



## Welcome to the Winter Newsletter 2010

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*The IHA would like wish everyone a Happy Christmas and a peaceful New Year.*



### MEETING WITH MINISTER MARY HARNEY WEDNESDAY 17<sup>TH</sup> NOVEMBER 2010



*Professor Suzanne Norris, Margaret Mullett, Minister Mary Harney and Frank O'Meara at Leinster House on Wednesday 17<sup>th</sup> November.*

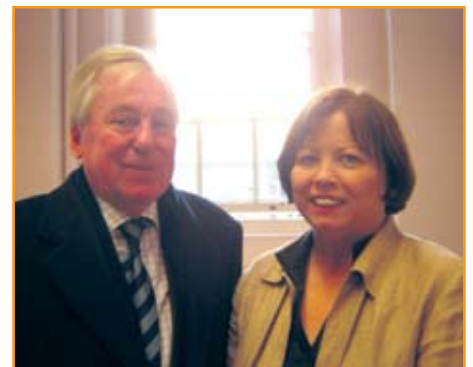
Minister Mary Harney met with Professor Suzanne Norris, Maurice Manning, Frank O'Meara and Margaret Mullett at Leinster House on Wednesday 17<sup>th</sup> November. On the agenda were some of the recommendations from the working party report of 2006 that the IHA felt should be revisited:

Funding must be prioritised to develop a Haemochromatosis Screening

programme. Information from this programme will provide essential guidance to policy makers in structuring a countrywide programme for HH service development.

The cost of venesection and the fact that timely access to treatment nationally is not universal is a matter of very serious concern to the IHA and seriously needs to be addressed. The HSE should set out a policy endorsing a framework for management of all aspects of Haemochromatosis.

On going mainstream funding should be provided through the HSE to the IHA to allow it to appoint an executive assistant and clerical support. Minister Harney's response was very encouraging. She is very aware of the importance of early diagnosis and treatment. Hopefully there will be a positive outcome from the meeting.



*Maurice Manning and Minister Mary Harney.*

### AN IMPORTANT MESSAGE FROM THE IRISH BLOOD TRANSFUSION SERVICE

Dr. Easen Naidoo has written to the IHA.

"Plans for a HH Clinic at the National Blood Centre (NBC) St James's Hospital, Dublin are underway. It is planned to run this Haemochromatosis clinic on a walk-in basis i.e. no referral would be required and probably no appointments. All patients must be fully 'worked up' by their GP's and have seen a consultant.

The IBTS is looking to recruit patients from all over the country. They have chosen the NBC as the clinic site because it is quite easily accessible, especially with the Luas right on its doorstep. Haemochromatosis patients can then present to the clinic; Monday to Friday from 8am to 3pm; and a unit of blood will be taken off them. None of the units collected will be used for transfusion purposes. However, these patients will be given the option to become donors. If they agree to become donors then they will be

assessed and will be referred to the next clinic that's in their region.

We plan to staff this clinic with at least 1 doctor, 2 nurses and a registration clerk. Staffing as well as the size of room and products required will all depend on the number of patients that attend the clinic.

To assist the IBTS in having a better understanding of the number of patients that would attend the clinic and consequent resource requirements, the IBTS is carrying out a survey and Dr Naidoo has asked the IHA to enclose a questionnaire, which he would like you to return to him as soon as possible.

This project is still in the very early planning phase but it is hoped to start the clinic very early on in the New Year. It is envisaged that if this walk-in Haemochromatosis clinic is successful, further walk-in clinics will be run in other venues".

Dr Easen Naidoo can be contacted at: haemochromatosis@ibts.ie

## EFAPH MEETING IN NIJMEGEN, HOLLAND SEPT 18TH 2010

The AGM of the European Federation of Associations of Patients with Haemochromatosis took place this year in Holland. The meeting was held in conjunction with the European Iron Club and delegates to EFAPH were invited to attend that meeting also. Margaret Mullett represented the IHA. One of the great advantages of membership of EFAPH and of the meeting is the exchange of information and the comparison of treatment and protocol in the various member countries. The delegates

gave an account of the procedures in their country and discussed the recommendations that they would like to see implemented. It was decided to have an Awareness Day in June 2011 and various activities for that day were considered. At the meeting it was agreed that the annual membership subscription for the IHA would be €200.

A survey on the cost of venesection showed that venesection is free in Spain, Portugal, Germany, Hungary and the UK. In Norway, France and

Belgium the cost is far less than in Ireland. In France venesection may take place in a hospital or blood centre but sometimes takes place in a mobile nursing unit or in a nursing centre. In Spain the treatment is always in a day hospital.

We are grateful to one of the French delegates, Brigitte Pineau, who has written her very interesting story for this newsletter.

Dr Maya Sanchez, a delegate from Spain sent us the paper on screening in Spanish blood donors.

## Brigitte - A FRENCH HAEMOCHROMATOSIS PATIENT

A mere household accident saved my life and that of my sister in 1991. I happened to break my foot cleaning the balcony in our Parisian apartment and ended up on sick leave for two months with a plaster up to the knee. This enforced break in my working life allowed me to realise I was abnormally exhausted for someone resting in a reclining chair most of the day! The plaster off, I visited a friend of mine who is a dermatologist, and complained about feeling tired. She was sure my exhaustion was due to an iron deficiency and prescribed a ferritin test before treating the disorder. Quite unexpectedly the blood test revealed a 600 ng/ml ferritin level. A second blood test confirmed the iron overload two weeks later.

I was referred to a haematologist and in 2 months the diagnosis was made: a liver MRI along with a liver biopsy revealed I was affected with Hepatitis C and Hemochromatosis. The genetic test was done in 1997 and showed I was affected with the double mutation of the C282Y gene. My parents both carry one gene and my sister and I carry the double mutation.

I was 37 when the diagnosis was made, married with two children aged 11 and 13. I had never heard about Hemochromatosis and I really thought my days were numbered. My parents got in touch with the French Hemochromatosis Association and they sent us information that proved a great help. That's how I gradually learnt about the disease and understood that if treated at an early stage, I would have a normal life expectancy.

Treatment was started soon after diagnosis: a 400 ml phlebotomy once



a week for eight weeks until my levels were normal. I still remember how tired I felt after each phlebotomy, I needed a two-hour rest in the afternoon the first two weeks. As time went by I felt so weak and dizzy that I had to stop working for a while. Twenty years ago, 400ml of blood was removed from females no matter how much they weighed. I now feel comfortable with 300ml phlebotomies twice a year (I weigh 44 kgs). Looking back, I think that my tanned complexion all year round had surprised a lot of people. When I gave birth in 1980, though I had spent the previous six months in bed because of the pregnancy, I looked so tanned that the hospital staff asked me if I was

back from a holiday in the sun! I first experienced the symptoms of Hemochromatosis in my early thirties. Chronic fatigue was the first of them. I felt really exhausted at the end of the day and my husband resented my going to bed early, thinking my sleeping was a way to get away from him. That could have been grounds for divorce! However, once the diagnosis was made, he learned how to adjust to my sleeping needs and stopped complaining.

Joint pains started very early. I remember not being able to get up in the morning one day, as my knee could not support me. It looked a bit swollen as if I were suffering from gout, although I am very thin. Our GP, at a loss for a diagnosis, gave me a shot that helped the knee to get back to normal within a few hours.

Aged 57, today my knees are badly damaged all the more since I have never spared them, being a good skier. The injections are given once a year to repair cartilage and they prove quite beneficial. The injection is rather painful but it is well worth it, as long as you happen to respond to the treatment. It is a luxury as the gel costs €267 euros a shot.

I have a very healthy diet and life style. I refrain from eating red meat; I drink a lot of tea and never have a glass of wine. I no longer do physically taxing sports. I go to the swimming pool at least once a week. I also exercise in a group under guidance once a week. I sing which adds to the physical activity and helps to calm me down when I feel stressed out. I would say I was born under a lucky star as that household accident in 1991 really saved my life and that of my sister.'

# BEETROOT IS BACK IN FASHION

Michael Rose

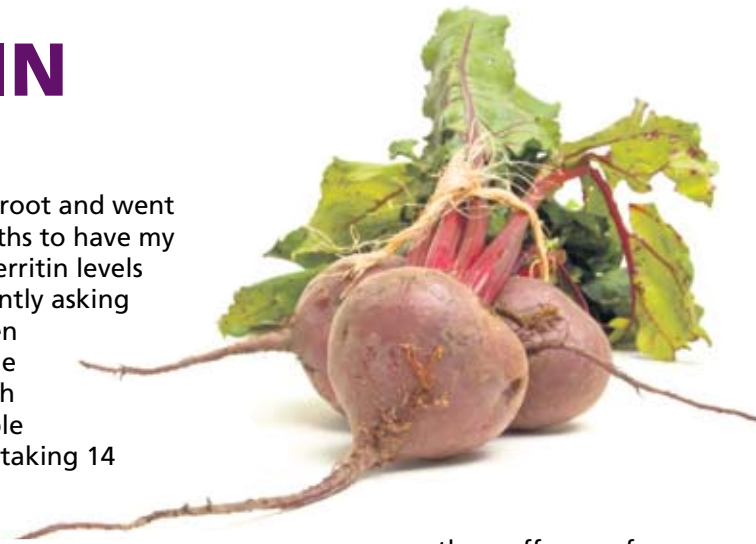
Michael Rose who is a member of the IHA has written to the Association telling us that in his case beetroot seems to be the answer to his high ferritin levels.

'During the early part of 1998 when I began to admit to feeling really ill (tired, heavy-limbed, upset stomach, lack of energy, headaches etc). I saw my G.P. who felt I was malingering with 'man flu' but referred me to a hospital where it was thought that I was a carrier of the Haemochromatosis gene. By chance, later that year, a friend mentioned a clinic she knew of in Moscow and arranged for me to visit. It was there that I was finally diagnosed as having the two genes for haemochromatosis. Incidentally, the gene for haemochromatosis was only discovered in 1996!

By now my stomach was so upset that the Gastroenterologist suggested that I be given Beetroot with my meals – even with my breakfast scrambled egg! This is a long established practice in Russia for intestinal disorders. The medical team on my case discovered that I had also contracted chronic pancreatitis and Type 2 Diabetes. On my return to Ireland in 2000, I

forgot about the beetroot and went regularly every 3 months to have my blood taken and my ferritin levels checked. I was constantly asking that my blood be taken more often to keep the readings at a level with which I felt comfortable – below 50. I was also taking 14 tablets of Creon per day for the pancreatitis along with numerous other medicines. Then, early last year (2009) I remembered the Beetroot! With nothing to lose I began to eat two or three slices (from the ordinary supermarket jar) every other day with my evening meal, i.e. 3 or 4 times a week. I have not needed to have my blood taken for 18 months. Each time I go for my appointment my levels are normal. I have also reduced my Creon from 14 to 4 tablets per day and I feel great. My diabetes is still there but my sugar levels are much more under control and I find my daily routine far less arduous. I cannot say that Beetroot is a miracle cure but I CAN say that it works for me.

Perhaps it could do the same for



many other sufferers of Haemochromatosis and Diabetes, particularly as beetroot has a high sugar content, but is released in a controlled manner, thereby balancing the body's blood sugar levels more effectively. According to a study at Queen Mary University of London, patients who drank a glass of beetroot juice a day had significantly lower blood pressure. In the UK sales of beetroot have leapt by over 10% in the last year.

Beetroot has many health benefits. It is one of the richest sources of folic acid and has high levels of important minerals as well as vitamins A, B6 and C and also powerful antioxidants.

Michael can be contacted by email: [ricola148@hotmail.com](mailto:ricola148@hotmail.com)

## MICHAEL O'CALLAGHAN

Michael has lived most of his life in Kerry. He was unaware that he had Haemochromatosis until he moved to Brussels when he was twenty-one. A routine check-up at that time showed his ferritin level was 1104mg. He immediately started Venesection to bring the iron levels under control.

Since then Michael has had over 25 venesections and now has his iron levels under control. He regularly visits his doctor in Limerick to check his iron levels and to ensure all is well. Overall the condition has not directly impacted on his lifestyle as he was lucky to have detected the condition early on. On testing, it was found that three other members of Michael's family also had the genotype. All of them are now being treated and are living their lives aware of the condition.

## A SPECIAL THANKS TO "THE WEB GUYS" MICHAEL O'CALLAGHAN AND EOIN O'SULLIVAN



On the left Michael O'Callaghan and Eoin O' Sullivan

IDEABUBBLE is the Web Development Company owned by Michael O'Callaghan and Eoin O' Sullivan. They are based in Mallow Street, Limerick and are both passionate about the Web and Technology. IDEABUBBLE donated its own

Website Content Management System to the IHA. This gives us more day to day control over our Website. They also donated the domain [ironoverload.ie](http://ironoverload.ie) as an accelerator domain to help people with the condition find the IHA easily!

Since the re-launch the site has gained a firm top position in Google and with the Search Engine Optimisation Boost package they completed on the new site the IHA has now already five times more visitors to its site (Sept 10<sup>th</sup> = 232 Visitors, Oct 10<sup>th</sup> = 1153 Visitors). The IHA greatly appreciates the time, advice and expertise given to us by IDEABUBBLE on a completely free and voluntary basis.

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## POPULATION SCREENING FOR HAEMOCHROMATOSIS - A STUDY IN 5370 SPANISH BLOOD DONORS

In 2003, Dr Maya Sanchez and a group of Spanish Researchers at the University of Barcelona screened 5370 donors (3467 men and 1903 women) for the C282Y and H63 D mutations. Serum iron, Serum ferritin and transferrin saturation were also measured. The results showed that eight blood donors (five men and three women) were homozygous for C282Y and 74 were compound heterozygotes (C282Y / H63 D). Four out of the eight C282Y homozygotes, all men had high serum ferritin and transferrin saturation. Only one of the compound heterozygotes showed elevated serum ferritin and transferrin saturation values.

### Conclusion;

The C282Y/C282Y in Spain is 1 in 1004 and this is clearly associated with an increase in iron parameters. Biochemical expression was found in 80% of the C282Y/C282Y men. Only one of the C282Y/H63 D compound heterozygotes showed elevated serum ferritin and transferrin saturation values. The results of this study have been published in the Journal of Hepatology (3892003) 745-750.

## UPCOMING REGIONAL MEETINGS

Limerick - Tuesday 30th November  
Kilmurry Lodge Hotel 8.15pm

Speaker: Dr Denis O Keeffe

Mayo General Hospital Castlebar  
Tuesday 7th Dec

Speaker: Dr Luke O Donnell

Waterford - Tuesday 18th January  
2011

Speakers: Dr Brian Hennessey and Dr Sean Nugent

Galway - Monday 14th March 2011

Speaker: Dr Valerie Byrnes

For further details, please see our website.

## AWARENESS DAY THURSDAY JUNE 2ND 2011

Our first Awareness Day last June was a great success. This year we hope to do even better and to extend the number of centres involved. We need your help. Please let us know as soon as possible if you are willing to be involved. Phone 018735911 or email: [margaretmullett@ireland.com](mailto:margaretmullett@ireland.com) The IHA is still being run on a totally voluntary basis and without your help it would be impossible to organise the event.

## THE PLOUGHING CHAMPIONSHIP IN ATHY SEPT 21-23

Thanks to all the helpers and friends who manned the stand and administered the survey that we conducted. Once again we felt that our attendance was very worthwhile despite the fact that the weather presented more of a challenge than in previous years.



Jim Browne and Ann Mc Garry at the Ploughing Championship.



Liz O Callaghan at the Ploughing Championship.

## CLONMEL MEETING TUESDAY 26TH NOVEMBER 2010



Dr. Clare O'Leary spoke at the Clonmel meeting



Nurse Evelyn McGrath and Nurse Breda Foley

The meeting held at South Tipperary Hospital was a great success. A comprehensive overview of the diagnosis and treatment of Haemochromatosis was given by three Consultant Physicians from the hospital: Dr Paud O'Regan, Dr Clare O'Leary and Dr Sam Kingston. The informative talks were followed by

a lively question and answer session. Dr O'Leary asked the members to fill in a survey on the different symptoms that HH sufferers present with. One young member said that she knew when she needed to give blood as she found herself getting very angry. Seemingly so did her father who also has HH!

## Dr Catriona Power (nee Little)

The untimely death of Dr Catriona Power took place on 12th July 2010. Catriona was a well known Gastroenterologist in Galway. She suffered from the debilitating symptoms of haemochromatosis for years before she was diagnosed, largely as a result of her own detective work. In a bid to help others avoid the

potential tragedy of developing the sometimes irreversible consequences of undiagnosed haemochromatosis, Gwenda and Catriona started the association in 1995. At this time very little was known about the disorder and their work was a great help in raising awareness. Sincerest sympathy from the IHA to her family on their tragic loss.

## DONATIONS

Thanks to Diageo for their very generous donation of €1000 to the IHA.

## RENEWAL OF SUBSCRIPTION

Membership renewal forms are enclosed with this newsletter. Please complete and return to Brendan Keenan. Your ongoing support through the annual subscription is greatly appreciated and is one of the main sources of income for the Association. If you no longer wish to be included in our mailing list, we would appreciate it if you would let us know as the cost of posting and printing is high. If your email address has changed or if you would prefer to receive the newsletter by email please let us know by emailing Kate: [kategeog@gmail.com](mailto:kategeog@gmail.com)