

Cobalamin News

SPECIAL FEATURES

- Initial survey findings
- PAS Symposium
- Join us on Facebook
- Documentary update
- Methylcobalamin infusions

INSIDE

- Online Support Networks 2
- B₁₂ Documentary 2
- Methylcobalamin Infusions 2
- Nurse Helpline 3
- Write to your MP 3
- PAS Forum 3
- Support Groups 4
- Legacies to the PAS 4

An insight into the diagnosis of P.A

Most of you will have completed the PAS's survey which examines the diagnosis and treatment of Pernicious Anaemia.

Since its launch a few months ago, the results of this investigation have proved suspicions of the problems faced by patients who develop the symptoms of P.A.

Perhaps the most shocking findings are those associated with the length of time patients had suffered symptoms before they were formally diagnosed with P.A; 18% of respondents had waited 10 years or more before finally being diagnosed!

Members who took part most commonly waited between 2 and 5 years to be diagnosed, while only 17.2% said that they had been diagnosed in 6 months or less.

One factor which is bound to have contributed to the lengthy diagnosis process is that 44.6% of those who answered were misdiagnosed before they learnt that they had

PA.

These other diseases include iron deficiency, an underactive thyroid, chronic fatigue syndrome and IBS.

Unsurprisingly, the survey highlights 'depression' as the most frequent

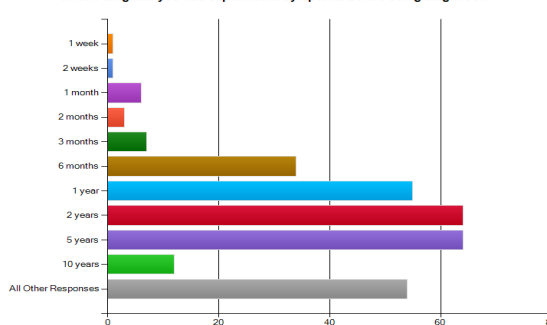
Other results in the survey have indicated that P.A. may be hereditary; 43% said that somebody in their family has, or had, the condition. This figure is incredibly high, particularly considering the amount of cases which, as we have discovered, can go undiagnosed.

This survey, whose complete analysis will be produced in the Spring, is a unique source of information which will expose the problems in misdiagnosis, and give evidence of

the need for alternative treatment options to be accessible on the NHS.

The survey is still available to complete on the P.A. website, if you have not yet done so, or hard copies can be sent through the post. Please contact us if you require any help or a copy of the survey for you to complete.

For how long had you had experienced symptoms before being diagnosed?



misdiagnoses.

The questions relating to the treatment of P.A show that 62.3% of those asked were unsatisfied with their current treatment.

90.4% of the survey's respondents are treated by Intra-Muscular injections and 42.7% of them receive these on a three-monthly basis.

PAS Symposium

A symposium will be held in the PAS office in Bridgend, South Wales in April 2011.

This event will be a wonderful opportunity to gather the work of academics and medics who have been investigating the problems with the diagnosis and treatment of Pernicious Anaemia and B₁₂ deficiency.

The PAS will also take this opportunity to discuss the findings of their own survey (see above).

We hope that this event will increase communication between academics and enable them to draw further conclusions from the work of others.

The organization of the meeting

is still in the early stages, but there has already been lots of interest and positive feedback.

If anyone knows of any research or information that could be used at this event or knows of anyone who may be interested, please do not hesitate to contact us at the PAS office.

Online Support Networks



Get PAS updates via your favorite social network site.

There are a growing number of ways to interact with fellow PAS members online. As well as the Society's website, where members are able to discuss topics on the forum, PAS now has accounts on Facebook, Twitter and Health Unlocked.

These social networking sites enable us to share stories and discuss queries.

The Facebook group - Pernicious Anaemia Society currently has 507 members who post

their thoughts, questions and advice for other members to see on the wall. There are also links to blogs, articles and competitions which may be of interest to members.

By following the PAS on Twitter, you are notified of any news or updates posted by the Society, making it easy to keep up to date with what's going on.

www.healthunlocked.com is the Society's newest Social Network interest. The relatively less well-known site is aimed directly at patients and care givers. As well as the usual discussion boards and links, it offers a Hospital Compare application to help you locate the most suitable hospital for your individual needs.

So, next time you're browsing the internet why not have a quick look to see what the PAS is up to.



B₁₂ Documentary

There is not long left to wait for the exciting new documentary about Pernicious Anaemia and B₁₂ deficiency.

The last few filming dates are going to take place this month and then "the arduous process of post production will begin" says Kimberly Epton, the documentary's producer.

The documentary, which includes the stories of many patients as well as interviews from medical specialists, will

premiere in mid to late January in London.

PAS hope to distribute the completed documentary to any interested television channels. Following this, the film will then also be available either on DVD or the internet.

PAS would like to say a massive "Thank you" to everyone who has participated in the making of this documentary, especially those who have

offered their stories to camera.

If anyone is interested in, or knows of anyone who may be interested in the corporate sponsorship of the documentary's premiere please email miranda@pasoc.org.uk or contact the PAS office.



Keep an eye out on the PAS website for information about our Charity Christmas Cards



Methylcobalamin Infusions

Methylcobalamin is a purer form of B₁₂ than Cyanocobalamin and Hydroxocobalamin. It is injected directly into the bloodstream so that the body can absorb the B₁₂ straight away for instant effects.

Methylcobalamin infusions are provided by members of the British Society for Ecological Medicine. This organization aims "to promote the study and good practice of allergy, environmen-

tal and nutritional medicine, for the benefit of the public."

The infusions are performed by trained doctors at clinics across the country, and the prices vary from £180 up to over £600.

For further information about this form of treatment you can access the BSEM's website www.ecomed.org.uk or you can contact the PAS. This is

an alternative treatment method to the typical injections, and anyone wishing to try methylcobalamin infusions should first discuss it with their doctor. Please note that the PAS does not recommend this alternative treatment but we do make members aware of it so that they can make an informed choice of treatment. Note that Methylcobalamin is not licenced for use in the UK.

Nurse Helpline

Although you can always contact the society's office to ask for information and advice, we are also able to refer our members to Nursing Sister Jane Kincaid.

This helpline has proved to be an excellent resource for patients who want some extra information from a knowledgeable medical professional who fully understands the problems they face.

An average of 6 members a month are referred to Jane for professional advice, and they have won-

derful things to say about her.

Jane is a great listener who evidently cares about the welfare of her patients. PAS member, Anna Hamilton, described her as being able to "give you a hug through the phone" and an "invaluable link" for members.

If you would like to speak to Jane, contact the PAS.

Remember, if you ever feel lonely or isolated, you can call the PAS office on 01656 769717.

Don't forget, we are only at the end of a phone if you fancy a chat.



The PAS is planning to hold a Fashion Show Fundraiser

in the new year...

..if anyone would

like to be

involved in this exciting project

in any way just get in touch

Make Your Voice Heard

The PAS is calling out to all members to write to their local MPs, to make them aware of how the diagnosis and treatment of PA is failing patients across the country.

Every letter written will make a difference, particularly if you live in one of the following areas:

- South Cambridgeshire,**
- Sutton and Cheam,**
- Guildford or Chelmsford.**



These constituencies are represented by ministers from the Department of Health, (Andrew

Lansley, Paul Burstow, Anne Milton and Simon Burns respectively), making it even more vital that they are aware of the problems involved with PA.

If you are unsure of who your local MP is, don't hesitate to contact us for help.

Online Forum

The PAS online forum is getting more and more busy as an increasing number of members share their stories.

Being one of the most effective ways to get a wide range of feedback, incorporating the opinions and experience of many, the forum has helped so many people.

The number of moderators on the forum is also growing, and it is being moderated almost 24 hours

a day, due to the world-wide location of members.

Those taking part in the forum include diagnosed sufferers of PA, members of their families and medical professionals.

One of our new moderators, JDee, is from northern England and encourages others to stay positive and to persevere with finding more effective treatment regimes.

After her father had been diag-

nosed with PA, he went on to develop

other medical conditions and JDee became convinced that this was not just a coincidence. This motivated her to find out more about PA and resulted in her discovering the Pernicious Anaemia Society. It was JDee's own awareness of the symptoms associated with PA and her involvement with the Society that led to her mothers' diagnosis.



JDee with her parents

Personal experiences such as these are what make the advice available on our forum so valuable to our members.

If you have a question or a topic you would like to discuss visit the forum, www.pernicious-anaemia-society.org

The Pernicious Anaemia Society
Level Four
Brackla House
Brackla Street
BRIDGEND
CF31 1BZ
U.K.
Tel. (44)(0)1656 769717

Main Contacts

Chair - Martyn Hooper
chair@pasoc.org.uk
Secretary - Michael Stevenson
secretary@pasoc.org.uk
Treasurer - David Connell-Smith
treasurer@pasoc.org.uk
Membership Secretary - Alex Critchlow
membership@pasoc.org.uk
News Editor - Lucy Loveluck
lucy@pasoc.org.uk
Canadian Delegate - Pat Kornic
canada@pasoc.org.uk
American Delegate - Ian McLean
usa@pasoc.org.uk
Mid-East Delegate - Fatima Parker
mideast@pasoc.org.uk
Australian Delegate - Daisy Loader
aus@pasoc.org.uk

Support Groups

There are currently eight Pernicious Anaemia support groups throughout the UK and another in New York City.

These groups, launched by members themselves, provide a point of contact for all members in the area.

When a support group is established, every member living nearby is contacted and invited to group meetings, but non-members are also welcome to attend.

Support group meetings are a casual gathering where sufferers of PA can discuss their own experiences and offer advice

and support to others. It is also a great way to meet some lovely and often inspiring people.

At the moment support groups are situated in S. Wales, East Lothian, New York City, New Hampton, Oldham, Tyne and Wear, Somerset, Sussex and Bristol. However, any member can set one up, and its a fantastic way to get in touch with others who are experiencing the same problems as yourself.



For any information about times and dates of meetings near you, or to set-up a support group in your area just contact the PAS who will be more than happy to help.

Do you have trouble reading this newsletter?
If so, please contact us about receiving future issues in large font or audio book.

Can You Find Room For Us In Your Will?

The Pernicious Anaemia Society still does not receive any government funding, and therefore depends on members' fees and generous donations to provide help and support for sufferers of B₁₂ Deficiency and PA.

Including the PAS in your will, whether you decide to leave a small donation or your whole estate, would tremendously aid our mission to provide the best possible service to our members.

In addition to kind one-off donations, a growing number of our members are setting up direct debits of £1 a month. This is an excellent source of reliable income, which makes a big impact on the Society.

If you are interested in leaving a legacy or making a donation of any kind to the PAS please contact us.

Share your Story

Would you like to write an article for the *Cobalamin News*, or have an article written about you?

Maybe you feel that your experiences can help or inspire others, or you would like to publicise your latest fundraising venture. Whatever you have to say, we would love to hear from you.

We are especially keen to hear from contributors from outside the UK. Please contact us if you are interested in contributing to future editions of this newsletter

Artists Needed

Kimberly Epton is looking for artwork to be included in the finalised B₁₂ documentary.

She is interested in a variety of styles of work including animations, sketches, paintings, photographs etc.

These will represent the feelings associated with the symptoms of PA.

If you are interested, or know of anybody who may be interested, please email kim@pasoc.org.uk or telephone 01656 769717.