



Welcome to the Summer/Autumn Newsletter...

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REPORT FROM AGM

The AGM which took place on May 24th was attended by 75 members. The IHA would like to thank Dr Murphy and the IBTS for generously sponsoring morning coffee and lunch.

Dr Murphy told members that the pilot scheme for donation of HH

blood is being extended to D'Olier Street in July. At present there are 200 HH patients attending the pilot clinic in Stillorgan.

Catherine Geoghegan was elected as a Director of the IHA. The other Directors have agreed to stay on as board members.

The IHA would like to thank Dr Gerard Clarke, Ms Ruth Kilcawley and Mr David Beggy for their excellent presentations.

A very informative and helpful question and answer session followed the talks.

Dr. Gerard Clarke's Presentation on Haemochromatosis at AGM



Dr Clarke is a Consultant Gastroenterologist at Portiuncula Hospital. He underwent fellowship training in Gastroenterology and Hepatology at Harvard Medical School.

Dr Clarke gave an overview of the Diagnosis and Treatment of Haemochromatosis. He explained the difference

between Hereditary (Genetic) Haemochromatosis and Acquired HH. Acquired HH is sometimes called Haemosiderosis and can be caused by:

- (a) Excessive blood transfusions (e.g. thalassaemia)
- (b) Toxins e.g. alcohol
- (c) Rare disorders of blood synthesis
- (d) Hepatitis C

Dr Clarke also spoke of Juvenile and Neonatal Haemochromatosis disorders which are extremely rare. These hereditary disorders are caused by a mutation of a completely different gene called Haemojuvelin. They present either as very young infants or teenagers/young adults. Heart disease is a prominent feature.

Complications of Haemochromatosis (if any)

- Arthritis.
- Liver disease (enlarged liver, cirrhosis, cancer, and liver failure).
- Pancreatic injury, possibly causing diabetes.
- Heart abnormalities, such as irregular heart rhythms or congestive heart failure.
- Impotence.
- Early menopause.
- Abnormal pigmentation of the skin, making it look grey or bronze.
- Thyroid deficiency.
- Damage to the adrenal glands.

Diagnosis

- Transferrin Saturation of > 45%.
- Raised Ferritin.
- Genotype (C282Y, H63D).
- Liver Ultra Sound or MRI
- Liver Biopsy.
- Oral Glucose Tolerance test
- Skeletal Survey (X-Rays).
- Testosterone / SHBG (Sex Hormone – Binding Globulin).
- Other Endocrine studies.
- Cardiac Echo or MRI.



Treatment

- Phlebotomy of approximately 500mls every one to two weeks until Ferritin is 20 (50).
- Maintenance phlebotomy one to six monthly to maintain below 50.
- Annual Liver Imaging Study (U/S) but cirrhotic patients should have MRI.
- AFP (alpha-fetoprotein) blood test every six months.
- Iron supplements should not be taken.
- Alcohol intake should be limited.

A Cautionary Note

Haemochromatosis can mask GI (Gastro Intestinal) cancer.

Two percent of the population over 55 will develop Colon cancer which is the most common cause of cancer death. Phlebotomy can mask low ferritin states which is one of the commonest means of diagnosing cancer early. Patients should consider routine screening. Screening should be mandatory if 1st degree relatives or many 2nd degree relatives have been diagnosed. Dr Clarke's presentation is available on our website www.haemochromatosis-ir.com.



Marie and Angie Broderick at AGM

HAEMOCHROMATOSIS HEALTHY EATING

Ruth Kilcawley BSc. Human Nutrition & Dietetics

Ruth outlined Healthy Eating Guidelines and stressed that it is important for everyone to eat a balanced diet.

- Eat foods rich in starch and fibre: at least six servings a day of either bread / cereals / potatoes.
- Eat at least five portions of a variety of fruit and vegetables a day to reduce the risk of death from chronic diseases such as heart disease, stroke, and cancer by up to 20%.
- Include 3 servings a day of either Milk, Cheese, or Yogurt.
- Calcium – Prevention of iron absorption.
- Protein + Calcium + Vit D required for osteoporosis prevention (15-66% HH).
- Eat two portions a day of Meat, Fish or Alternative.
- Reduce the amount of fatty food you eat and avoid foods high in sugar and high in calories as this can lead to Obesity / Type II Diabetes / CVD.
- Eat the right amount of food to be a healthy weight and take regular exercise.

With Regard to Haemochromatosis

- The body has no mechanism for excreting iron absorbed from the diet, except incidental losses.
- The amount of iron absorbed depends on a number of factors.
- Phlebotomy is the recommended treatment for removing excess iron. Each unit of blood removed contains 200-250ml of iron.
- While there is no special diet, it is important to be aware of the effect of food on your condition.
- It is also important to reduce risk factors you CAN control: Smoking, Diet, Weight and Physical Activity Level.

Alcohol

- If you drink alcohol keep within recommended limits as alcohol can increase iron absorption.

- Red Wine is high in iron. Guinness is not any higher than other beers.
- Breakdown of alcohol puts extra pressure on the liver. Thirty grams of alcohol per day causes liver damage due to iron overload. It increases the risk of primary liver cancer in persons with cirrhosis. Alcohol contributes to obesity and should only be consumed in moderation:

Men – less than two drinks per day

Women – less than one drink per day

Liver damage – do not drink alcohol

Shell fish

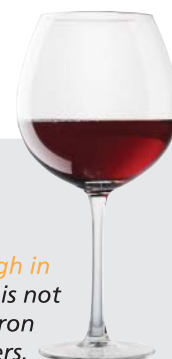
- Avoid raw shellfish, ensure it is cooked well before eating.

Food Fortification

- Read labels and avoid fortified foods.
- Breakfast Cereal - Shredded Wheat, Porridge, Muesli and Branflakes are not fortified.
- Cereal Bars are fortified.

Multivitamin Supplements

- If a healthy diet is followed, there is no need for additional supplementation.
- Only take Multivitamin Supplements under medical supervision if specific deficiency exists.
- Vitamin C - 500mg/day.
- Inorganic metals such as cobalt, manganese, zinc and lead are present in some multi-vitamins. These metals can be stored in the body in large amounts and phlebotomy may not remove them.



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A PATIENT'S PERSPECTIVE – DAVID BEGGY

David Beggy gave a very entertaining and informative talk at the AGM.

David is an All-Ireland winning Gaelic footballer from Meath. He won two All-Ireland Senior Football Championships in 1987 and 1988. He also received two "All Stars" while playing with Meath as well as playing rugby with Leinster. Having come from a rugby playing background, David, with no underage pedigree in GAA, burst onto the scene in the summer of 1986 and went on to become a huge favourite with the Meath supporters.

“Over the past two years he has had weekly venesctions and is now a 'new man' and is full of energy.”

In 2007 RTÉ's Charity "You're A Star", David teamed up with other former GAA All Stars, Jack O'Shea and Barney Rock to raise money for the 'Gary Kelly Cancer Support Center' and went on to win the show.

David raced against a greyhound in Shelbourne Park for charity, and won! David ran half the track, while the greyhound ran the full track, his reasoning being the dog has four legs and he only has two. David ran 265 yds and the greyhound ran 530 yds. The bookmakers were not pleased.

From the age of 18 and for the following 20 years David attended various doctors for a variety of complaints including stomach and chest pains. He was continually tired and would have to go for a rest before and after training sessions. He found it hard to get out of bed in the morning and was tired even after a good night's sleep. Every medical test result was negative and David began to think that he was a hypochondriac. He thought that he was going to be like that for the rest of his life and would have to accept the fact.

Fortunately, two years ago, at the age of 39, David was required to have a medical examination at work. David's ferritin level was very high and a diagnosis of HH was confirmed. Over the past two years he has had weekly venesctions and is now a 'new man' and is full of energy.

He is involved in sports training, fund-raising with the "All Stars", and working full time: something he never thought was possible. He said that for him, being diagnosed and treated, has been a life changing experience.

David has promised to help the IHA to raise awareness of HH.

Please contact us if you have any suggestions or media contacts.



FLORA MINI MARATHON – MONDAY JUNE 2ND 2008

The sun shone once again for the women's mini-marathon. Over 40,000 women ran, jogged or walked for their favourite charity. Several members of the IHA and their friends participated and others who were not able to take part contributed generously. Sinead Kissane who is a sports presenter with TV3, ran the marathon for the IHA. She donated the €1,000 sponsorship given by Flora to the IHA. Sinead from Ardfert, Co Kerry, is well known to many sports fans. She won her first national medal in the 200m at the national Community Games in Mosney in 1998. When she joined UCD in 1996 she joined their athletics club where she won silver medals in the 400ms at the Intervarsities and also competed for UCD at the Colours Track and Field, Cross Country and Road Relays.

Another IHA participant at the marathon was Jola Karwowska from Poland. Jola is here to learn English and was instrumental in getting an article on Haemochromatosis published in the Polska Gazeta on May 29th 2008.

Sinead Kissane who is a sports presenter with TV3, ran the marathon for the IHA.



From left: Ann, Mary, Ann, Clodagh, Eavan, Jola and Margaret.



FROM AUSTRALIA: SCOTT'S STORY

'The idea that iron overload symptoms in males do not appear until late in life is unfortunately not always true. Of course, I had to be one of the few to prove it too! Just after the streamers were lowered for my 30th birthday celebrations, I began to notice the multiple generalised symptoms of iron overload. However, they're so vague one can be fooled into believing they're not real and when spoken of, others looked at me sideways like I'd just arrived from another planet. That all changed quickly when my prospects sagged in the bedroom.

How could this be happening to me? Hypogonadism: iron's merciless effect on my pituitary gland. My first doctor spent a few appointments trying to convince me it was stress ... you know the type of stress patients don't have any awareness of and only doctors can diagnose. The second doctor nailed it by the second blood test, but I had to wait what seemed like an eternity for genetic testing to confirm that I was C282Y homozygous. I desperately wanted to begin venesections and testosterone treatment as I began to feel androgynous. My emotions were subtly changing and I was

even feeling teary-eyed during sad movies.

Was I about to take up knitting too? Maybe bingo as well? That's enough to make the biggest needle phobic bolt toward the vampires. Over the next year, I took out the gold medal for the quickest drop in ferritin yet. Things eventually began to look up for me and I'm happy to say that now I feel quite normal. However, I'll never forget my early encounter with haemochromatosis.'

Thanks to Scott and the Australian Association for sharing this interesting story with us.

Photo Gallery



President Mary McAleese and the IHA chairperson, Margaret Mullett

Blood donors from across Ireland were welcomed by President Mary McAleese at a special reception in Dublin on 14th June 2008. More than 150 donors and recipients attended the Irish Blood Transfusion Service event at Áras an Uachtaráin, which was staged to mark World Blood Donor Day. They were joined by clinicians and representatives of the Irish Cancer Society, the Irish Heart Foundation, the Irish Kidney Association, the Northern Ireland Blood Service and the IHA.



Mairéad Lynch and Theresa O'Connor at AGM

FORTHCOMING EVENTS

EFAPH (European Federation of Associations of Patients with Haemochromatosis)

The forthcoming annual meeting of EIC (European Iron Club) will be held in St. Gallen (Switzerland) on September 17th -20th 2008.

On Saturday September 20th, the annual EFAPH meeting will take place.

Regional Meetings: To be arranged

A number of regional meetings will take place in the coming year. We would appreciate help in organising these information meetings. If you have any suggestions for venues or speakers please contact us at 01 873 5911 or email margaretmullett@ireland.com.

Details of meetings will be available at a later stage on the website.

National Ploughing Championships

The National Ploughing Championships 2008 will take place at Farnley, Cuffesgrange, Co Kilkenny from Tuesday 23rd to Thursday 25th September. It is expected that over 150,000 visitors will attend the show. This year Michael Campbell of Europlan Health and Safety will sponsor a stand for the IHA. Help with manning the stand would be greatly appreciated. Please contact margaretmullett@ireland.com or leave a message on the voice mail 01 873 5911.