

- Ground-breaking research will help explain PA in families.
- New Technology used to discover hereditary PA
- Tests to begin soon.

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The Platelet

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P.A. Soc To Play Key-Role in New Research

After being contacted by a Genetic Scientist from a leading U.K. University, the society is now one of three partners in a research project that is seeking to understand and explain the inherited nature of Pernicious Anaemia.

The research will be based on small blood-samples or mouth swabs from 535 individuals. The DNA will then be abstracted and analysed.

Members from the U.K. will provide blood samples whilst those from outside the U.K. will be asked to provide a mouth swab which will then be posted back to the United Kingdom. The mechanics have yet to be confirmed and the society will be contributing towards the postal costs of the overseas participants with grant funds that are being applied for.

It is hoped that the trial will start in as little as eight weeks but the full results will not be known for at least eighteen months.



Keeping it in the family— P.A. and genes.

The research is an example of the **partnership model** that is favoured by funding institutions for research. The tri-partite arrangement comprises of a Geneticist and his team, a Haematologist and her team and members of the Pernicious

Anaemia Society.

Secrecy is the by-word of such research collaborations but hopefully by the next issue of this newsletter, we will be able to reveal the names of the researchers and the University Hospital where the research will take place.

Any members who would like to volunteer to take part in this historic and ground-breaking project please contact Martyn at

chair@pernicious-anaemia-society.org

Explanatory information sheets and clinical pro-forma are available now. The tests pose no health risks and the blood sample will be small.

Society is awarded first lottery grant

The society has benefited from a grant made by **Awards for All Wales** which is part of the Big Lottery Fund.

The award, for £3,200 is being used to purchase a new computer, printer and software that will be used solely for Society business.

Stationery will also be bought. These items are really replacements for what has been used before.

However, the money will also permit the society to raise awareness of its existence among people who do not have access to the internet or do not

have internet skills.

Posters are on order which can be placed in doctors surgeries along with an information leaflet that will augment the ever-popular article on PA written by Suzi and Pat. Please contact us if you can help distribute these when they become available.

PERNICIOUS ANAEMIA AWARENESS WEEK



Tap 'Pernicious Anaemia' into Google and this society features as number eight in the results. That's pretty impressive and allows those sufferers who search for information on the condition to find the help and support that

Raising Awareness needn't be traumatic

they seek. However, for the enormous numbers of sufferers who do not have internet access or skills there is, to quote a researcher' "a paucity of information " on the condition.

To allow non-internet users to gain information and advice we need to publicise our existence And in order to do that we will be holding an Awareness Week where, hopefully, radio, television

and the press will at least give us a mention. One little letter in a national newspaper led to fifteen people writing to the society asking for advice and guidance. So if we can concentrate on getting publicity across all media we should be able to reach the very people who need us.

Anybody prepared to appear on radio or television please contact the chairman in order that we can arrange something. The producer of one very popular radio show is very keen to cover the story. The Date? 3rd—7th September 2007.

WE NEED THE PUBLICITY TO INFORM SUFFERERS WHO DO NOT USE THE INTERNET OF OUR EXISTENCE.

WEAR YOUR WRISTBAND DURING AWARENESS WEEK

Remember to wear your wristband during the week of 3rd—7th September. You'll be amazed how many people will ask you what charity you are supporting. And word of mouth advertising is the best form of advertising there is. Perhaps you can persuade your family and friends to also wear a band.

If you haven't yet purchased a

band they are now available at the reduced price of £1 per band. They are available at our online e-bay shop or you can send a cheque or money order to the Society's PO Box (details on the back page). Members from outside the United Kingdom can



use PayPal or contact the chair for more ways in which to pay. Please use a currency converter to send the appropriate amount of money.

If you can take a picture of you wearing a band in an unusual, or famous or exotic location please send the photograph to us so that perhaps we can publish them in our next edition of this newsletter.

Please Find Me A Home—if only for a week!

Passively gathering dust in one of the Trustees' garage, two hundred beautifully sculpted donation boxes are desperate to find a new home. And what better time to offer these unemployed individuals new accommodation than during Awareness Week?

These boxes are usually to be found next to point of sales in shops, restaurants and filling sta-

tions. But some members have used them as swear boxes at their place of work, or simply as a piece of desk furniture.

There is one group of members who are even organizing themselves to station themselves outside a major retail store and rattle the tins in the hope that some shoppers will make a donation.

If you have found a place where one of these boxes can be put to work please contact us so that we can supply you with a letter of authentication as well as a box. And remember that if you are planning to collect outside a store you will need the manager of that store's permission.



Beautiful, colourful and functional—a classic design combination.

RESEARCH PROPOSAL ONE — DIAGNOSTIC TOOL



A leading Haematologist has joined forces with a clinical Psychologist and the society

to try to develop a Diagnostic Tool for Pernicious Anaemia. The word 'tool' means an aid to effective diagnosis for P.A. and the Haematologist has long been keen to develop one.

The Society is applying for third-party funding for the project which will cost around £20,000.

PSYCHOLOGY OF P.A.

What is important is that members

of the society will play a key role in the research.

The Psychologist will try to determine what exactly we mean when we say that we feel 'tired', 'exhausted', 'fatigued'. These words are all very general terms and in order that quicker and more effective diagnosis can take place the medics will, for the first time, try to define what type of 'tired' we are.

And more importantly the Psychologist will try to determine what we mean by 'foggy' days and the Haematologist will determine whether there is a link between the 'fog' and B12 levels.

If you would like to take part in this research please contact us so that we can place you on the list of volunteers. The study should begin in January 2008 and will centre around a questionnaire that is being developed by the Psychologist. Hopefully the Tool will be published in medical journals in the autumn of the same year.

**FORUM
USERS
IDENTIFIED
THIS AS
BEING THE
SINGLE MOST
IMPORTANT
ISSUE TO BE
RESEARCHED.**

RESEARCH PROPOSAL 2 — RECEPTORS

This is a major piece of research that centres around the issue identified by users of the Forum as being the most important to investigate.

Why some sufferers of P.A. need more regular injections than others is the single most contentious issue relating to P.A. This is the issue that leads to most frustrating, unnecessary suffering and, in many cases, to the breakdown of

doctor/patient relationship.

There has been no direct research in relation to this and so when the society was contacted by a Haematologist and Bio-Chemist with a research proposal the invitation to fund the research was eagerly accepted.

The science involved is complex, and there has been some research in the same sort of area.

Why some patients absorb B12 easily and others don't is the main theme of the research.

The Haematologist concerned believes that if this process is understood, then it will explain why some of us need more regular doses of B12 than others. Hopefully this will bridge the gap between treatment needed and treatment prescribed.

AND THE ONES THAT GOT AWAY.....

Injections of Hydroxocobalamin as the way that Pernicious Anaemia is treated may be under threat in the U.K..

A salesman for a Pharmaceutical Company contacted the Society asking for , and expecting an enthusiastic response to the proposal to introduce a Nasal Spray that would replace the injections. Members were asked for their experiences with the spray and he

was told that patients who had used it were unimpressed. The spray is available in the U.S.

The salesman provided figures— there are 400,000 PA patients in the U.K. The cost of an injection and syringe is about £1. The cost of a nurse to administer it (especially as most PA sufferers tend to be elderly and receive the attention of a community nurse) was around £10. Injections are

given at least four times a year so the sum is £10X400,000X4 = £160,000,000 savings per year if a spray was used.

A week later we were contacted by a leading Professor of Medicine asking if we would like to be funding partners into the development of oral B12. As 'on demand' injections were considered to be a more important issue than the introduction of an oral replacement the offer was declined.



Not All Research Invitations Are Accepted.



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Pernicious Anaemia Society

The Pernicious Anaemia Society exists to provide support and information for people with Pernicious Anaemia, their family and friends. It is registered with the U.K.'s Charity Commission, registration number 1115195.

Membership of the charity is free and roughly one third of members are from outside of the U.K. and the vast majority of these members are from the English speaking world.

We want to involve members of the society as much as possible and if you would like to contribute to this newsletter please contact us—any offer of help in any way is always warmly received.

Chairman's Update

Almost two years ago I asked users of the forum to volunteer to become potential trustees of the society. The aim was to get the society recognized as a charity as it was becoming clear that, until we were able to quote a charity number, no organization or group of people would take us seriously and listen to our views.

Not only did the Trustees bring invaluable skills and experiences to the job, but also they showed great courage in allowing me full executive powers to develop the society to meet our aims and objectives. They continue to be a great source of advice and support when it is needed. I thank them for their co-operation and help.

We have come a long way in twelve months and, as the articles in this first edition of the new newsletter show, we are now taken seriously by medical professionals and other charities and with some of whom we have built an alliance.

A real landmark was reached last month when we were awarded our first grant of public money which endorsed us as a bona fide support charity. Hopefully this will be the first of many such grants which will be used to further the aims of the society to help sufferers of P.A. and their families.

The plight of those sufferers who do not have access to the internet has been brought home to me by two alarmingly similar requests for advice that I received from relatives of octogenarian male sufferers. The treatment, or rather non-treatment, that these two gentlemen received were strikingly similar and horrific. I fear that there might well be real problems with the treatment regimes for elderly patients and has led me to immediately raise the issue with Help The Aged and Age Concern. Both of these charities are now aware of the problems uncovered by these two cases and I have been assured that the situation

will now be monitored.

Membership of the society continues to grow steadily with, on average, three new members joining daily. There are still many hundreds of users of the forum who have not yet joined which is disappointing as I am continually being asked how many members there are of the society. I appreciate the signatures that many of you have attached to your postings on the forum in an effort to get forum users to join us. The Awareness Week will hopefully raise our profile and generate more new members.

The next few months will see me occupied in writing bids for research grants and putting together a business plan for the future of the society. If any of you have any ideas for future projects or any other suggestions on how we can improve what we are doing please let me know.

Best Wishes

Martyn

