

## SPECIAL POINTS OF INTEREST:

- The culmination of three years of research and patient experience has been published by the Society.
- A milestone in that it concentrates on issues from the patient's viewpoint
- The result of research conducted by the Society's Management Council which can now be downloaded

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# Groundbreaking Review

The culmination of three years research and patient experiences has been published by the society.

The Review is just that – a review and summing up of all we have discovered and know about Pernicious Anaemia. Some of this information is unknown to doctors and other medical professionals and those who are aware of it are genuinely surprised at our findings.

The Review is another milestone as it is the only publication of its kind that concentrates on the Symptoms, Diagnosis and Treatment of Pernicious Anaemia from the patient's viewpoint. In this respect it is every bit as im-

portant as the scientific explanations of the disease.

The review was the result of research conducted by members of the society's Management Council from the U.K, as well as internationally, and has taken a year to compile.

It also drew on the results of our online polls and online



focus groups that have been held. Some of the more interesting facts to emerge include:

- In the 1960s in the

U.K. the routine treatment was monthly injections. This was changed to three-monthly in the 1980s.

- A Research Institute was established in the 1920s in Michigan U.S.A. with the specific remit to find a cure for Pernicious Anaemia.
- There is no single test to accurately diagnose Pernicious Anaemia.
- A new, more accurate and patient centred list of symptoms has been produced.

A downloadable copy of the Review will be available on the website after March 27th or hard copies can be obtained by contacting us.

## Volunteers

The Society was able to secure rented offices during the autumn of 2008 in a converted Fire Station just outside Bridgend, South Wales.

This has meant that for the first time, PAS has been able to recruit a number of part-time volunteers to aid with administration, accounts, funding, and membership duties.



Alex Critchlow, Membership Secretary says, "It's a win-win situation. The volunteers develop their existing skills, learn new skills and gain valuable experience. Whilst the society benefits from their abilities and enthusiasm, it helps us to meet the needs of our ever growing membership base."

All volunteers are recruited through BAVO (Bridgend Association of Voluntary Organisations) and are able to attend training courses in order to enhance their skills and knowledge.

The team are proving to be invaluable to the Society and as a direct result of their efforts, it has allowed the Society to hold its first Seminar & Social Event (*please see overleaf*)

## Spring 2009 Seminar & Social Event

On Saturday 21st February of this year, the Society held its first Seminar & Social Event at Bryngarw House, Bridgend.

The event was attended by local members and presentations were given by Consultant Haematologist Dr. Vinod Devalia ("The Difficulties in Diagnosing Pernicious Anaemia"), GP Dr. Joseph Chandy ("B12

Deficiency With Neuro-Psychiatric Symptoms") and the Society's Chairman, Martyn Hooper ("A Review of the Symptoms, Diagnosis & Treatment of Pernicious Anaemia").

Specialist Registrar & Research Fellow, Dr. Siddharth Banka was also in attendance and gave a short update on his genetics research.

The event was considered a great success by all who attended and members were able to receive a wealth of information about the condition and gain encouragement and support from fellow sufferers.

It is hoped that in the future the Society will be able to hold similar events nationally. If you would like to help with this then please contact the Society.



It is hoped that similar events will be held nationally in the future.

*"Spring into Awareness on March 27th, then Fall into action by September 23rd"*

## Year of B12 Awareness

March 2009 sees the launch of a "Year of B12 awareness", with the last week in September being declared "Vitamin B12 Awareness Week".

Sally Pacholok, R.N and Jeffrey Stuart, D.O are spearheading a national effort in the U.S.A. to alert the public to the dangers of vitamin B12 deficiency, and it is hoped that the Perni-

cious Anaemia Society will play a part in raising a similar level of awareness in the UK. B12 deficiency is a worldwide problem and can be considered a hidden epidemic.

The campaign is due to begin on March 27th and the Society intends to make its Review (*see front page*) available for download on that date.

The Society also plans to hold a demonstration in London during the fourth week of September. More details will be available on the website nearer the time and in the next issue of this newsletter.

If you would like to take part or help in anyway to raise awareness then please do get in touch with us.

## Invitation to Participate in Research Study

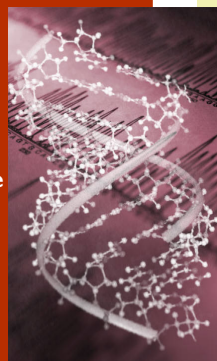
The Regional Genetic Service at St. Mary's Hospital in Manchester, are undertaking a study on the Genetics of Pernicious Anaemia and are looking for participants with a family history of Pernicious Anaemia to

take part.

It is hoped that the genetic test may help to identify the genes important in Pernicious Anaemia and therefore may be able to aid with diagnosis as well as lead to an understanding of why some people are more likely to

get the condition than others.

The research study is entirely confidential and further information can be obtained via Dr Siddharth Banka at the Department of Clinical Genetics, St. Mary's Hospital on 0161 2766269.



"We know that inherited factors are important in why some people develop Pernicious Anaemia"

## Low Dose Naltrexone—a help for P.A. Sufferers?

By Corrine Day, Ct., U.S.A.

Naltrexone is a drug approved by the FDA in 1984 in a 50mg dose for the purpose of helping heroin or opium addicts. It blocks the effect of such drugs. By blocking opioid receptors, naltrexone also blocks the reception of the opioid hormones that our brain and adrenal glands produce: beta-endorphin and metenkephalin. Many body tissues have receptors for these including virtually every cell of the body's immune system.

In 1985, Bernard Bihari M.D

discovered the effects of a much smaller dose of naltrexone (approximately 3mg once a day) on the body's immune system. He found that this low dose, taken at bedtime, was able to enhance a patient's response to infection by HIV, the virus that causes AIDS.

*[Note: Subsequently, the optimal adult dosage of LDN has been found to be 4.5mg.]*

In the mid-1990's, Dr. Bihari found that patients in his practice with cancer could benefit from LDN. In addition,

people who had an autoimmune disease often showed prompt control of disease activity while taking LDN.

I was prescribed LDN in August of 2008, with high hopes of some sort of relief. I have PA, Hashimotos Thyroiditis, possible Rheumatoid Arthritis and possibly Coelic.

Much to my dismay I've had no success with LDN, however my sister-in-law who has MS, has been helped tremendously.

There is an informative website where you can find out more at:

<http://www.lowdosenaltrexone.org/>



## Membership & Monitoring Form

Towards the end of January 2009 the Pernicious Anaemia Society's membership stood at just over 2,300. The majority of our members are from the UK with nearly 600 from overseas. The society has seen a big increase in members over the past 18

months. From October 2007 to December 2008 we saw a 500% increase in numbers

Membership continues to grow daily, which shows there is a great need for our society. We are the only organisation in the

world to offer support and advice to sufferers of Pernicious Anaemia and their families.

The society has now adopted a geo-demographic monitoring form which all members will be asked to fill-in via the Society's website.

**In January 2009, the PAS membership stood at 2,300**

## Flora London Marathon 2009

Our very own 'Marathon Girl' and Pernicious Anaemia Society member, Chrissy Bladen from Southampton, will be running in the London Marathon on Sunday 26th April.

Chrissy, an undergraduate education assistant at Southampton University was diagnosed with Pernicious Anaemia

last year and turned to running as a way of coping with the 'strange tiredness'.

She has competed in several 10K races and Half-Marathons, and has been training hard for the Flora London Marathon 2009 over the last few months.

To date, her training has

been going well and if you would like to sponsor Chrissy then forms are available from the PAS office and online.

I am sure you will join with us in wishing Chrissy all of the best for the Marathon and expressing our thanks for her hard work on behalf of the Society!



**Chrissy after running the Cardiff Half-Marathon in October**

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#### We want to hear from you.

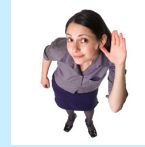
Please help us to produce the next edition of this newsletter.

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.

#### DIARY DATES:

- March 24th LTCA Wales Conference, All Nations Centre, Cardiff (Martyn our Chairman is speaking)
- March 27th "Year of B<sub>12</sub> Awareness" launched
- April 26th London Marathon  
Good luck Chrissie!
- September 23rd "Vitamin B<sub>12</sub> Awareness Day"
- 24th - 30th Sept "Vitamin B<sub>12</sub> Awareness Week"
- December 5th AGM - Birmingham

## The Founding Of The Simpson Memorial Institute

In 1923 a wealthy Detroit industrialist named Thomas Henry Simpson joined many thousands of others to die of pernicious anemia that year. Before his death he told his wife that he wanted to found a hospital or similar institution.

Detroit is near Ann Arbor, Michigan, the home of the University of Michigan, one of the most prestigious universities in the United States. In November 1924, Simpson's widow, Mrs. Christine McDonald Simpson, offered the University of Michigan \$400,000 to build, equip and staff a research facility that would bear his name: The Thomas Henry Simpson Memorial Institute for Medical Research. At that time it was the largest endowment to the Medical School in its history. The endowment stipulated that: The activities of the Institute are to be devoted, primarily, 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, with the proviso, however, that if a cure be found for that disease, either by the directors of this Institute or



Simpson Memorial Institute

by some other person, the work and activities of the Institute shall be continued in perpetuity in the investigation and seeking of a cure or cures for such other disease or diseases as shall from time to time be determined upon by a committee of three members

of the Faculty of the Medical Department of the University of Michigan, selected by the Board of Regents. (emphasis added)

At its November 1924 meeting, the Board of Regents accepted her offer on the terms she specified. In June 1925 construction started and a year later it was completed. After a lengthy search, Dr. Cyrus C. Sturgis was selected as Director. With Mrs. Simpson in attendance, the Thomas Henry Simpson Memorial Institute for Medical Research was formally dedicated on February 10, 1927. Thus began the operations of the only facility ever founded anywhere in the world specifically dedicated to the study, treatment and cure of pernicious anemia.

Next installment .... Thomas Henry Simpson, the man.