

RESEARCH POINTS TO THE BENEFITS OF PRO- BIOTIC DRINKS

- **Good Gut Bacteria seem to aid the absorption of B12**
- **Many members already know of the benefits**
- **Another addition to the Information Library**

INSIDE THIS ISSUE:

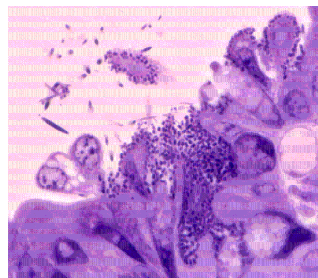
- Information Library 2
- First Collection Tin 2
- New Display Stands 2
- Research Update 3
- Good News for E-bay 3
- The Expert Patient Programme 4
- Contact Details 4

Good Gut Bacteria & P.A.

When Dr. Zeena Nackerdien first became interested in looking at a possible link between Good Gut Bacteria and Vitamin B12 she wanted to use this newsletter to inform the world about her findings. Unfortunately the work was too long for publication here but it has now been published as part of our Information Library.

"I have been intrigued by how good gut bacteria influences absorption of B12 because I know from the site forum that some members find the probiotic yoghurt drinks really beneficial" says Zeena, "To my knowledge no patient-friendly reference exists to explain why this might be so. I had the notion that Good Gut Bacteria, or Probiotics, actually helped in the absorption of Vitamin B12. and so started to sift my way through the published works on

the subject. My conclusion from a literature analysis is that there is promising evidence for believing that certain good bacteria help, directly or indirectly, in the absorption of B12."



A mouse colon infected by the bacterium *Citrobacter rodentium* (dark purple dots) - a Bad Gut Bacterium.

Zeena is a member of the society and fellow sufferer of Pernicious Anaemia, and she works as a micro-biologist at the

Rockefeller University in New York.

So how can we make sure that we get enough Good Gut Bacteria?

"Good Bacteria can be found in yoghurt, kefir, vegetables and Swiss-type cheeses. What is remarkable about all of this is that these bacteria can actually survive the journey through the gastrointestinal tract—a very hazardous voyage." says Zeena.

As to which brand of the many probiotic yoghurts available is best, Zeena would not be drawn. "It's a case of finding out which one works best for you" she says.

The paper, entitled '**B12 and the benefits of Good Gut Residents**' is now available to members—see the contact details on the back page.

P.A. Society Research Fund

The society now has a separate bank account that will be used to accumulate funds for much-needed research.

The reason the fund has been set up is because many charitable trusts, or individuals, will only contribute to a specific project and are reluctant to make donations to the society unless they know exactly what the money will be used for.

Pernicious Anaemia is the only

major long-term medical condition that does not have a robust and trustworthy **Diagnostic Tool** that can be used by medical professionals to arrive at a quick and accurate diagnosis of the condition. The development of a diagnostic tool is seen as a priority by the society and following consultations with a Haematologist and Clinical Psychologist the development of the tool will be the fund's prior-

ity. The cost of developing the tool will be just £15,000 and it will be available to doctors world-wide. If you would like to make a donation to the fund please make cheques payable to *PA Society's Research Fund*. This will ensure that your money will be used solely to fund the research. Members outside the U.K. should contact the chair for information on how to donate.



The Information Library continues to grow

NEW ADDITIONS TO INFORMATION LIBRARY

The list of fact-sheets that are available continues to grow and there are now six articles in the series with more being written.

Produced by members for members, updated versions are now available on:

Pernicious Anaemia

The Symptoms of Pernicious Anaemia.

The Consequences of Pernicious Anaemia

Self-injecting B12

Good Gut Residents and B12 (the full version of the cover

story).

Sub-Acute Combined Degeneration of the Cord Secondary to Pernicious Anaemia.

New articles are being written and will be available soon including:

Getting more regular B12 injections

Pernicious Anaemia and Pregnancy,

The leaflets will help fulfill the needs of GPs in the U.K. in the future as they will be used as part of the government's

Information Prescription initiative. Information Prescriptions is based on the idea that newly diagnosed patients do not only need medical prescriptions on diagnosis but also need easily understandable information about the condition along with details of any patient support groups relating to the illness, details of any websites etc.

The leaflets will be available on the new look website soon and will continue to be available in hard copy for non internet based members of the society free of charge.

“The new box is coming along too—it’s quite heavy already”

Welcome in the Valleys

A collection tin placed in a small but busy post office in the South Wales valleys has broken the previous U.K. record for the amount of money collected in the tin.

The two staff at the Pontypriidd office, Robert and Mary agreed to place the bright red collection tin in December 2007. By February it was full and contained £29.83 breaking the previous record by

over £7. When we visited the pair Robert told us that the replacement tin was quickly filling up. When he reached for the tin however, it was not there. Someone had stolen it by somehow burning through the security chain.

We'd like to say a big thank you to Robert and Mary and sincerely hope that the thief never develops Pernicious

Anaemia—even he or she doesn't deserve that.



Our thanks to Robert and Mary

Display Stands

The new stands will help raise awareness of the Society.



Following a successful application for a grant from Awards for All Wales, the society now has modern Display Banners that will replace the old-fashioned, but still functional, Display Boards.

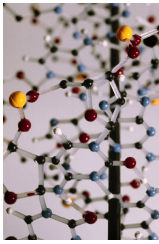
The Banners, in both English and Welsh, are used at various conference venues where they attract the attention of attendees at the conferences. If you know of a Conference or Exhibition that is local to you where the Banners or Display Boards could be displayed please contact the

society in order that we can arrange delivery.

The Conference or Exhibition need not be associated with medicine or health care. Raising awareness of the society among the General Public is just as important as raising awareness among medical practitioners and professionals.

Genetic Research Update by Dr. Siddharth M. Banka

Pernicious anaemia (PA) as you all know is an autoimmune condition characterised by low serum Vitamin B12 levels leading to megaloblastic (large red blood cells) anaemia, glossitis (inflammation of the tongue) and neuropathy (disease of the nerves). It is known that PA can affect members of the same family. It can also coexist with other autoimmune conditions such as hypothyroidism and Addison's disease. This indicates that there might be variations in the genes which predispose some people and families towards PA.



Research is now well underway and involves members from outside the U.K.

We, at the Genetics Department in Manchester University, are setting up a study under Dr. William Newman, Consultant Clinical Geneticist, to understand these genetic factors. These factors could be useful in developing new tests to help in the diagnosis of PA. This can also help in early identification of individuals at high risk of developing PA or other autoimmune conditions and could help in instigating preventative measures or early treatment. This would also help in developing a better understanding of PA and other autoimmune conditions which can help in new treatment strategies in the future.

For this study we aim to enrol more than 1000 patients with PA. If you wish to be included or want to know more about the study please contact me. We look forward to hearing from you.

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We needed to develop a three-year Business Strategy and a two-year Business Plan

Three Year Strategic Plan Written

Membership of the society continues to grow and the demand for information, advice and support means that our resources are now fully stretched. This is an important time for the society. For the past year and a half since being registered as a charity we have been unable to set clear targets because it was impossible to anticipate what demand there would be for our services. Eight-

een months on it has now become evident that the initial requests for information, advice and support was not just because we were a new resource. Membership continues to grow by an average of four a day and the demand for our ever-expanding Information Library and requests for advice about a diverse range of subjects means that the society now needs to plan for the future.

A draft Strategic Plan along with associated Business Plans have now been written and are out for consultation. If you would like to read and comment on the draft plan please contact the chair of the society (email details on the back page). The plan will be amended if necessary and adopted by a meeting of the Trustees in the May meeting in Birmingham U.K.

EBay Users Can Now Contribute To The Society



A recent email from Mission-Fish (the charity run by ebay) was a delightful and unexpected surprise. It confirmed that one generous person had listed an item for sale on ebay, and by simply clicking the link

that asks if any of the proceeds of the sale were to go to a charity, had raised £15.14 for the Charity funds. The item had shown that 20% of the final sale would be donated to us. Not only was this a kind gesture, but a simple and effective way of not only raising funds, but also a great way of raising the profile of the Society among the millions of

the daily ebay users throughout the world. A big thank you to that anonymous person. If you are an ebay user, or if you know of family or friends who use the service, please consider donating a percentage of your sales to the society—however small that percentage is. And a reminder that you can still buy our Wristbands on the Society's own ebay listings - pernicious-anaemia-society

Pernicious
Anaemia
Society



providing advice and support

The Pernicious Anaemia Society

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The Aims of The Pernicious Anaemia Society

The Charity's objects (the Objects) are to:

- (1) Promote and protect the physical and mental health of sufferers of Pernicious Anaemia through the provision of support, education and practical advice.
- (2) Advance the education of the general public in all areas relating to Pernicious Anaemia.
- (3) 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.

Expert Patient Programme

If your life is limited by Pernicious Anaemia and you would like more control over your health, the Expert Patient Programme can help you to manage your condition better.

The E.P.P. Is available in most countries (although it may be known as something else) and is available free of charge in the U.K.. It is a self-management programme that can help make positive changes to your life.

"The programme takes the view that people living with long-term health conditions often know what they need to manage their situation" says Donna Davies of EPP Wales.

So how does it work?

"Most long-term conditions have common problems that include uncertainty, anxiety, shortness of breath, fatigue, difficult emotions, stress, tense muscles and depression. The programme provides

skills and confidence and enhances G.P. care.

The Expert Patient Programme is comprised of six weekly sessions that each last 2½ hours. Each session looks at ways to help manage the effects of long-term health conditions and these sessions include:

How to take care of your health

Relaxation Techniques

Managing Symptoms



Working together to improve your condition.

Managing Pain

Dealing with anger, fear, depression and other emotional changes

Better communication with health care teams, family and friends

Planning for the future and getting the most out of life.

"The course was first developed at Stanford University and it has developed in other countries as well" says Donna who adds "and there is every reason to believe that sufferers of Pernicious Anaemia could benefit from attending the session."

U.K. Members can find out about their local EPP team by 'phoning Donna or Keith on 01656754400 or 01792 326500

International members should contact their local medical centre for information about their country's programme