy; you would be bled. If you had an inflammation, apoplexy or a nervous disorder; you

would be bled. If you suffered from a cough, dizziness, headache, drunkenness, palsy, rheumatism or shortage of breath; you would be bled. Even if you were haemorrhaging blood; you would be bled.

The barber's shop was the place to go. The barber's pole originated as a symbol for blood-letting. The brass bowl at the top represented the bowl where leeches were kept. The bowl at the bottom represented the bowl for collecting blood. The red and white spirals had their origins in the medieval practice of hanging bandages on the pole to dry after they had been washed.

When George Washington was ill with a throat infection, doctors treating him conducted at least four bleedings in 24 hours. It is unclear today whether he actually died from the infection or from shock caused by blood loss.

Patients were routinely bled until they fainted. This was taken as a sign that the right amount of blood had been removed. Fortunately times have changed!



Shellfish: A Word of Warning

People with iron overload should avoid consumption of raw shellfish such as oysters and should take care when walking barefoot on the beach or swimming in oceans.

A bacteria called *Vibrio Vulnificus* lives in coastal, marshy areas and is often a contaminant of shellfish. This bacteria is harmless for people with normal iron levels but when transferrin is highly saturated with iron, it can prove to be deadly.



Women's Mini Marathon Monday 2nd June 2008 Time to Start Training!

Entry online at www.florawomensmarathon.ie or on entry forms available in the *Herald* every Thursday and Saturday from 28th February 2008. Closing date for entries is 22nd April 2008.

Sponsorship cards and T shirts are available from margaretmullett@ireland.com. In 2007 well over €6,000 was raised. Sincerest thanks to all of you who participated by running / jogging or walking the 10K and a special thanks to all the sponsors.



British Liver Trust

A patient information booklet on Haemochromatosis entitled 'Fighting liver disease' has recently been produced by the British Liver Trust.

Tel: 0044 20800652 7300

Email: info@britishlivertrust.org.uk

Web: www.britishlivertrust.org.uk

ACKNOWLEDGEMENTS

The IHA would like to thank Castle Golf Club for giving a very generous contribution of €1500 and Baxter Healthcare who continue to help by sending our brochures and posters to every GP in the country. We would like to thank Michael Campbell of Europlan for sponsoring the IHA Stand at the Ploughing Championship show. Also sincerest thanks to Coughlan Coleman Hughes for organising €600 in sponsorship for the Cork meeting. The insurance companies, who contributed were New Ireland, Caledonian, Eagle Star, Irish Life and Canada Life.

Thanks also to the members who have already sent back their renewal form. In case you have forgotten to return it, we are including it again with this newsletter. Please disregard if you have already paid. The membership fees and the money raised by the marathon are at present our main source of income.