



Welcome to the Spring Newsletter

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CHRISTEN MEGSON TELLS HER STORY IN THE DAILY MAIL

Freelance journalist Christen Megson from Devon blamed her desperate tiredness, aching joints and lack of energy on being a mum. She told her story in the UK edition of the Daily Mail on Tuesday March 6th 2012.

'This time last year, I had convinced myself that I was going to die. I would just let whatever was making me feel so ill take me away.

I have a wonderful family, three beautiful boys, a great job and a loving husband, but I didn't want to be around. Initially, I'd blamed the desperate tiredness, shooting abdominal pains, aching joints and lack of energy on being a busy working mum.

Anyway, as a freelance journalist, illness was not an option; I just had to get through it. I hid it well, but my husband Shaun watched me change. The fun-loving, enthusiastic woman he married had gone. Instead, he found himself with a forgetful, miserable, bumbling negative wife whom he said he didn't recognise.

He begged me to go to the doctor. 'Why?' I said. 'It's just tiredness, and they'll only tell me to rest — fat chance.'

One Sunday, when we'd had friends over for lunch and a good bottle of wine or two, I cracked. I finally said it: 'I think I've got cancer. After months of misery, the game was up, and out it all came in sobs.

Our next step was a visit to the GP. A battery of blood tests and scans followed — all clear. Then a second wave of bloods to investigate further — again all clear. It was a relief, but



something was still not right. Then she found it.

The phone call came while we were driving to London for a weekend — 'I've got something,' she said, and went on to explain I had raised levels of a protein called ferritin, which binds iron in the blood. High levels suggested I was storing too much iron in my body and one more test might confirm I had a genetic condition called haemochromatosis.

There it was, the first time I had heard the word, and the root cause of the imaginary deathbed scenario playing in my head all of this time. Hee-mo-chroma-tosis. My enemy had a name. It's a long word for a hereditary disorder that causes the body to retain iron and I was saturated with it. The body uses iron from food to make

haemoglobin, the red pigment in blood that transports oxygen round the body.

The treatment was painless and cheap. There is no way to remove iron from the body except via the blood — the body then starts to use some of the excess stored iron to make new red blood cells.

Every pint that's removed takes with it 200mg of iron and lowers ferritin levels by 25. As I had a ferritin count of 900, it was going to be a long haul. The blood-letting began; a pint every two weeks at first, to give the body time to adjust, but after the first two sessions I hit a physical low — I had become anaemic. My body was not re-making the lost blood fast enough, but after a rest from treatment and an adjustment to three-weekly visits, the programme was well underway.

As the months went by, I became acutely aware that I was getting better. I am now in the 'maintenance phase' and will need to give blood routinely for the rest of my life.

Instead of years of chronic disease or even premature death, I can look forward to a healthy old age. As for my family, Shaun has been tested and is clear, and my mother and siblings have been screened, too. I only hope that by the time my children are old enough to be tested, far more will be known about the effects of iron overload.'

Thanks to Christine and the Daily Mail for giving us permission to share her story with you.

HAEMOCHROMATOSIS IN A BRAZILIAN TAPIR AT AUSTRALIAN ZOO

Australian Veterinary Journal Volume 90, No 1-2, January /February 2012

The tapir is a large browsing mammal similar in shape to a pig with a short snout. Tapirs inhabit jungle and forest regions of south America, Central America and Southeast Asia.

Their closest relatives include horses and rhinoceroses. The four species of tapirs that have been identified are classified as endangered or vulnerable species.

Haemochromatosis causes excessive accumulation of haemosiderin in tissues. Increasing recognition of Haemochromatosis in horses and rhinoceroses led investigators to examine their closest relatives the tapirs, for evidence of abnormal iron accumulation. Lowland tapirs are excellent swimmers and divers, but also move quickly on land, even over rugged, mountainous terrain.

They have a life span of approximately 25 to 30 years. In the wild, their main predators are crocodiles and large cats such as the jaguar which often attack tapirs at night when they leave the water and sleep on the riverbank. They are known to run to water when scared.

A 23-year old female Brazilian



tapir held in a zoo on the east coast of Australia had shown loss of body condition over a period of approximately six months. The animal developed clinical signs and laboratory findings consistent with liver failure. When the animal was eventually euthanased a diagnosis of hepatic haemochromatosis was made based on hepatology.

Two other healthy Brazilian tapirs in the same collection were tested and

had chronically elevated serum and tissue iron concentrations. The tapirs were a 17-year old male and an 18-year old female.

Those findings suggest that haemochromatosis should be considered in the management of this species in zoos in Australia and elsewhere.

ANNUAL GENERAL MEETING SATURDAY MAY 26th 2012

The meeting will take place at the Irish Blood Transfusion Service, St James's Hospital, Dublin 8 on Saturday May 26th 2012. The IHA would like to thank the IBTS for again making the centre available to us and for generously sponsoring coffee and lunch. Family and friends are welcome. Coffee will be available from 10.30am. A brief business meeting will commence at 11.15am and will be followed by guest speakers Professor Suzanne Norris, Consultant Hepatologist at St James's Hospital and Michelle O Doherty who will speak from the patient's perspective. Dr Willie Murphy will give an update on the progress

that the IBTS has made with regard to the proposed walk-in clinics for Haemochromatosis patients.

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.

FLORA WOMEN'S MINI MARATHON IN DUBLIN, BANK HOLIDAY MONDAY, JUNE 4th 2012



We urge all members to persuade friends, family and colleagues to run, jog or walk the 10K route for a great day out.

Sponsorship cards and T shirts are available from Margaret Mullett on 01 4922705 or email margaretmullett@ireland.com

BLOOD TESTS AND VENESECTION

(as reported in the Australian Society Newsletter)

Regular blood tests during venesection therapy for haemochromatosis are vital. They enable you and your doctor to monitor the effectiveness of the treatment, decide when you have reached your treatment goals and ensure you do not become anaemic during treatment. Ironically, it is possible to become iron deficient during treatment. It is important that you are aware of what these tests mean and discuss your results with your doctor. The three indicators measured during treatment are serum ferritin, transferrin saturation and haemoglobin.

The aim of venesections is to reduce serum ferritin to 50µg/l and to maintain it between 50 to 100µg/l, with a normal haemoglobin level. Your doctor will take blood samples and request tests for 'iron studies' which measure the serum ferritin and transferrin saturation level. The other indicator tested is haemoglobin.

If possible, it is a good idea to have the samples taken at the same time as venesection is performed, to limit the number of needle punctures you have to endure, particularly when you are being venesected frequently.

It is not always possible though. For instance the Australian Red Cross Blood Service does not include 'iron studies' blood tests when performing therapeutic blood donations but they will measure your haemoglobin before every donation.

Serum Ferritin (SF)

The serum ferritin level reflects body iron stores. It is measured in micrograms (µg) per litre (l or sometimes shown as capital L). When a person has iron overload, the serum ferritin levels can range from 300µg/l to 10,000µg/l. It is recommended to initially reduce the level to 50µg/l by frequent venesection and then to maintain the level around 50 to 100µg/l. Measurement of serum ferritin is useful at the start of treatment to help as a guide as iron is mobilised. The tests may go up or down from one venesection to the next, for a number of reasons, but after regular venesections the level will gradually fall. Individuals with very high levels will take a long time to reduce their levels. Do not be concerned by this, as



over a six month period there will be a reduction.

We recommend monthly or two monthly testing of serum ferritin during iron unloading treatment. When the levels approach 100 µg/l tests after each venesection will help you get close to your target.

Transferrin Saturation (TS)

Transferrin Saturation is a medical laboratory ratio expressed as a percentage. It is the ratio of serum iron divided by total iron binding capacity multiplied by 100. The measurement reflects iron mobilisation from storage to utilisation. Transferrin Saturation is very important in the diagnosis of haemochromatosis. However, once the diagnosis has been made and venesections started, this test ceases to be of importance except to your doctor.

As a general goal, keep the saturation below 45%. The test must be performed after fasting. Your Transferrin saturation may also be elevated for other health reasons.

Haemoglobin (HB)

It contains iron which acts as a magnet for oxygen which is then transported to the cells and tissues around the body. The concentration of haemoglobin in the blood is measured in grams per litre (g/l). The haemoglobin level is probably the single most useful test during venesection therapy and should be taken either before or after treatment. The range should be maintained between 110 g/l and 160 g/l. Below 110 g/l tiredness and weakness will be experienced. When starting

venesections haemoglobin can be used to monitor your progress with every venesection. It can be a guide to alert your doctor that iron is falling too rapidly.

Setting and monitoring goals

Your doctor will set goals and guidelines for venesection with you. If the haemoglobin blood tests are too low then signs and symptoms of anaemia will occur. It is important that you keep your doctor informed about how you feel and that your doctor listens to you. If you experience any problems contact your doctor. If you feel unusually tired after venesection then the frequency of venesection may need to be reduced.

A serum ferritin level of 20 – 50µg/l signals the end stage of treatment. The goal is then to keep the range between 50 to 100µg/l with normal haemoglobin level.

Maintenance

Regular maintenance venesection therapy should continue life-long. In follow-up sessions blood tests can be done in three months' time to check haemoglobin and serum ferritin. The combination of results will act as a guide and together with how you feel will indicate when the next venesection should be performed. Remember it takes a long time for iron to accumulate but there are always exceptions. Your maintenance venesection therapy will be assessed and venesection may only be required every two, three or six months on a regular basis for the rest of your life.

Further information can be found at:
www.haemochromatosis.org.au/

ADDITIONAL INFORMATION

- Awareness Day**
 We would like to thank all the members who have already volunteered to help with the Awareness Day on Thursday May 31st. A list of the venues will be posted on the web-site. If you find that you can help, please contact us by emailing: kategeog@gmail.com or leave a message on the answering machine (01) 8735911. We will need well over a hundred volunteers to cover all the shopping centres and would greatly appreciate your help. If you have any media contacts or if you would be happy to do a radio or TV interview, please let us know.
- A member of the UK Society**
 mentioned in the newsletter, that she was seen by the Dermatology (skin) clinic because of a persistent itchy skin. She is happy to report that it disappeared after using a prescribed cream called "Xepon" half a dozen times.
- 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. Sending you a text or email is the quickest and cheapest way for us to contact you.
- Sincerest thanks to all the members who renewed their membership and gave generous donations.
- Remember to check the IHA web-site to find out if there are any meetings of interest to you.
www.haemochromatosis-ir.com

REGIONAL INFORMATION MEETINGS

Wexford, November 15th 2011

A very informative and well attended meeting took place at White's Hotel, Wexford. The speaker was Dr Colm Quigley, FRCPI, Medical Director Wexford General Hospital. Dr Quigley succeeded in simplifying a very complex topic and discussed the various issues that concerned the patients. Those who attended were delighted to have their many questions answered by an expert.

Athlone, Co Westmeath, February 22nd 2012

The meeting took place at the Sheraton Athlone Hotel and the speaker was Dr Gerard Clarke, MRCPI, FRCPI, Consultant Gastroenterologist, Portiuncula Hospital, Ballinasloe, Co Galway.

One 120 people, including former Minister Mary O'Rourke, attended the meeting. Dr Clarke's excellent presentation was followed by a very informative question and answer session.

Achill, Co Mayo, February 29th 2012

The speaker was Dr Luke O'Donnell,

FRCPI, Consultant Physician, Mayo General Hospital. This great meeting was organised by Dr Edward King, Nurse Margaret Mc Fadden, and the team at Pollagh Surgery, Achill, Co Mayo. There was an incredible turnout as over a hundred people attended the meeting. Dr O'Donnell gave an excellent PowerPoint presentation. Dr King chaired the meeting and with Dr O'Donnell answered the many relevant questions. The practice kindly provided tea and coffee and this gave people an added opportunity to mingle and ask the doctors questions of a more personal nature. Everyone expressed their appreciation and felt that they had benefited greatly from the evening.

Tullamore, March 26th 2012. The Speaker; Dr Gerard Crotty FRCPI. Venue is the Tullamore Court Hotel. Full report in the next news letter.

The Irish Haemochromatosis Association would like to congratulate Margaret and the team on a most successful meeting.



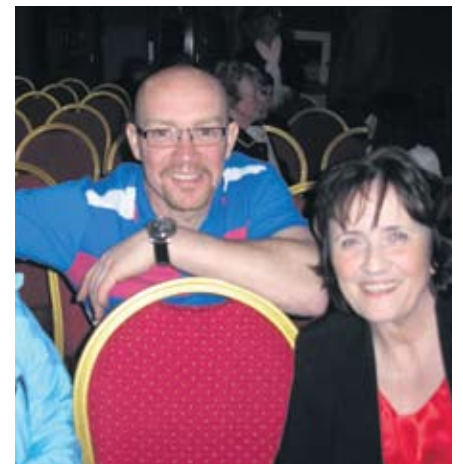
Pictured at the Achill meeting are: Dr Edward King, Margaret McFadden, Dr Luke O'Donnell, Dr Paddy Lineen



Pictured at the Athlone meeting are: Mary O'Rourke with Dr Clarke and Martin Monaghan.



Margo McNamara and Joan Western who attended the Achill meeting.



Michael O'Malley and Bridget Corrigan at the Achill meeting.

Disclaimer: The IHA believes the information in the newsletter 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.