



Cobalamin News

SPRING 2022



CONTENTS

- * Take part: A new Survey to start a Pernicious Anaemia biobank
- * PhD studentship researching the treatment and management of Pernicious Anaemia
- * Pernicious Anaemia Research Update
- * Our continuing work on the JLA PSP top 10 research questions
- * Personal Stories
- * Support Group News
- Book Review

Take part: A new Survey to start a Pernicious Anaemia biobank for upcoming research projects

We need your help to ensure we can initiate a series of new investigations and research programmes that will over time contribute to new, improved and timely diagnosis, treatment and management of patients suffering from Pernicious Anaemia and clinical B12 deficiency worldwide.

As a first step, we want to identify a group of patients with established vitamin B12 deficiency caused by Pernicious Anaemia. If we can successfully identify and collect data from such a cohort (such a group is called a cohort in research terms) we will plan specific research that will aim to understand how best to diagnose and treat patients with Pernicious Anaemia. A range of studies is being planned, ranging from general and more focused questionnaires, collection of blood samples, and genetic studies involving family members, notably those also diagnosed with Pernicious Anaemia/vitamin B12 deficiency, as well as state of the art studies that will, for example, use widely available digital wearables such as Fit-bits and Apple watches to track in real-time the range of symptoms our patients experience across every treatment cycle.

We hope to use information and results from our studies to be able to provide guidance to medical practitioners to facilitate a timely diagnosis of this disease and to be able to devise more personalised treatment and management programmes for our patients.

Please rest assured that before any research projects are launched, the project(s) will be approved by the relevant scientific agencies and ethics committees.

Interested in being involved?

Participate in this survey here:

[TAKE THE SURVEY](#)

PhD studentship researching the treatment and management of Pernicious Anaemia



We have a very exciting announcement to make. In partnership with the School of Biosciences & Medicine, University of Surrey, the Pernicious Anaemia Society has agreed to joint fund a full 4-year programme of research for a PhD student to investigate and develop a better treatment regimen for patients with Pernicious Anaemia. The prospective post-graduate student will undertake cutting-edge research into treating and managing what is often a debilitating disease. For the first time this research will take the experience of the individual patient into account, resulting in an individually tailored management plan to help the patient manage their disease. This ground-breaking scientific endeavour will take a new approach to the science behind the treatment of Pernicious Anaemia and is likely to expose shortcomings in the way in which the disease is currently treated.

The Pernicious Anaemia Society will be actively fundraising from a range of sources for our contribution and we hope that our members will help support this endeavour by fundraising, contributing, responding to surveys and spreading the word.

Applicants for the PHD will be sought shortly and further details can be obtained from Dr Kourosh Ahmadi (k.ahmadi@surrey.ac.uk)

If you would like to make a contribution to this important programme, please go to [our campaign-page here](#).

And if you can identify a possible source of funding whether it be an individual or organisation, please let us know by emailing research@pasoc.org.uk.

Pernicious Anaemia Research Update

This is the first in what we hope will become a series of regular updates from the scientific literature brought to you by Dr Kourosh Ahmadi (University of Surrey). The aim is to summarise important research findings that are relevant to those with Pernicious Anaemia.

It has been an important year for studies into the genetic susceptibility to Pernicious Anaemia. The first study by Kari Hemminki's team was conducted on patients diagnosed with Pernicious Anaemia from Swedish hospitals, and their family members, was published in the journal [Autoimmune Diseases](#). The study showed, what we have suspected for a long time, that PA runs in families but the causes of the disease are diverse and complicated. The [Estonian Biobank Research Team](#) took this finding many steps further in another study. They used the latest technologies to scrutinise the genome of PA patients at a very fine resolution and for the first time they identified 5 separate genes that increase an individual's susceptibility to PA. Interestingly, many of these genes have also been previously shown to affect susceptibility to other autoimmune diseases that PA patients often also exhibit, including type I diabetes, vitiligo and thyroid disease.

In an important review published in [Therapeutic Advances in Gastroenterology](#), S Rustgi and colleagues elegantly discuss the importance of timely and uniform diagnosis of Autoimmune Gastritis (AIG) with or without Pernicious Anaemia and provide important insight into the epidemiology, risk factors, and clinical management to thwart further complications, including gastric adenocarcinoma. Although there is lack of uniformity in reporting AIG among pathologists as reported by [MS Bloomquist](#) and colleagues, [J Marley](#) and colleagues used data from half a million participants from the [UK Biobank](#) to estimate the prevalence of upper gastrointestinal (GI) cancers among those patients that suffer from long-term conditions (LTC), including Pernicious Anaemia. The investigators showed that patients with LTCs are generally at higher risk of developing GI cancers. As previously shown patients with PA were shown to be at much higher risk of developing stomach (gastric) cancer. This was supported by another study that was published in the Journal [Frontiers in Immunology](#).

Finally, an interesting study was published in the journal [Anticancer Research](#) which used a new non-invasive Biomarker Test called GastroPanel® to diagnose autoimmune atrophic gastritis, a major cause of PA, in asymptomatic subjects. The aim here was to identify individuals at a very early stage of disease. A total of 1,283 asymptomatic "healthy" adults (mean age: 38 years) were screened by the GastroPanel® test of which 46 individuals had biomarker profiles indicating AG. The investigators invited these 46 individuals for further examination including gastroscopy and blood tests (parietal cell, intrinsic factor and thyroid peroxidase antibodies, and analysis of vitamin B12 and iron) leading to a confirmed diagnosis in 33 of the 46 individuals. The investigators believe that GastroPanel® represents an attractive screening tool for AAG highlighting its usefulness in identifying those at early stage of the disease.

Our continuing work on the JLA PSP top 10 research priorities

As reported in our Winter Newsletter and following the completion of the JLA process, we sought to find three groups of scientists and clinicians to look at and meet the challenges posed by some of the PA JLA PSP uncertainties. Following meetings over the last couple of months, we are pleased to confirm that three groups have been formed and they have started work on their specific area. The first group are looking into the diagnosis of Pernicious Anaemia which, as you will recall, was the number one PSP question; the second group is looking at the treatment of PA, whilst the third group is looking at the functional outcome of treatment for PA.

The British Society for Haematology state in their guidelines that the most important point when assessing patients with suspected PA, is their clinical presentation which is why, developing a Functional Outcome Score could change the way in which patients are treated, regardless of what their test results say. We are very lucky to have a wonderful partnership with the brilliant people working in these groups and we will keep you posted as work progresses.

In case you missed it, you can read the full report of the Priority Setting Partnership with the Top 10 Research Priorities for Pernicious Anaemia [on our website](#), on the website of the [James Lind Alliance](#), or by [clicking here](#).

Personal Stories

Whether you are newly diagnosed, still struggling for an answer, or a long-time member with PA, we would love to hear from you to contribute to our new series of Personal Stories. We know that these stories resonate loudly with our members and provide comfort in what is often a challenging journey to getting appropriate treatment and support. If you are willing to share your story with our members, either here in our newsletter or on our website (or both) please contact katrina@pasoc.org.uk who will provide our outline template and requirements for what is required. By sharing your story, wherever you are in the journey you will really help your fellow members and support our ongoing drive to raise awareness to the wider community.

Personal Story: David Connell-Smith



I am David Connell-Smith, I am 76 years old and have been a trustee of the Pernicious Anaemia Society almost from its formation.

I first began to feel very tired and hazy in the nineties. I had a history of being diagnosed anaemic every year or so when I gave blood and was

given the usual iron tablets. I visited my GP in about 1996 who took a blood test and said I was extremely anaemic. He put me on the usual iron tablets but after several weeks and more blood tests I was referred to Colchester hospital as I was still anaemic. This resulted in an endoscopy and a colonoscopy which found nothing. Various tests and appointments at the hospital drifted on until in February 2002 when I was referred to the Consultant Haematologist. More blood tests, a barium Xray and a special scan for Meckel's diverticulum, all of which proved nothing. I seem to remember I had more than one endoscopy but it was long time ago to remember the details. Eventually my GP called me in and told me I had PA, no explanation, just I would need three loading injections then three-monthly injections for life and all would be well.

It was at this point that I resorted to Google to try and find out more about PA and discovered the PA website and all the information this gave on the condition. This has been my only source of information. The PAS was also asking for help from anybody with accounting and charity knowledge. As I was a Finance Director of a large charity, I volunteered my services and have been a trustee of the society ever since.

I cannot remember that the injections made a lot of difference to my feeling tired and mussy. I tried a doctor in Cardiff who gave me an infusion of cobalamin, this made no difference. I tried various tablets from Amazon but these didn't help. I obtained cobalamin from an online veterinary medicines shop, which was extremely cheap compared with overseas suppliers, to self-inject, this I think helped. As recommended by the PA society I told my GP I was self-injecting and was told that as I was putting unknown substances into my blood, he would no longer take any blood tests from me. As I was moving to a new village at this time, I changed my GP. Eventually the online supplier asked what animal I

was treating and that I needed a prescription from a vet to continue.

My new GP has continued the three-monthly injections even through the lock down, but is pedantic on not a day before the three months. I found out my medical record is marked beware this patient is a trustee of PAS. I have a blood test nearly every year but the only result I get is the receptionist saying no problem.

I retired from full time accountancy 11 years ago, but for the last few years of working I found that I had to do as much of my work as possible in the morning as I was in a little mussy dream world in the afternoon and could not concentrate. I volunteered with the National Trust as a guide at Flatford, home of John Constable, but had to give it up as some days I could not even remember Constable's name let alone dates and other family names, which was very embarrassing when in front of a group. I find that I have good days when I only feel a little mussy and tired, other days I do not feel "with it" all day and cannot concentrate on anything. I find I am better in the summer when I can be out in the sun for much of the day. I cannot work on a computer for long without my concentration fading. I have the usual problem of not being able to find even the most common of words, my wife is used to having to fill in words for me as I speak.

I have been alarmed over the years at the lack of knowledge of PA by GPs and by hospital doctors and nurses. If they have even heard of it, they just think a 3 monthly injection is all that is required and all symptoms will disappear. All the GPs I have seen over the years were frightened to disobey the NICE guidelines in fear of being struck off.

The society has worked hard over the years to get PA recognised by health professionals and at last it seems with the NICE review some notice is being taken that the diagnosis and treatment of PA has fallen short of that expected. The charity is supporting the research into the 10 Uncertainties identified during the JLA process which hopefully will lead to an improvement in the diagnoses and treatment.

The Healing Journal

Guided Prompts and Inspiration for Life with Illness

by Emily Suárez

*Book Review by
Katrina Burchell*

Like many people with Pernicious Anaemia I have been on a journey of personal discovery which has involved accepting that PA and injections are for life, that I need to manage what I can do and my expectations and, most importantly, the lightbulb discovery moment that I need to be kind to myself and occasionally demand kindness from others.

This book by visual artist and chronic illness sufferer, Emily Sunez, is an excellent reminder of that need to look after yourself beyond the “prescription” treatment. The journal style is a useful way to dip in and out depending on how you are feeling. The beautiful water colour illustrations are a great distraction and I keep the book on my work desk and flick through it just to look at the images. The sunflowers and the lemons always cheer me up.

The book is in the form of a journal with pages to write in and questions to reflect on as well as tasks you can do to help keep your mind on track. I’m always a little cynical about anything too “new-age-y” but this is far from that and really focuses on the things people with chronic illnesses need to ask and remind themselves. There are positive affirmations alongside the drawings and then questions or “to do tasks” to help you take 5 minutes or so to reflect. For example, thinking about what things which help you sleep, or how you felt in certain situations if someone made you feel sad or angry or reminding yourself about the positive sides of PA (and there are some – haven’t you given yourself and others a good laugh about some crazy brain fog moment?). I didn’t want to write in my Journal, I have a pathological hatred of defacing books but it comes in an online version too and I was more than happy to jot my thoughts in that format and it was great to look back on them after a few weeks and see if I felt the same or update them with progress. In that respect it feels like chronicling the journey through the ups and downs of living with Pernicious Anaemia.

The book is small enough to slip into your bag but with a hard cover will survive regular use. The online version is easily accessible and the images are equally entrancing in that version. As the publisher says “this is a perfect gift for a loved one” but in my view it is a perfect gift to yourself too.

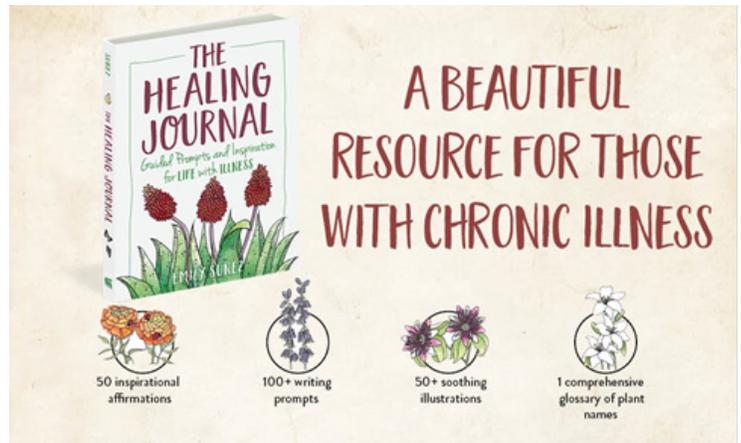
You can get a copy of the book from the following places:

<https://theexperimentpublishing.com/catalogs/fall-2021/the-healing-journal/>

Facebook.com/experimentbooks

@experimentbooks

Don’t forget that if you purchase this through smile.amazon.co.uk you will be directly benefitting The Pernicious Anaemia Society with a donation.



Live in the UK and shop at Amazon?

Support the PAS while you shop at no extra cost to you!

Here’s how:

Go to <https://smile.amazon.co.uk>

Log in as usual; Select Pernicious Anaemia Society, Start shopping!

Make sure you go via AmazonSmile every time you shop.

When you shop at smile.amazon.co.uk, you’ll get the exact same shopping experience as amazon.co.uk with the added bonus that Amazon will donate a portion of the purchase price to the Pernicious Anaemia Society (0.5%). Don’t forget to tell your family and friends too!



PAS Support Groups

Our Support Groups are a vital part of the PAS. They are an excellent way to relieve the feeling of isolation that many patients feel and they provide the opportunity to hear how others are dealing with their condition. Our existing Support Groups have been set up regionally and are led by our wonderful volunteers.



Unfortunately, during lockdown periods face to face support group meetings had to be cancelled. Some of our existing groups have used ZOOM to hold their meetings which has been well-received, but some of our members, dealing with the additional stress that Covid brought and technology challenges, did not want to meet by Zoom or did not get the same level of support. Our Support Group Coordinators kept in contact by other means but there definitely has been “something missing” from the support services the PAS provides by not being able to provide opportunities to meet in person. We are hoping we can start up meetings again very soon.

Anticipating the need to re-energise our Support Group activities we applied to Magic Little Grants for a Grant of £500 to re-introduce in person support groups once lockdown rules were removed and we were very grateful to receive this amount on 3rd December 2021. With this money we will help establish first meetings, train new and existing volunteers and update our website and materials available to the Support Group Coordinators. The organisation behind Magic Little Grants is [Local Giving](#). UK members may be familiar with this organisation as they are behind the often advertised People’s Postcode Lottery.



On 23rd March we held a Support Group Coordinators Zoom meeting where we discussed the value and importance of Support Groups and shared experiences and ideas for 2022. We also explained our training programme which is now being put together for new coordinators and will help make sure attendees understand how and why certain things like inclusivity, GDPR, and attendance list are needed. We discussed the need to have regular dates in the diary for members and asked that a minimum of 4 meetings a year were held either in person or via Zoom. We explained how the volunteers in the office provide support including sending email invitations to the relevant geographical areas and social media notices about the events.

We have recently had two members express interest in setting up Support Groups and we hope that they will soon be up and running with their groups, one in the Kew area of London and the other in Chicago, USA. For existing groups, we expect group meetings to start up again soon and will send you an email invitation for the group(s) you are interested in as soon as we know the date(s). Contact details for our groups can be found on our [Support Group website-page](#). We will keep you posted when the new groups are up and running. We'd love to expand our network of Support Groups so please take a look and see at our website page which shows where there are gaps and if you feel you can help get in touch with us. Please consider forming a group in your area. We know that these are well received and often a really important resource for people newly diagnosed or struggling to be heard. Arranging a minimum of 4 meetings a year with help and support from the team in the office and with feedback and ideas from other Support Group Co-ordinators can be individually rewarding and will be much appreciated by members and the Society.

Are you able to arrange online and/or in person meetings regularly? Interested? Want to know more? Get in touch! You will be given an informal introductory meeting with the PAS team, training and support.

Email to: info@pasoc.org.uk or call +44 (0)7783 318525

What's On

30th April - Support Group Meeting East-Sussex

11th June - EGM

September - Annual General Meeting (TBD)

8th October - Online Mini-Conference

12th October - Pernicious Anaemia Awareness Day

How members of the public can influence research

Across the UK, organisations that fund research want to involve patients and the public in their work. This helps funders shape the research we pay for and ensure the findings will be relevant to the people they might affect.

A [survey of public contributors](#) involved in research across England has shown that patients and the public are involved across many different stages of research. Plus, the majority of people enjoy the experience and feel they are making a difference. You could be part of this group, find out more about how to get involved:

Take a look at the [NIHR Public Information Pack](#), to learn more about how to get started

Search for opportunities to get involved from across the UK on NIHR's database, [People in Research](#)

If you live in [Northern Ireland](#) you can get involved in research

Browse opportunities to [get involved in research in Wales](#) or [FAQs](#)

Use your experience to get involved in [research in Scotland](#)



Our Social Media

The Pernicious Anaemia Society has a [Facebook](#) page, and we are also on [Twitter](#), [Instagram](#) and [LinkedIn](#). We haven't posted much in the last few months, not least because we have been tied up with the JLA PSP work and, because we are a very small team, we have to prioritise our work. However, if you do see a post, you can help us maintain our profile, by re-posting. Thank you!

Our Helpline

Our helpline continues to support many of our Members so we want to acknowledge our wonderful Helpline Volunteers for their ongoing support and commitment. Thank you ladies!!



PAS Support

Call the Helpline

01656 817085

Monday-Friday between 8.30am and 12.30pm.

Volunteers: Alex, Kathy, Jane, Alex, Karyl

Send us an email

For members who live overseas or prefer email:

support@pasoc.org.uk

Questions about your membership:

membership@pasoc.org.uk.

For general questions:

info@pasoc.org.uk