

SPECIAL POINTS OF INTEREST:

- The Society continues to go from strength-to-strength with its first Regional Support Group
- Regional Support Groups aim to raise awareness of B12 deficiency and Pernicious Anaemia
- Contact Carrie-Anne directly for information

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New Surrey Support Group Set Up

The PA Society continues to go from strength-to-strength and the next stage in its evolution is taking place with the birth of its first Regional Support Group in Surrey, U.K.

Group organiser Carrie-Anne Carr explains; "I have set up the Support Group to provide a forum that will bring together those who are suffering with B12 deficiency or PA, and who wish to share their experiences with each other.

"I was diagnosed with PA after years of tests and on the strength of what I had read about it I

was able to help my mother, my two daughters, a friend and two other members of her family get diagnosed with PA/B12 deficiency.



Carrie-Anne of the newly formed Surrey Support Group

We have been lucky enough to have each other in order to share our experiences and it helps to realise that you

are not alone in this uphill struggle to get diagnosed and then receive the correct treatment for a decent quality of life.

"My aim is to raise awareness of B12 deficiency so that others can hopefully benefit from it and help stop needless suffering.

"I look forward to hearing from anyone local wishing to join."

Carrie-Anne can be contacted on:-
carrie@pasoc.org.uk
 07506 430030
Surrey Support Group for B12 deficiency & PA Sufferers

Membership Fee

The last year has seen a great increase in the number of members joining the Society. With our membership growing so quickly and the demands on our services being stretched, it has been decided to charge all new members a one-off lifetime membership fee.

Martyn Hooper, Chair of the Society, says "Our



membership continues to increase rapidly and the demands for our services are now so great that we need a reliable source of funding to continue to provide our services. We now have to make a very modest charge to become a member.

"As of April 2009, all new members have been charged £15—the fee being based on the amount we receive in voluntary subscriptions by paper members".

The new £15 fee will enable the society to update its website, publish information booklets, cover postage costs and volunteer expenses.

Existing members will not be charged but are encouraged to make a donation.



Other research proposals will study the efficacy of current treatments

“...symptom relief appears to happen fairly quickly afterwards”

Research Proposals

The Society's Constitution clearly states that one of the Objects of the Society is to “promote research into the causes and treatment of Pernicious Anaemia, and into the implications of Pernicious Anaemia on other medical conditions, for the public benefit.”

The Society has submitted several research proposals to organisations such as the National Institute for

Health Research and the Big Lottery Research Fund.

These proposals include one for the Transcobalamin II receptor, which would allow doctors to find out why some patients need more frequent injections than others, and another for the development of a more robust and accurate diagnostic tool for the condition. Yet another concentrates on

Juvenile Pernicious Anaemia.

Other research proposals will study the efficacy of current treatments and also attempt to find a cure for Pernicious Anaemia. The Society has also been actively encouraging its members to participate in the *Genetics of Pernicious Anaemia* research study via the Regional Genetic Service in Manchester. Please contact us if you would like to take part in this important research.

Methylcobalamin Infusions

The Society has recently been made aware of the fact that there are several private doctors who practice ‘ecological medicine’ within the UK who are able to offer patients methylcobalamin infusions.

These infusions are given intravenously along with other vitamins and trace elements. The entire process takes between one

and two hours to complete as almost two pints of the liquid infusion is injected into a vein and symptom relief appears to happen fairly quickly afterwards—often with spectacular results!

These doctors are also able to provide sufferers with injectable methylcobalamin for sub-cutaneous use. The

usually prescribed Hydroxocobalamin is not licensed for sub-cutaneous use.

Members of the Society who are interested in this form of treatment are encouraged to find a local practitioner by searching the British Society for Ecological Medicine website www.ecomed.org.uk/practitioners Or contact us for more information.

Meet The Volunteers

Since securing rented offices in September 2008, the Society has been able to utilize the skills and services of local volunteers.

Anna Trzyna (Membership), Bethan Arrowsmith (Admin.), Abigail Torres (Accounts), and most recently Fiona Black-

well (Grants Administrator) have all become instrumental in the day-to-day running of the PAS office and are finding the work enormously beneficial. Anna, who is originally from Poland says, “I like my job. It is very useful. It is a great way to gain experience in administra-

tion. It allows me to improve my English as well as my I.T. skills”.

If you would also like to find out about volunteering with the PAS then please contact the Society.

01656 724163



Left to Right,; Bethan, Fiona and Anna.

Juvenile Pernicious Anaemia

It used to be known as 'the old ladies disease' but it is now obvious that Pernicious Anaemia affects people of all ages with the majority of diagnosis being made on patients aged 35 – 45.

Adults can, usually, make amendments and alterations to their lifestyles in order to best manage their condition - but spare a thought for our younger members and fellow sufferers who have to battle with a strict, rigid and structured school day.

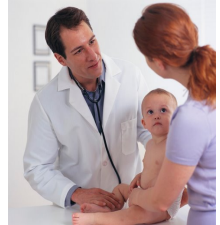
"We are getting more and more requests for information and support from family members who are related to young people who have been diagnosed with Juvenile Pernicious Anaemia" says The Pernicious Anaemia Society's Chairman Martyn Hooper.

"On two occasions we have had to provide an advocacy service on behalf of the child, because he or she struggles to cope with the school day – especially in the afternoons.

Unfortunately, most people in education are not aware that patients can still be symptomatic even after treatment has started and this leads to children being labelled as having Behavioural Problems."

The society is seeking to remedy this problem by raising awareness of this issue by using posters and school visits. A grant has been applied for to this end.

Our youngest member with Pernicious Anaemia is 18 months.



Easy Fundraising.org

If you already shop online, you will now be able to help the Society at no extra cost to yourself through purchases you would make anyway, simply by signing up to the EasyFundraising.org website www.easyfundraising.org.uk

By using the links from 600+ Brand Name retailers on the

EasyFundraising website, each purchase you make will generate a cash-back donation to the Society. You will find the Pernicious Anaemia Society on the list of charities registered there.

The service is easy to use and is completely free to

join.

Please register now and show your support by remembering to use the EasyFundraising the next time you buy online!

"Up to 15% of every purchase is donated, depending on which retailer you select and what you buy"

Flora London Marathon 2009

As readers of the last Cobalamin News will be aware, Pernicious Anaemia sufferer and PAS member, Chrissy Bladen, had been training hard for the Flora London Marathon 2009 and was due to participate on behalf of the Society on Sunday 26th April.

Chrissy, who is an under-

graduate research assistant at Southampton University had been diagnosed with Pernicious Anaemia in 2008 and has already competed in several 10K races and Half-Marathons.

Unfortunately due to an administrative error on behalf of the Flora London Mara-

thon team, Chrissy was not allocated a place on this occasion but will be able to participate in 2010's Virgin London Marathon instead.

Our sincerest apologies go to Chrissy and again, our thanks for all of the training and hard work already undertaken.

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We want to hear from you.

Please help us to produce the next edition of this newsletter. With our membership growing by between 15 & 20 a day, more and more people are turning to the society for information, help and support.



We want to get you, our readers, involved so that

the stories that appear here are about issues that interest or affect you. Please contact the editor by email: **bethan@pasoc.org.uk** or by writing to the address opposite. We are also aware that things are happening outside the U.K. and so any contributions from members outside the U.K. would be particularly welcome.

DIARY DATES:

March 27th "Year of B₁₂ Awareness" launched

June 5th & 6th BAVO Volunteer Information Day (Bridgend town centre)

September 23rd "Vitamin B₁₂ Awareness Day"

October will be B₁₂ Awareness Month

October 26th-30th will be B₁₂ Awareness Week

December 5th Annual General Meeting (Birmingham)

Thomas Henry Simpson, The Man By Ian McLean, San Francisco, U.S.A.

Last issue it was explained how the Thomas Henry Simpson Memorial Institute for Medical Research at the University of Michigan was formally dedicated in February 1927 to the study of pernicious anaemia, the alleviation of the suffering of persons afflicted with that disease, and the discovery of a cure for same. But, who was this man, Thomas Henry Simpson, who died of pernicious anaemia in 1923 at the age of 64 and whose wife, Christine McDonald Simpson (based on his wishes) donated \$400,000 to the University to establish the Institute?

Tom Simpson was born (1859) and raised in the small town of McConnelville, Ohio. His family, which was of limited means, also included his father (Thomas William Simpson), his mother (Kate Love Simpson), and an older brother (John Love Simpson). He attended local public schools (government-financed). As a young man he worked in a local foundry but at about age 21 moved to Detroit, Michigan to seek and earn a fortune in the malleable iron industry.

Tom Simpson was a master of business and organization starting a number of businesses in Detroit during his career. He was also very active in civic affairs.

He never forgot his home town and the people there. A generous man, he sent



Thomas Henry Simpson

candy each Christmas to all the children of McConnelville, donated memorial statues to the fallen of McConnelville

from the Civil War and World War I, and willed the Simpson family home in McConnelville to serve as the Kate Love Simpson Morgan County Library in honor of his mother. He also willed \$175,000 to be divided among 88 employees of the Michigan Malleable Iron Company which he owned and managed.

In 1898, Thomas Henry Simpson married Christine McDonald. They loved to travel worldwide. He lived out the remainder of his life with her until his death from pernicious anaemia at their home in Detroit. As evidence of the standing he had achieved in malleable iron industry and in the civic affairs of Detroit, those serving as honorary pall bearers included, among many other notables, Henry and Edsel Ford.

Thomas Henry Simpson was a remarkable and generous man. Next installment ...Christine McDonald Simpson, the woman.