



Welcome to the Spring Newsletter...

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PRIZE WINNING PROJECT AT THE RDS YOUNG SCIENTIST EXHIBITION



"HAEMOCHROMATOSIS: DO WE KNOW ENOUGH?"

Congratulations to Paula Butler and Annette O'Shea from Scoil Aireagail, Ballyhale, Co. Kilkenny. Paula and Annette won first prize in the Senior Category (Social and Behavioural Sciences) at the Young Scientist Exhibition at the RDS on January 14th. They also won the Irish Blood Transfusion Services special award. The pupils conducted a comprehensive survey of 300 people in Kilkenny to find out:

- how many people were aware of this disorder
- did they know the seriousness and prevalence of it
- were people aware of the connection between this disease and excess dietary iron
- were people aware of which foods contain high levels of iron
- how many people took fortified cereals
- how many people took vitamin/mineral supplements

- how did those who knew about HH get their information

The results of their survey showed that not enough is known about haemochromatosis (HH).

34% of those interviewed had heard of HH but only 19% could mention any one fact about the condition. Only 3.6% knew of the serious consequences of HH and only 6% made the connection with iron. Only one person surveyed knew of his carrier status. 43% of women and 24% of men, without medical advice, take iron tablets when tired. The corresponding figures for vitamin/mineral supplements are 64% and 36%. Only three people or 1% were aware that breakfast cereals were a source of dietary iron. Again only three people had heard about HH in the Doctors surgery. Among the recommendations suggested by the students would

be a major Government-funded awareness and education campaign, all supplements containing significant amounts of iron to be available on prescription only, the iron content of all supplements to be highlighted, the fortification of foods to be investigated and the issue of screening for HH to be examined.

It was also suggested that there should be a Haemochromatosis Awareness Week dedicated to educating people about HH. The medical profession were urged to investigate how detection of this condition could be improved.

The Irish Haemochromatosis Association commends this research and congratulates the pupils on their excellent and very worthwhile project. The results of the survey show that there is still a lot of work to be done in alerting the public and medical profession to this most common but under-diagnosed disorder.

ANNUAL GENERAL MEETING 2006

- Date:** Saturday, May 27th 2006
Venue: Irish Blood Transfusion Service, St. James's Hospital, Dublin 8. We would once again like to thank the IBTS and the medical director Dr. Murphy, for making the facilities available to us and for generously sponsoring coffee and lunch. For catering purposes, please let us know as soon as possible if you will be attending; this can be done by returning the reply slip posted out with the official AGM announcement or by phoning (01)8735911.
Time: 11 am Registration
Speakers: Professor John Crowe, Consultant Gastroenterologist, Mater Hospital has very kindly agreed to speak at this years AGM. See enclosed agenda for further information.

Please note that one of the current Board Members is retiring this year. In light of this, nominations for future Board Members are required to be sent in writing to the Secretary of the IHA, Ms. Ann Campbell, 7 Ashleigh Green, Castleknock, Dublin 15, at least 10 days in advance of the AGM. We currently have more than 600 members of the IHA and whilst we are very happy with the exponential growth experienced in the last few years, it does mean that the workload on the secretariat, treasurer and Board members has increased significantly.

We would very much welcome nominations for future Board members who have the time and expertise required to be an active member of the Board who meet several times a year. This year, David Morton is retiring from the Board, and we would like to take this opportunity to thank David for the tremendous support he has given to the Board since his joining as a founder member in 1995. David we hope you will now have sufficient time to enjoy sailing the high seas.

Volunteers

We would like to thank all those members who have helped with fundraising, mail-outs, meetings and manning stands throughout the year. As ever, we welcome any further support for the coming year. With this in mind, if at any stage you feel you would like to be involved, please do not hesitate to contact Margaret Mullett at email: margaretmullett@ireland.com

LOTTERY FUNDING

The IHA is pleased to announce that Mary Harney, An Tánaiste and Minister for Health and Children allocated the IHA 25,000 Euro in funding from the National Lottery in December 2005.

WORKING PARTY

A working party has been established by An Tánaiste to look into haemochromatosis in Ireland. It will be chaired by Maurice Manning.

Members of the working party are as follows:

Mary Jackson, Dept. Of Health and Children

Margaret Mullett, Chairperson, IHA
Brendan Gallagher, Board Member, IHA
Dr. Suzanne Norris, Consultant Hepatologist, St. James's Hospital
Dr. William Murphy, Medical Director, Irish Blood Transfusion Service

The working party will meet to discuss the current issues facing the IHA with a view to writing a report which will be presented for discussion with the Department of Health.

MARIA'S STORY

"I was diagnosed with haemochromatosis in May 2002 at the age of 28. My second son was born the previous January. After his birth I was totally exhausted. My first son was born in Nov. 1999, so he was now two years old and with a new baby in the house I put all my tiredness down to motherhood. During my pregnancy with my first baby I took iron tablets on the recommendation of my then GP. I never had any major complaints at this point but I do always remember my ankles being awfully sore and swollen especially first thing in the morning. Over the next 2 years I would dread jumping out of the bed in the morning as it would feel as if my ankles were going to break under me. This would last for a while until they seemed to free out, as it were. Getting up at night to my son was the same and having to go down the stairs for a bottle was agony. When I was expecting my second son I was again told by the GP to take iron tablets. During this pregnancy I had a lot of stomach pain and swelling of the legs and ankles with the usual pain. I put all this down to being pregnant but

now I know better. After my son was born I spent the next 5 months totally exhausted. I used to drink loads of coffee in order to try and stay awake and look after my boys. I often nodded off feeding the baby. I decided one day to buy myself a tonic at a chemist's; this was full of iron in order to give myself more energy. That March I had my son at a new GP for his injections and I told him how I was feeling. I thought I was going out of my mind. People were sick of listening to me complaining of how tired I was. On that day my GP did blood tests. He brought me back 3 times to repeat these tests as he could not believe the results. I was diagnosed with haemochromatosis and a ferritin count of 3650. He referred me to a consultant in our local hospital which is 30 miles away from where I live. At this stage if I had to do this journey or any car trip I would always have to stop the car and walk around as if I was checking on the kids in the back, just to get some air to wake me up. As on many occasions I would feel my eyes closing and my head nodding. I might have to stop three times on a journey. I

had my first venesection on May 27th 2002. The nurse on duty welcomed me to the unit and said this will be your new home for quite some time – and she was right. I spent the next two years attending that unit once every week for a venesection. After that every two weeks and gradually once a month until my ferritin levels dropped. Then every two months after that – it seemed hard to keep it low and at the moment it has gone back up to 173. When it came below 1000 I started to feel much better and not as tired. Now I never have any pains in my joints, only feeling tired when my levels seem to rise. My husband is a carrier and so my sons will need to be tested when they are older. At least they will never have to go through what I did. I was the first in my family to be diagnosed and had never heard of haemochromatosis before. My brother has been diagnosed with it but with a low ferritin count. My other three siblings are carriers. Knowledge is a wonderful thing." **The IHA thanks Maria for sharing her story with us.**

PAT KENNY INTERVIEW

Maurice Manning, President of the Human Rights Commission and Dr. Suzanne Norris, Consultant Hepatologist, St James's Hospital were interviewed on radio by Pat Kenny on Thursday the 9th February 2006. Maurice is a member of the IHA and has been a great help to the association.

Three years ago Maurice developed type 2 diabetes and on investigation his doctor discovered that he had haemochromatosis. Since being diagnosed he has given almost 80 units of blood and at this stage is feeling great. He has now reached the maintenance phase and probably won't have to have venesection for another year.

He said that it is only when you have been through something and you are feeling better that you realise how unwell you had been. Members of his family were also tested and some had the genotype whereas others did not. Maurice stressed the importance of raising awareness. People should know

that it is very easy to diagnose and very easy to treat. He mentioned the huge need for the Government and the Department of Health to be involved. A nationwide survey needs to be carried out to see how extensive the condition is.

Dr. Norris explained that haemochromatosis is a genetic condition that results in too much iron being stored in the body due to the inheritance of two abnormal copies of the HFE (haemochromatosis) gene, one from each parent. If undetected (unfortunately a lot of people do not know that they have it), it can result in damage to various organs. Damage to the liver can cause cirrhosis. Damage to the pancreas can cause diabetes,

damage to the joints can cause arthritis and the heart can be affected causing heart failure.

The important point is that it is a disorder which doctors can screen for, and if detected at an early stage and treatment is put in place the serious complications can be offset and prevented. People who are treated at an early stage have a normal life expectancy and enjoy a normal life.

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doctors to think that the person could have haemochromatosis. The majority of people will present with chronic fatigue that does not get any better no matter how much you rest.

However, fatigue is a symptom of many different conditions and doctors may not necessarily think about haemochromatosis as the cause. Nevertheless, if an individual has fatigue that cannot be explained by any other cause, or joint pain that is not arthritis, haemochromatosis should be considered.

The simple blood tests for ferritin and transferrin can be carried out in the doctor's surgery. Ferritin measures the iron in your blood and transferrin measures the iron

carried in your body. If these tests are above the normal level, this is an indication that there is a problem with iron overload and a genetic test should be carried out.

Dr. Suzanne Norris is very concerned that haemochromatosis is not being picked up in time. In her first year back from London, where she worked for several years, she had six male patients who presented with liver cancer as their first presentation.

On testing these patients it was found that they had haemochromatosis. Dr. Norris felt that this is really shocking when you think that a simple blood test could be done at an early stage of the disease and prevent organ damage.

Regarding diet, Suzanne does not recommend an iron free diet as a certain amount of iron is needed on a regular basis for bodily functions. For example carrying oxygen around the body and helping cells repair themselves. She stressed that vitamin C is not recommended for people with haemochromatosis. Vitamin C is an

unstable compound so to make it stable, to put in tablet form, the pharmaceutical industry puts iron as an inert substance with it, consequently Vitamin C tablets are full of iron. If you take Vitamin C with a meal it increases the iron absorption ten times. Pat Kenny asked what happened to the blood that was venesected. Dr. Norris explained that unfortunately it was not accepted here. Hopefully this is gradually changing and the largest hospital in Norway now accepts blood from haemochromatosis patients.

The association thanks Dr. Suzanne Norris and Maurice Manning for their invaluable help in raising awareness.

RTE NEWS FRIDAY 10th MARCH

On Friday 10th March, RTE News featured an interview with Dr. Suzanne Norris, Paul Nestor and Dr. Willie Murphy, Medical Director IBTS. Dr. Norris explained the effects of iron-overload and said that the haemochromatosis gene is four times more prevalent in Ireland than elsewhere. Paul Nestor is a young man who has recently been diagnosed with haemochromatosis. Paul was filmed having venesection in hospital. His diagnosis came about after he presented with joint pain and headaches. At present he is having a unit of blood taken every week. He regrets the fact that this blood will be incinerated.

Dr. Murphy was asked as to why copious pints of venesected blood are being rejected by the IBTS. He explained that the problem lies in the motivation of the donor. The blood has to be given for altruistic reasons. The IBTS is keen to find a way to get around the problem and hopes to have a solution by the end of the year. Incidentally, Dr. Willie Murphy has informed the I.H.A. that a proposal has been submitted to the IBTS Board Medical Advisory Committee, to be considered at their next meeting in April. The proposal is to design and implement a special clinic held regularly at key points, separate

from routine clinics - initially in Dublin and Cork, but they could be held in any major centre if there is demand and utility. Donors would present with a prescription for phlebotomy, and would be assessed for fitness to undergo a phlebotomy on the day. The clinics would require a medical officer to complete the initial assessment for phlebotomy and provide the follow up plan; the actual phlebotomy could be done by current IBTS protocol, and the donor assessment thereafter could similarly be done according to current protocols. Dr. Murphy will let us know the outcome of the Board meeting.

MINI MARATHON - JUNE 5th 2006

www.womensminimarathon.ie

It's that time of the year again to get back in training. Please see below all the relevant information for this year's Women's Mini - Marathon in Dublin. We had phenomenal support last year and we hope to build on that again this year so get those runners on! IHA sponsorship cards and T-shirts have been ordered and will be available in due course. Please call 01-873 5911

GENERAL INFORMATION

Date for Flora Women's Mini Marathon in 2006:

Bank Holiday Monday 5th June 2006

Time:

3pm

Distance:

10k through South Dublin

Closing Date:

Tuesday 25th April 2006

Minimum age:

14 yrs

Fee:

€13 Runners, Joggers, Walkers, Visually Impaired and Wheelchairs

€20 Runners only to include Champion Chip.

There will be an extra charge of €1 for entries made online.

Runners now have the opportunity to accurately measure their time and finishing position by taking up the option to have a Champion Chip issued to them. Only runners with a Chip will be accepted for the official results.

Entry Forms:

All participants must enter on an official entry form, which

will appear in the Evening Herald every Thursday and Saturday from Thursday 2nd March 2006 or online from our web site. No photocopies will be accepted.

PLEASE NOTE:

As the number of entries will be strictly limited, to avoid disappointment we would ask you to send your entry in a.s.a.p. as entries will be rejected after the closing date or when we have reached our maximum number if earlier.

Acceptance Letter:

This letter is sent out to you after we receive your completed Entry Form and Fee and entitles you and a friend to free admission to the Women's World Show in the RDS on Fri, Sat and Sun of June Bank Holiday weekend.

Collection Point:

This is where you bring your Acceptance letter to collect your Race Number prior to Race.

Race Information:

All information regarding the race, map of course, location of toilets, baggage area, water stations, assembly areas, and meeting points will be in the Programme given to each participant when collecting race number.

REGIONAL MEETINGS INFORMATION

Galway Mayo Institute of Technology, Galway, Wednesday March 1st 2006

Speakers: Dr. John Lee, Consultant Gastroenterologist, UCHG and Nurse Kiera O'Hehir, Haemochromatosis Specialist Nurse UCHG



Picture above: (left to right) Fran Mullaney - IHA, Rosaleen Mc Court - IHA, Nurse Kiera O'Hehir, Haemochromatosis Specialist Nurse UCHG and Dr. John Lee, Consultant Gastroenterologist, UCHG

Glencarn Hotel, Castleblaney, Co Monaghan, Thursday March 2nd 2006

Speakers: Dr. Prega Pillay, Consultant Gastroenterologist, Monaghan County Hospital and Dr. Mary Flanagan, G.P. Castleblaney



Picture above: (left to right) Dr. Mary Flanagan, G.P. Castleblaney and Dr. Prega Pillay, Consultant Gastroenterologist, Monaghan County Hospital.

The huge attendance at the meetings indicated the level of interest in haemochromatosis.

The IHA would like to thank the excellent speakers who gave so generously of their time and expertise. The question and answer sessions which followed the lectures were very helpful and greatly appreciated.

Resource Book recommended

- Living with Haemochromatosis: Expert answers to your questions on overload by Gregory T Everson, Director of Hepatology University of Health Science Centre. A healthy Living Book Hatherleigh Press ISBN 1-57826-104-X.