ADDITIONAL INFORMATION

The IHA hopes to take a stand at the 2011 National Ploughing Championships (NPC), which will take place from Tuesday 20th to Thursday 22nd 2011 in Cardenton, Athy, Co Kildare. **All offers of help to man the stand will be greatly appreciated.**

The IHA would like to thank The National Lottery Fund for their support.

A special thanks to Rose Tubridy for her incredible fundraising on behalf of the IHA.

Thanks to Kay De Loughry and the ladies of Delgany Golf Club who organised a fashion show and donated the proceeds of the raffle to the IHA.

We would like to thank all members who have already renewed their membership fees. Please note that for security reasons, we advise that membership renewals are best made by a postal order or a crossed cheque.

If any member would like to have their name deleted from the data base, please let us know. If you have a new mobile number or email address send it to us by emailing kategeog@gmail.com or leave a clear message on the answering machine 01 8735911

DON'T FORGET DUBLIN MEETING Thursday April 14th 2011 at Beaumont ALL welcome

INFORMATION MEETING ON HAEMOCHROMATOSIS

ROBERT ADAMS LECTURE THEATRE

BEAUMONT HOSPITAL

Thursday 14th April 2011 at 7:30pm

The speakers are :
Professor Frank Murray FRCPI
Dr Stephen Patchett FRCPI
Dr Gavin Harewood FRCPI

Consultant Gastroenterologists, Beaumont Hospital

This meeting will provide an opportunity to talk to experts in the field and meet other people interested in the disorder.

AMERICAN HAEMOCHROMATOSIS SOCIETY

Countless Irish Americans unknowingly suffer from Haemochromatosis says staff writer Molly Muldoon in a recent article in the American paper *Irish Central.* Sandra Thomas who runs the American Haemochromatosis Society in Florida is urgently seeking to alert Irish Americans to Haemochromatosis.

According to the Centers for Disease Control, Haemochromatosis, is now the most common genetic disorder in the United States with an estimated 32 million silent carriers.

Sandra Thomas has been using St. Patrick's Day celebrations and Irish gatherings everywhere as a platform for discussing what she describes as "The Celtic Curse".

Sandra's mother died of liver cancer caused by iron overload. A carrier of the disease herself, she is committed to spreading awareness of the condition.

Sandra says her mother's dying wish was that everyone would get tested for hereditary haemochromatosis/ iron overload, so they wouldn't have to go through what she was going through.

The chair of the American Haemochromatosis Society now encourages everyone who has Irish lineage to get tested for the hereditary disorder.

www.americanhs.org

Photographed at the Castlebar meeting are Jean Walsh, Mary Feeney, Margaret Mullett and Ann McGrath

Nurse Catherine Kearney attending the Limerick meeting

Dr. Brian Hennessy, Consultant Haematologist at Waterford Regional Hospital spoke at the Waterford meeting.

Disclaimer: The IHA believes the information in the newletter 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.

Irish Haemochromatosis Association

Carmichael Centre, North Brunswick Street, Dublin 7

Spring 2011

Welcome to the Spring Newsletter 2011

In this issue:

- **Annual General Meeting**
  Saturday May 28th 2011, at IBTS
- **National Awareness Day**
  Thursday June 2nd 2011, Nationwide.
- **Women's Mini Marathon**
  Monday June 6th 2011, Dublin
- **Upcoming Meeting in Beaumont,**
  Thursday April 14th at 7.30pm
  Speakers: Professor Frank Murray, Dr Gavin Harewood and Dr Stephen Patchett, Consultant Gastroenterologists, Beaumont Hospital.
  Venue: Robert Adams lecture Theatre
- **Report on Regional Meetings**
  Waterford: Tuesday, January 18th 2011
  Limerick: Tuesday, February 22nd 2011
  Galway: Monday March 14th 2011
  Mayo: Tuesday March 29th 2011
  Dublin: Thursday April 14th 2011

FEATURES

- **Cork: Dairy Farmer Michael Murphy**
- **American Haemochromatosis Society**

ANNUAL GENERAL MEETING SATURDAY MAY 28th 2011

The meeting will take place at the Irish Blood Transfusion Service, St. James's Hospital, Dublin 8 on Saturday May 28th 2011.
The IHA would like to thank the IBTS for making the centre available to us and for generously sponsoring coffee and lunch. Family and friends are welcome. Coffee will be available from 10.30 am. A brief business meeting will commence at 11.15 am and will be followed by guest speakers Professor Suzanne Norris, Consultant Hepatologist at St James's Hospital and Anthony Ryan, a Research Geneticist from St James's Hospital who will talk from the patient's perspective.
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.
The address of the secretary is:
Ann Campbell
7, Ashleigh Green,
Castleknock,
Dublin 15.

CORK DAIRY FARMER

Cork dairy farmer Michael Murphy couldn't understand why he was feeling so tired. "It was gradual, so I didn't think there was necessarily anything wrong with me," he says. "I just thought I had less energy than before."
Friends had also commented on how he often sounded out of breath when they were talking to him on the phone. He didn't suspect that there might be something wrong with him. However. Michael admits that, like most men, he wasn't the greatest at having medical check-ups.
A phone call from his sister, a Dublin GP, was to prove an eye-opener, and could ultimately have saved his life.
"She hadn't been feeling very well herself, and the usual tests hadn't revealed very much but, given that she's a doctor, she went for one or two extra tests, and the one for excess iron was positive. As Haemochromatosis is hereditary, she told the other four of us immediately."
All three brothers had high levels of iron, but Michael's were the highest.
"My levels were about 2,200 when I was diagnosed in January 2008. My system had been absorbing and retaining too much iron for a long time."
In one sense, Michael felt relieved when he was diagnosed because it explained his fatigue. "It made me suddenly realise that I had actually been feeling quite a bit under par."
Since then, Michael has had 80 pints (units) of blood extracted to lower his iron levels. "Initially, blood was taken off every week," he says. "My doctor said that we needed to decrease the iron levels, in the short term, almost to the point where I would be anaemic, because it's not just about iron levels in the blood, it's also the saturation level. "In the initial stages, I would have been somewhere between 90 and 100% saturation. The saturation level is now down to 35%."Once blood was taken, Michael began to feel better. "I could notice the difference after seven or eight pints had gone," he says. Now he has a pint of blood removed every three months to keep his iron levels under control.
He is thankful that there was someone with medical knowledge in his family and that the condition was discovered when it was.
"If my sister hadn't noticed it, I could have been hit by something serious, like stroke or diabetes. It mightn't have been attributed to excess iron either. No one might have known what caused it"

Thanks to Margaret Hawkins for allowing us to reprint this article from Farmer's Journal July 2010

FLORA WOMEN'S MINI MARATHON IN DUBLIN, BANK HOLIDAY MONDAY, JUNE 6th 2011

Last year €6,000 was raised for the IHA. Sincerest thanks to all concerned who either participated in the marathon or supported the event. This year we are urging all members to persuade friends, family and colleagues to run, walk or jog the 10k route for a great day out.
The closing date for entries is Wednesday 27th, April 2011 or when the maximum number of entries has been reached. Entry forms for 2011 will be available on www.florawomensminimarathon.ie and in the Evening Herald from Wednesday 2nd March 2011.
Sponsorship cards and T shirts are available from Margaret Mullett on 01 4922705 or email: margaretmullett@ireland.com. This year the President of the IHA , Mary O'Rourke, is participating on behalf of the IHA .

GALWAY PRESENTATION

Dr. Clifford Kian, Nurse Angela Moore and Dr. Valerie Byrnes.

The IHA would like to express our appreciation to Dr. Valerie Byrnes, Nurse Angela Moore and Dr. Clifford Kian for their excellent presentations at the Galway meeting.
Dr Valerie Byrnes' presentation was supported by a comprehensive overview of the genetics of Haemochromatosis delivered by Nurse Angela Moore and a presentation by Dr. Clifford on his research.

Dr. Clifford Kian, MRCPI is looking at the factors that may affect the rate of iron reaccumulation following iron depletion i.e. why some patients with HH need more frequent phlebotomy than others. He is also looking at Bone Mineral Density (BMD) changes with iron depletion by checking BMD in male C282Y homozygotes. BMD is measured using a Dexa scan. He hopes to discover if phlebotomy improves BMD in patients with hereditary haemochromatosis. His research will include a survey of a control group who do not have HH.

Extract from Dr. Byrnes' Presentation

Haemochromatosis (HH) is a condition characterised by the gradual accumulation of excessive iron stores which can cause organ damage. It is an inherited disorder. Patients with HH continue to absorb iron from the diet despite excess stores. This is due to the inheritance of an abnormal gene (HFE) which fails to regulate the absorption of iron into the body. There is no stop signal. It is caused by a genetic defect known as the Celtic Gene. It is thought that the Vikings brought it to Ireland. It was probably a useful mutation at the time of the famine, when iron was in short supply.

Excess iron is toxic and may cause irreversible damage to body tissues and organs in which it is stored. Iron is an essential micro-nutrient for the manufacture of red blood cells, however it is toxic when in excess.

Iron overload may be Primary as in the case of Hereditary Haemochromatosis or Secondary which is acquired. Secondary may be caused by Multiple Blood Transfusions, Chronic Liver Disease, Alcohol, Fatty Liver Disease or Hepatitis C. Dr Byrnes explained in detail the diagnosis of HH, its different stages, its symptoms and potential organ damage if undiagnosed and left untreated.

NATIONAL HAEMOCHROMATOSIS AWARENESS DAY THURSDAY JUNE 2nd 2011

Volunteers are needed to help with the Haemochromatosis Awareness Day on Thursday June 2nd 2011.
It is proposed to have information stands at the following venues (see list below). We urgently require volunteers in these venues to distribute brochures and information to anyone who is interested in learning about iron overload and the importance of early diagnosis.
Also, if you have any contacts in the media who might highlight the event, please let us know.
If you can help (even for an hour or two) please email: margaretmullett@ireland.com or leave a message on the voice mail at 01 8735911. The venues are:

Dublin
Dundrum Shopping Centre
Swan Shopping Centre Rathmines
Nutgrove Shopping Centre
St Stephen's Green Shopping Centre
Ilac Shopping Centre, Henry Street
Ashleaf Shopping Centre, Crumlin
Frascati Shopping Centre, Blackrock,
Donaghmede Shopping Centre,
Dublin City Council Offices, Wood Quay,

Cork
Douglas Court Shopping Centre
Mahon Shopping Centre
Wilton Shopping Centre

Galway
Corrib Shopping Centre, Galway
University Hospital, Galway

Limerick
Crescent Shopping Centre, Limerick

Other venues
Mayo General Hospital, Castlebar
Mid Western Hospital, Clonmel
Louth County Hospital, Dundalk
Marshes Shopping Centre, Dundalk
Letterkenny General Hospital, Co Donegal
Dunnes Shopping Centre Ennis, Co Clare
Manor West Shopping Centre, Tralee, Co Kerry
Market Cross Shopping Centre, Kilkenny
Longford Shopping Centre, Longford
Our Lady's Hospital, Navan, Co Meath
Monaghan Hospital, Monaghan
Whitewater Shopping Centre, Newbridge
Portlaoise Shopping Centre, Portlaoise
Tesco Shopping Centre, Roscommon
Tesco Shopping Centre, Sligo
Mullingar Shopping Centre, Co Westmeath
Ardkeen Shopping Centre, Waterford
Gorey Shopping Centre, Co Wexford

REPORTS FROM REGIONAL MEETINGS

Waterford: Tuesday 18th January 2011 at the Whitfield Clinic Medical Centre.
Speakers: Dr. Sean Nugent, Consultant Gastroenterologist at the Whitfield Clinic and Dr. Brian Hennessy, Consultant Haematologist at Waterford Regional Hospital.
The meeting was attended by a record number of people and the excellent presentations were followed by a very informative and interesting Question and Answer session.

Galway: Monday 14th March 2011 at Galway Mayo Institute of Techonology.
Speaker: Dr. Valerie Byrnes, Consultant Gastroenterologist, University Hospital Galway and Staff Nurse Angela Moore.
A report on Dr. Byrnes' presentation is featured in this newsletter.

Mayo: Tuesday 29th March 2011 at Mc Hale Park Castlebar.
Speakers: Dr. Luke O 'Donnell, Consultant Gastroenterologist Mayo General Hospital, Castlebar and Staff Nurse Jean Walsh, Mayo General Hospital, Castlebar.
The meeting was very informative and well attended. The IHA would like to thank Nurse Jean Walsh and Nurse Mary Feeney for providing a very welcome cup of tea before the meeting.
Dr. O'Donnell told the meeting that the gene pool in the West of Ireland is very pure as over the years people didn't tend to marry people from outside the area!

Limerick: Tuesday February 22 nd at the Kilmurry Lodge Hotel
Speaker: Dr Denis O' Keeffe, Consultant Haematologist at the Mid Western Regional Hospital. A full report is included in this newsletter.

The IHA would like to thank Dr. O'Keeffe for his detailed and informative overview of the diagnosis and treatment of Haemochromatosis. In addition he raised issues that need to be addressed nationwide in relation to the ongoing treatment of HH patients. His talk was followed by a lively Question and Answer session, during which one member of the audience raised the interesting possibility of a self-test for ferritin.

Dr. Sean Nugent, Consultant Gastroenterologist at the Whitfield Clinic

Dr. Luke O 'Donnell, Consultant Gastroenterologist Mayo General Hospital,

Dr. Denis O' Keeffe, Consultant Haematologist at the Mid Western Regional Hospital.

LIMERICK PRESENTATION DR. DENIS O' KEEFFE

Screening for Haemochromatosis

Dr. O'Keeffe discussed the importance of carrying out the following tests and procedures when diagnosing HH.

- Transferrin Saturation > 55% Males, and > 50% females
- Ferritin > 300 Males, > 200 Females
  If bothTS and Ferritin are rasied, HH is indicated
- Genotype
- Liver Ultra Sound
- LFT's (Liver function tests)
- Cardiac Echo
- Liver biopsy if ferritin level > 1000

Dr O'Keeffe explained that Transferrin is a protein found in the blood and it transports iron around the body. It should not be more than 50% saturated with iron. Dr. O'Keeffe compared Transferrin to a bus carrying passengers. Ideally this particular bus should only be half full!
Ferritin on the other hand is a storage protein. The amount found in serum is directly related to iron storage in the body. (It has been suggested that we think of Ferritin as a big sink when this sink gets full, Ferritin and its iron can be changed into a precipitate called Hemosiderin which can accumulate in certain organs.)

Penetrance of HH symptoms among HH homozygotes

Dr. O'Keeffe observed that while the majority of symptomatic patients are homozygous for C282Y (i.e. they have two copies of the C282Y mutation), the majority of HH homozygotes will never have a significant complication. With 1% of the population expected to be homozygous for C282Y, it is estimated that with a population of 360,000 the Mid-West region has a population of approximately 3,600 C282Y homozygotes.
It is important to note that not all the people who have the two genes develop the disease.

Penetrance is the proportion of people who have the genotype and go on to develop the phenotype. Genotype is the genetic make-up whereas phenotype is the physical expression of the genotype and involves other factors as well.

Dr. O'Keeffe distinguished between Biochemical Penetrance and Clinical Penetrance.

Biochemical Penetrance is when the Ferritin and Transferrin Saturation levels are raised above certain levels. Clinical Penetrance involves clinical features of HH such as arthritis, skin pigmentation and liver disease. It is very difficult to estimate the degree of Clinical Penetrance.
Penetrance is variable and is influenced by factors such as the population studied and a combination of genetic and environmental factors, such as alcohol consumption, diet, gender, hepcidin, viral infections, etc.

In conclusion, Keeffe emphasised the issues that need to be addressed:

- **A national agreement on protocols for when to venesect and to what targets.**
- **A national primary care programme to enable equity of access to care for all people with HH including prompt referral for venesection.**
- **A national decision on screening and research.**