pas Pernicious Anaemia Society

Cobalamin News

Issue 40 WINTER 2024 6 December 2024

Contents

Research Highlight:

In this newsletter, we discuss the recent research completed by Genomics England in respect of Megoblastic Anaemia.

Our office and helpline will be closed for the holidays from 23rd December until 6th January

Get in touch: 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.

PAS Support

- **01656 817085** - *Mon-Fri 8:30am-12:30pm*
- **support@pasoc.org.uk** - *members who live overseas or prefer emails*
- **membership@pasoc.org.uk** - *membership questions*
- **info@pasoc.org.uk** - *general questions*
- Helpline volunteers: Liz, Kathy, Alex, Karyl

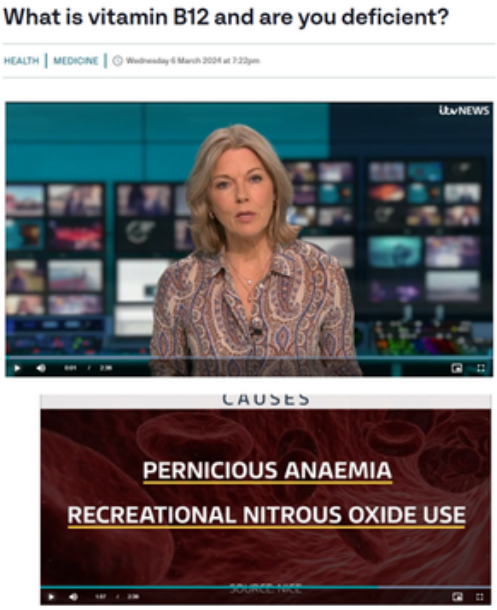
CEO's Introduction

from our CEO, Katrina Burchell

2024 has been a year of amazing progress for the Pernicious Anaemia Society. Sometimes, our small group on the management committee, our trustees, and our volunteers forget to recognize just how much we do with such a small team and with limited resources. 2024 has definitely seen us punching above our weight as a small charity. It is impossible to cover everything we have achieved or put in progress over the last 12 months, so this review contains some highlights and gives us an opportunity to reflect on what we have done, take a few deep breaths as we relax with family and friends over the Christmas break, and continue building on these foundations in 2025.

January to March

The first half of the year saw the CEO working intensely on the restructuring and future planning for the organization. With the treasurer, we focused on updating and improving all our financial reporting systems, auditing, and financial obligations to ensure that we were fully compliant with all charity regulations and up-to-date with knowledge on changes that impact charity regulation. With the Office Manager, we ensured that systems were future-proofed and introduced all the new systems and processes that were required by our insurers. Working with ZS consultancy, we carried out an in-depth review of our communication, membership, and fundraising strategies and came up with a list of ideas for improvements and some fine-tuning which we have already started to put in place. With two of our trustees, Andy and Tara, we built a 3-year business plan and a fundraising grant application calendar.



Alongside all this activity, Katrina also took part in the GW4 fatigue study research and attended numerous online meetings with organisations where our input and/or their knowledge can benefit our members. For example, we contributed to the Prescription Coalition, the Neurological Alliance, CluB-12 and the B-12 Alliance. We had conversations with MP's who had concerned constituents approaching them, and meetings with our research PhD's on existing and new projects.

Most important in this first quarter was the build-up to the publication of the anxiously awaited NICE Guideline on B12 Deficiency in over 16s, finally published on 6th March 2024. A huge number of hours had been invested in lobbying for improvement in the content and in discussing our strategy for dealing with the areas that the guideline failed to adequately address. We were delighted that our efforts with journalists resulted in Pernicious Anaemia making it onto ITV News on the day the guideline was published.

April to June

During the second quarter of the year, work focused on the Guideline and our statement on the areas we felt had not been properly addressed. It was clear that NICE also had no plan to ensure that the Guideline was accompanied by training for GP's and nurses, and we intensified our own activities with regard to creating education packages for patients and healthcare professionals. Through our membership of the B-12 Alliance we contributed to their working group on education for doctors on B12 deficiency in general. Our social media campaigns began to see an increase in engagement and conversion into membership. Membership of the Society is so important to us because it is through these numbers of patients with lived experience that we can really contribute to research and lobbying activities.
Our statement on the NICE Guideline and our blog post series on our website were very popular, often being quoted in other material. By the end of May, we had completed all the review work with ZS Consultancy and we can't thank them enough for the amount of free time they gave to help and support us. We held a seminar online that was really well attended, with Dr Willemina Rietsma and Katrina Burchell talking about the NICE Guideline which is still available to download via our shop: Making a Difference – The NICE Guideline on B12 deficiency

During the period, Katrina was also appointed Chair of the B-12 Alliance, the patient representative group of CluB-12, together with others who have an interest in improving the lives of patients and educating healthcare professionals about B12 deficiency. This group is working on various communication, lobbying, and education projects, which enhance the work that PAS is already doing. Conversations with organisations with similar issues, such as Parkinsons charities, ME/CFS and Guts UK, as well as Thyroid UK ensure that Pernicious Anaemia and the work we do is brought to the attention of a wider audience. We re-launched our shop and focused on selling a mixture of merchandise and downloadable educational material as well as looking at some creative ideas. We have, for example, created some cross stitch patterns for our characters Cross stitch patterns and entered into arrangements with paper and eCard companies as well as blood testing organisations in case these are helpful to our members. If you have left sending your cards out a bit late, then you can send some eCards here via Personalised Charity Cards & eCards supporting Pernicious Anaemia Society (makingadifference.cards) or here Pernicious Anaemia Society eCards (DontSendMeACard.com)

July to September

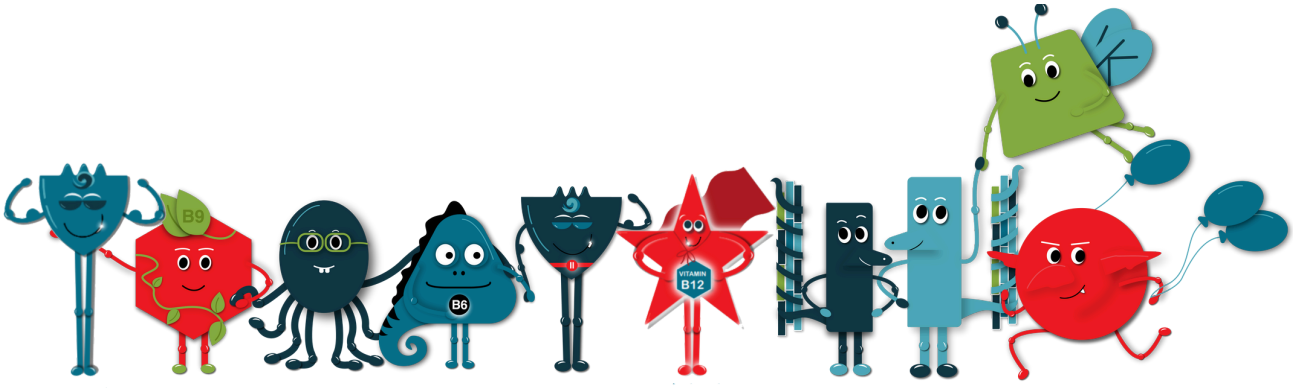
We headed into our 3rd year with our social media external team at ElementsOBM and reviewed and updated our strategy. Significant progress has been made on numbers of followers and engagement, and we also started to see an increase in membership and donations as part of our campaigns. We held our AGM and worked with our auditors to sign off last year's accounts. We are committed to research spend with two universities which means we need to find funding for this and lots of other projects; improving our membership data as well as changing membership categories to annual and lifetime is part of the changes necessary to ensure we comply with GDPR. Our treasurer wrote to all legacy members, and we are very grateful to those who updated their membership accordingly and want to thank again all those who set up standing orders for regular donations on top of their annual membership fee.

All the hours of work by the CEO, treasurer, helpdesk, and support group volunteers and trustees are provided free of charge and voluntarily. Many of these people have Pernicious Anaemia and have other full- or part-time jobs or health issues. The traditional holiday period here in the UK did not see the work drop off as we began our fundraising and grant application work and held our annual AGM. We saw an increase in enquiries from healthcare professionals and had some new people join the Society who have a specific interest for career or research reasons. In September, our CEO, Katrina Burchell, spoke at the CluB-12 annual meeting and set the tone of the first day, encouraging the researchers, doctors, and scientists present. With responses to our calls for more personal stories, we updated the selection on our website and discussed ideas around a future "patient council."

October to December

In October, we held our annual seminar with speakers Katrina Burchell, Alfie Thain and Clara Plattel. This seminar is also available for download from our shop if you were unable to attend. We are aware that we cannot always find times that suit our global audience or are necessarily attractive to people who work and have Pernicious Anaemia – being able to concentrate and staying awake are often important signs and symptoms of B12 deficiency, and for many these are the first to signal that we are due an injection. Technology has allowed us to record and offer these seminars for download and raise funds for our ongoing work, so do keep an eye on the shop for future recordings. In November we held a seminar about iron deficiency (common in people with PA) with Professor Toby Richards, and our CEO's recording on *How Vitamin B12 works in your body* was uploaded to the shop. One of our supporters, Nicole Sennett (Sewn by Sennett) organized a craft fair in October and donated the proceeds from the raffle, pitches and tea and coffee stall to the Pernicious Anaemia Society totaling an amazing £716. Her local mayor and deputy mayor attended and took away leaflets, which they posted on their social media, contributing to raising awareness of our charity. We are very grateful to Nicole for organizing this event. She has three close relations with PA and was inspired by our call for people to do something for PA-Day on 12th October. Volunteers who offered to run marathons or half marathons this year and next are also held in our high esteem. We'd love to see other activities take off in the community, so if you have ideas or want to help us fundraise for important research then get in touch at info@pasoc.org.uk

We introduced our gang of characters and you will see more of these in social media, blogs, on our website and in presentations in the future. We believe that these initiatives will help patients better understand their condition and contribute to more constructive discussions with their friends, family, and health care providers.

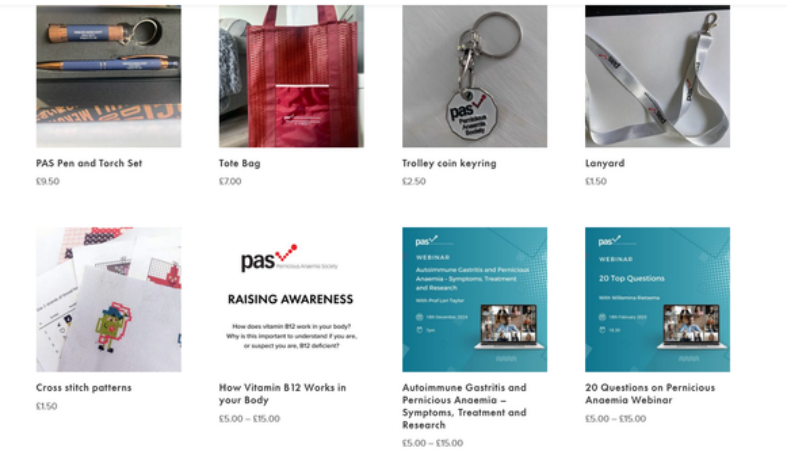


This quarter also saw discussions on potential new research projects with universities throughout the UK, collaborations with some USA organisations, an approach from an Artificial Intelligence organisation to discuss ideas around health and medical AI, and a successful grant application from the Postcode Lottery to help towards our education material fund. Our support groups, reinvigorated by our office manager, have been holding in-person and online meetings for new and existing members, and this year we held new group meetings in Sweden and Australia/New Zealand, as well as re-establishing some support groups in the UK that had "gone quiet" during lockdown. We also commented on Lord Darzi's report into the state of the NHS and on a report on Health Inequality in Leeds, where we provided evidence of the relevance to that community on the connection between the lack of education and awareness about B12 deficiency and Pernicious Anaemia versus their specific population, prescribing habits of their 100+ GP practices and lack of adherence to the Nice Guideline.

Writing this review has left me in a state of virtual exhaustion, gratefulness, and pride! Reflecting on what we have achieved and the support I have received from many in practical and more subtle ways, I believe that we are building great foundations for the future of the Society and realizing our goals of improving diagnosis and treatment.

Our Shop

Looking for a Christmas gift or stocking filler? Maybe there is something suitable in our Pernicious Anaemia Society Shop. A gift for a friend or even yourself, and your contribution is also a gift to the Pernicious Anaemia Society as all profits from the shop go to the valuable work we do.



You might be interested in our new educational material including this one where our CEO explains how Vitamin B12 works in your body; How Vitamin B12 Works in your Body

Or if you are looking for a crafting project over the holidays, maybe download our cross-stitch patterns and make them into cards or decorations. Send us photos of your finished article and we might publish them in the next newsletter! Cross stitch Patterns

Support Group News

Information about past & upcoming support group meetings

Past

9th November Chicago Support Group

Julie, our Chicago based support group volunteer, held another successful group on 9th November 2024. The group discusses a multitude of subjects, all PA related I hasten to add, as well as discussing research papers. It is a really successful group which is due to Julie's passion and commitment. Thank you Julie.

27th November South Wales Coffee Morning

A Coffee Morning was arranged on Wednesday 27th November for our South Wales members. Unfortunately, no-one attended which left us with a dilemma - who is going to eat all the mince pies?! Karyl, the support group volunteer for South Wales, will arrange another event in the new year, this time via Zoom, which might suit not only the South Wales members, but any member that might want to pop in. As ever, the details will be advertised on our website in due course.

Upcoming

21st December Online Support Group Meeting

Held by Benita, East Sussex

23rd December Online Support Group Meeting

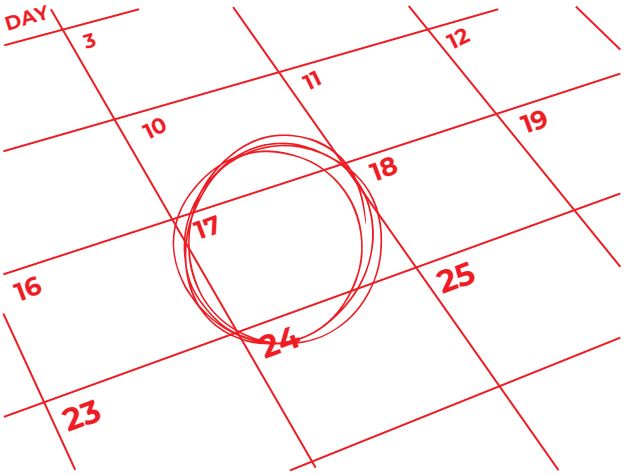
Held by Karen, Scotland

Two of our Support Group volunteers, based in East Sussex and Scotland, will be holding an online support group meeting on Saturday 21st December and Monday 23rd December. They would love to see some of our members on the day, and again, a gentle reminder, you do not have to live in the East Sussex area or in Scotland to attend. It doesn't matter where you live, you are very welcome to attend!

Please note, you will need to register for these events - just click on this link , login and you will find the link in your membership account.

What's on & Key Dates

- **18th December 2024 @ 19:00** - Autoimmune Gastritis and Pernicious Anaemia – Symptoms, Treatment and Research. A presentation by Professor Lori Taylor, followed by a Question and Answer Session with Lori and Dr Willemina Rietsema, chaired by PAS CEO, Katrina Burchell.
- **21st December 2024 @ 11:00** - East Sussex Online Support Group Meeting.
- **23rd December @ 11:00** - Scotland Online Support Group Meeting.
- **21st January 2025 @ 18:30** - The need for an international treatment standard for B12 deficiency with Bettina Borre Buhl.
- **18th February @ 18:30** - 20 Questions on Pernicious Anaemia - Q&A session with Dr Willemina Rietsema, focussing on frequently asked questions from our help desk and submitted questions from the audience. Questions to be submitted in writing to info@pasoc.org.uk no later than 31 January 2025.



More info about these events:
https://pernicious-anaemia-society.org/our-events/

Get your ticket for the webinars via our shop
https://shop.pernicious-anaemia-society.org/

Our webinars are also recorded and will be made available for sale after the event.

Upcoming Seminar - Autoimmune Gastritis and Pernicious Anaemia

18 December

Please join us for our next interesting seminar and discussion. Visit our PAS Shop to get your ticket for this event. Please note that all our seminars are now recorded and will be available after the event for those in different time zones to purchase and listen in their own time.

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Autoimmune Gastritis and Pernicious Anaemia – Symptoms, Treatment and Research

A presentation by Professor Lori Taylor followed by a Question and Answer Session with Lori and Dr Willemina Rietsema, chaired by PAS CEO, Katrina Burchell.

Lori Taylor is a Professor of Integrative and Functional Nutrition at Saybrook University in Pasadena, California, USA. She holds a bachelors degree in biochemistry from UC Berkeley and master's degrees in education from Stanford University and Nutrition from Bastyr University. She has been a clinical dietitian and educator for over 25 years, specializing in autoimmune and GI disorders. Lori is an active member of CluB-12 and her paper *Creating a Framework for Treating Autoimmune Gastritis—The Case for Replacing Lost Acid* was published in February 2024.

Lori will talk about the findings in her paper and the other hypotheses she is working on in the area of autoimmune gastritis. Autoimmune gastritis is characterized by the destruction of gastric parietal cells, resulting in low or non-existent stomach acid. Many patients with the autoimmune disease pernicious anaemia also have damage to parietal cells or their lack of intrinsic factor contributes to gastric issues and symptoms like IBS and IBD or low stomach acid. In many cases the prescription of Proton Pump Inhibitors (PPIs) has been the go to for GP's to prescribe inevitably making the symptoms worse for patients with PA as PPI's are known to deplete vitamin B12. Lori will talk about her research into mealtime acid supplementation, vitamin C and the theory that acidification could also reduce the potential for hypergastrinemia and the production of N-nitroso compounds, consequently reducing the risk of gastric cancers. This topical subject following the NICE Guideline use of the wording autoimmune gastritis, and references to atrophic gastritis as terms for Pernicious Anaemia is something that we think will be helpful for our members to better understand.

Dr Willemina Rietsema is a GP with a specific interest in Pernicious Anaemia, B12 deficiency and in ongoing research in this area. She is a co-founder of CluB-12, an international collaborative of researchers and educators interested in all aspects of vitamin B12. Willemina served on the NICE committee for the drafting of the *Guideline on B12 Deficiency in over 16s* and works for the NHS as a GP appraiser and out of hours GP. Her own experience and in-depth knowledge of B12 deficiency symptoms and treatment and her long term support of the Pernicious Anaemia Society through speaking at events and being involved in published papers gives her a uniquely insightful understanding of this condition.

Conferences & Meetings

In the last three months we have had a significant number of important meetings with universities, researchers, healthcare professionals and funding organisations. In addition members of the management team have attended seminars and online meetings with NIHR, RGCP, Health and Care Research Wales, the Tinnitus and Fibromyalgia charities. These meetings move us forward with our networking and raising awareness targets.

A report & discussion on the need for international treatment standard for B12 deficiency - Bettina Borre Buhl

21 January 2025

Based on the paper published in 2024 by Emil Buhl , Bettina Borre Buhl , Linda Skibsted Kornerup & Ebba Nexø, Bettina reports on the findings of their research review that focuses on current practice predominantly relying on more than 50 years old data.

What is still recommended and why are these guidelines so often not followed?
What is the relevance of re-testing?
And why symptoms rather than normalising blood test results are so important to resolve for the patient.

This seminar will review the findings of the report and discuss what clincical studies and strategies are really needed going forward to improve the treatment of people with Pernicious Anaemia and B12 deficiency symptoms. Visit our PAS Shop to get your ticket for this event.

Rachel Barnes PhD update

We are pleased to share with you an update from researcher, Rachel Barnes, who we are supporting with her PhD at the Quadram Institute. We are delighted with the progress made to date.

“Just a little update for you all.
I am currently beavering away at my PhD and have two threads that I am currently working on. Both, I hope, will help us gain valuable knowledge and foresight into exciting new developments. Firstly, I have been granted permission to audit the GP notes of all B12 patients within England and Northen Ireland, and this will allow me to gain the figures that will show the scale of the problem.

Secondly, I have submitted a new research proposal which will test the theory of B12 loss in urine. I hope to use these results to look at different diagnostic tests, and also to highlight the difference within B12 patients and their symptomatic control. I will continue to update you and hope to forge new insights into B12 as I continue with my research.”

Research

We are delighted to announce that we have now created a specific page on our website which is dedicated to updating you on our research collaborations and on improving understanding of research into Pernicious Anaemia.

On this page you will find news of our collaborations with research institutes, articles about existing and past research and news about the priorities for research including the James Lind Alliance and the recommendations from NICE.

Read our first article published here by Dr Willemina Rietsema about *Research Priorities for B12 Patients*.

Our Research Page is now live!

Find the page here

Help Us Understand and Improve the Management of Pernicious Anaemia

We are excited to share an important opportunity for all UK Pernicious Anaemia Society members to participate in a research study. This study, led by the research group at the University of Surrey in collaboration with PAS, aims to better understand the experiences of those living with pernicious anaemia (PA), with a particular focus on iron deficiency.

While iron deficiency is a key part of this research, the survey is important all UK PAS members to complete regardless of whether you have experienced iron deficiency or anaemia. Your input will help us paint a better picture of the challenges faced by those with PA, from diagnosis to treatment and symptom management.

By participating, you will be contributing to:

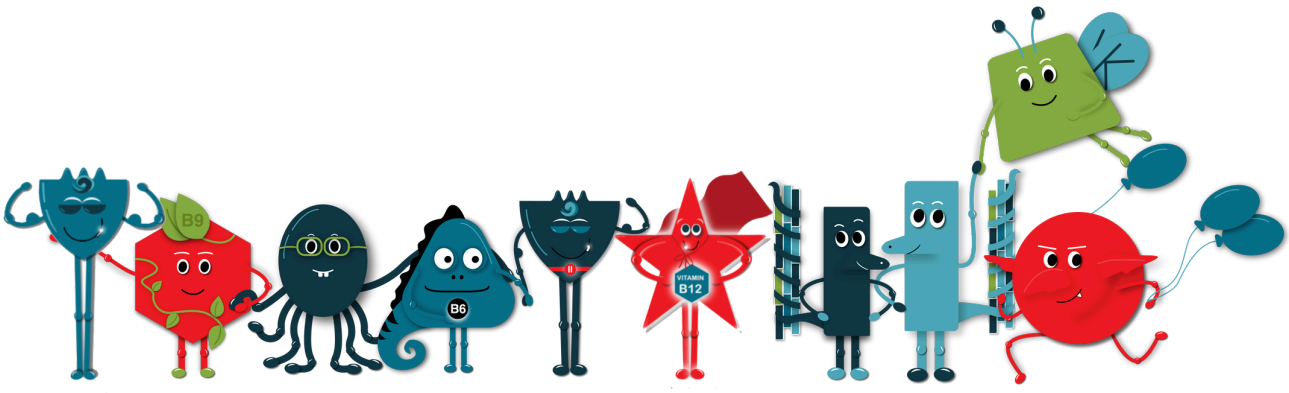
- Identifying gaps in current clinical care for PA patients.
- Improving understanding of the relationship between PA, vitamin B12 deficiency, and iron deficiency.
- Helping to shape future research towards tailored treatment guidelines.

The survey is quick and easy to complete it should take around 15-20 minutes and covers key areas such as your medical history, treatment experiences, and symptoms. Your responses will remain confidential, and only anonymised data will be analysed for this study.

To take part in this study, you must:

- Have a confirmed, probable, or suspected diagnosis of pernicious anaemia.
- Be over the age of 18 and living in the UK.
- Have access to the internet to complete the online survey.

If you would like to participate, then please follow this link to complete the consent form, after which you will receive the link to the survey.



Update on the Pernicious Anaemia Society Survey Research Study

We are happy to update you on the survey you generously participated in!

This study originated from the survey shared with PAS members in 2022, which is now also completed by new members on registration. Your valuable input has been key to carrying out this work.

We are pleased to share that the findings from our study have been translated into a research article. While the article is currently under review for publication in a peer-reviewed journal, the research is accessible as a preprint for anyone interested. You can read it using the link here.

An overview of the study

The study analysed data from over 1,000 PAS members, examining key areas such as diagnosis, comorbidities, family history, and management practices.

Key findings included:

- **Delays in getting diagnosed** - Over one-third of participants experienced delays of three years or more before receiving a diagnosis of pernicious anaemia, indicating gaps in current diagnostic practices and the need for improved awareness and protocols in both primary and secondary care.
- **Different Diagnosis Approaches** - Participants were diagnosed using a variety of tests and combinations of tests. However, there isn't a clear, reliable method that all doctors use for diagnosing PA. This contributes to the delays many people face in getting diagnosed.
- **Variable Treatment Practices** - More than half of the participants reported receiving vitamin B12 injections more frequently than the recommended guidelines. This highlights the need to create more tailored treatment plans that better suit individual needs.
- **Other conditions** - Nearly half of the participants had one or more additional autoimmune diseases, with conditions such as Hashimoto's disease, vitiligo, and rheumatoid arthritis being the most common. This shows that PA often presents with other conditions, such as other autoimmune diseases, and clinicians should consider the whole picture when treating patients.
- **Family Connections** - Many people said their family members also had PA or other autoimmune diseases. This suggests that PA may have a genetic or inherited component, which could help researchers better understand the condition in the future.

Your participation has been instrumental in this research. On behalf of the research team at the University of Surrey, we thank you for your time, effort, and commitment.

We will keep you updated on the progress of the publication and any subsequent developments. Thank you once again for your contribution to advancing our understanding of pernicious anaemia.

Alfie Thain

Seminar 26th November on Iron Deficiency and Pernicious Anaemia

Following a brief introduction from our CEO Katrina Burchell about the background and link to iron deficiency and B12 deficiency/Pernicious Anaemia, Professor Toby Richards gave a large audience of members of PAS a talk about iron deficiency as a disease and anaemia as the consequence of that disease. He pointed out that iron deficiency is a majorcause of disability worldwide with many suffering for years. Explaining how iron is absorbed, used and lost using great analogies of custom and border control it soon became clear how oral and infusions of iron work to address deficiency and symptoms. A lively and engaged Question and Answer session followed and Professor Richards' clear and thoughtful replies were much appreciated.

Iron deficiency is a disease prevalent in women but affecting men too, especially because of gastric issues. It is a condition which we have found is not so well understood in primary care and our members will definitely benefit from listening to this seminar which is available to download in our shop for those who were unable to listen on the day: Understanding Iron Deficiency and Its Connection to Pernicious Anaemia. Those who attended with purchased tickets will also be able to obtain a link to re-listen by sending an email to info@pasoc.org.uk.

Please remember that the purchase of access to the seminar is for your personal use only and the link may not be shared with others. The whole or any part of the recording may not be shared on social media or with any other organisation without express written permission from PAS. The cost of the tickets goes directly to funding the work of PAS including providing helpline services, education, raising awareness and funding research.

Professor Toby Richards

Professor Toby Richards is a practising surgeon, an honorary professor of surgery at University College London and honorary professor of anaesthesia at Monash University.

Specialised knowledge in Iron Deficiency Management, Iron Infusions, Clinical Trials. Research

PAS Annual Seminar

Our annual seminar took place on 12th October 2024, the day we nominated for PA-Day and we were delighted to hear presentations from our CEO, Katrina Burchell, Aflie Thain from Surrey University and Clara Plattel from the B12 Institute. The seminar was well attended and received.

Katrina recapped the NICE Guideline, pointing out the good and the bad parts as far as the Pernicious Anaemia Society is concerned and made some observations on the patient and doctor response to their publication in March 2024. So far patients are not seeing much improvement in GP awareness and education. Katrina talked about the education programmes she is working on for the Pernicious Anaemia Society for both the healthcare profession and for patients and the general public. These will be presented in different formats and alongside other projects for raising awareness, will hopefully help disseminate correct information about diagnosis and treatment and dispel many of the myths which those on a journey with PA often encounter from their GP. Katrina also introduced a new information video which is available in our website shop called "*How Does Vitamin B12 work in your Body*" which introduces our new gang of characters and is aimed at anyone with an interest in this area.
http//shop.pernicious-anaemia-society.org/product/how-vitamin-b12-works-in-your-body/

Pointing your doctor or nurse practitioner in the direction of our education material where they can spend a very small sum of their training budget might be a good idea! Alfie Thain then presented his research to date and discussed future ideas and plans about iron deficiency alongside pernicious anaemia, subdivisions of pernicious anaemia and wearable technology for symptom tracking. Clara Plattel then presented the important highlights from the research papers which were published after the 2023 Conference on B12 deficiency which covered B12 deficiency *At the Bookends of Life* and looked at B12 deficiency in pregnancy, childhood, adults and elderly. There is so much still to learn about B12 deficiency and Pernicious Anaemia but this seminar was a great reminder of all the impressive work which has already been done, especially in the last 2 to 3 years with our involvement in the NICE Guideline, our reaction thereto and our research building on the James Lind Alliance Priority Setting Partnership. A question and answer session completed our seminar with very useful comments and ideas for future topics and seminar ideas.

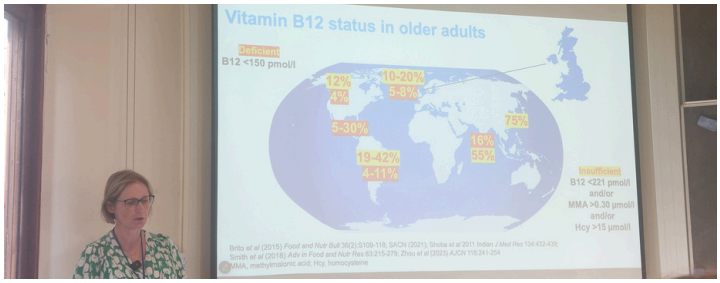
The PAS Annual Seminar can be purchased in our shop if you were unable to attend on the day. If you attended but would like to listen again to the seminar please email info@pasoc.org.uk and those with already purchased tickets will be given access to view.

A Global Gathering: The Third Vitamin B12 Symposium / CluB12 2024 in Cambridge

This September, the historic halls of St John's College, Cambridge, played host to a remarkable event: the third Vitamin B12 Symposium / CluB-12 2024. Over two days, on the 19th and 20th, experts, scientists, and medics from all corners of the world came together to discuss the latest research and advancements in the field of Vitamin B12. Katrina Burchell, CEO of the Pernicious Anaemia Society and Chair of the B-12 Alliance delivered a compelling talk that shed light on the ongoing collaboration between patient advocacy groups and the medical community, specifically addressing the NICE Guidelines and how these groups are working to raise awareness of B12 deficiency and its impacts. Her message was clear: unity and education are key to improving healthcare outcomes for those affected by B12 deficiency.

The event delved into a range of fascinating topics. From epigenetics and cognition, to Parkinson's disease, maternal B12 deficiency, and the importance of folate fortification and questions about B12 fortification. The discussions were both stimulating and thought-provoking. New advancements in biomarker determinations sparked lively debates and paved the way for further exploration in these areas.

The symposium fostered a vibrant atmosphere of networking and collaboration. Attendees left not only with new knowledge but also eager to continue their work in improving understanding and treatment of Vitamin B12 deficiencies. The venue of St John's College Cambridge and dinner in St John's Hall was a fitting setting for such a prestigious event. The historic architecture and elegant surroundings provided a unique and memorable backdrop for the discussions and networking. It was clear that this event had achieved its goal: bringing together brilliant minds to share, learn, and push forward the boundaries of Vitamin B12 research. The involvement of the Pernicious Anaemia Society in these events helps raise awareness of the issues facing patients, the areas where research would make a practical and significant difference and helps us better advise our members and lobby for changes through education and raising awareness.



Fundraising

Hospital Saturday Fund

We are delighted to announce that following an application for a grant from the Hospital Saturday Fund, we have been awarded a grant of £2000 towards our University of Surrey research project, which will help us continue to support Alfie Thain and the team there as they continue to work on the important research projects on B12 deficiency and Pernicious Anaemia. We still need to raise a significant sum for this and other research projects, so our efforts will continue with further grant applications and calls for support.

Donation from the Postcode Lottery

We are also really pleased to announce that we also received a kind donation from the Postcode Lottery as a contribution towards our Health Care Professional training module as announced in our Annual Seminar by our CEO. We are now working closely with Konektis, a specialist software developer, on an eLearning programme.

Craft Fair

On Saturday 5th October Nicole Sennet of Sewn by Sennett held a craft fair and donated proceeds from the raffle and various activities at the end of the event to the Pernicious Anaemia Society.

Nicole who has family members with Pernicious Anaemia and understands the impact on their lives, raised more than £700 for the charity and we are truly grateful for her enthusiasm and passion to make this event a huge success. The event was attended by local dignitaries and was a resounding success for the local community and stall holders.

Picture to the right: Nicole with our CEO Katrina Burchell, Mayor of Wisbech, Sidney Imafido and PAS Treasurer Nicola Finck

Make a Donation:

Donate here on our website

‘Silly Rules’ Survey

The Bevan Commission has launched a survey regarding ‘SIlly Rules’

The work aims to identify ‘unhelpful rules’ or ‘administrative barriers’ that contribute little or no value to care.

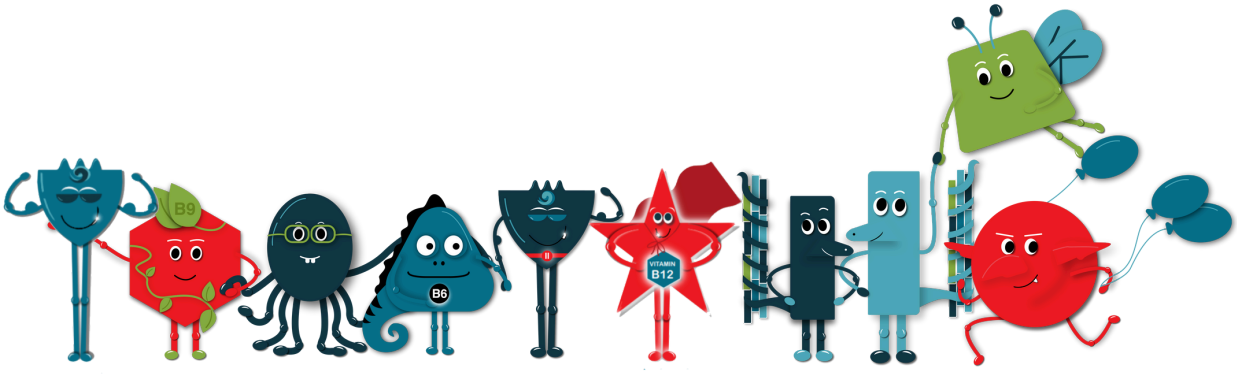
This is a great opportunity for you to report, via their survey, what you think are ‘Silly Rules’ in relation to Pernicious Anaemia/B12 deficiency.

To complete the survey, click here.

Healthwatch Survey

There is an organisation called Healthwatch that is asking people (England only) to share their experiences and carry out a survey to tell them how changes to ‘NHS and Social Care Services’ can make their care better.

To complete the survey, click the link.



Research Highlight

Future research Genomics England - The Generation Study

The Pernicious Anaemia Society is very pleased to have worked with Genomics England after being invited to be the contact organisation for haemotologists and families of babies diagnosed with megaloblastic anaemia.

We will be issuing an information leaflet and providing advice as required. Patient organisations like ours have played a vital role in the development of the Generation Study, and we look forward to continuing to collaborate with Genomics England as the study progresses. You can learn more about the study by visiting https://www.genomicsengland.co.uk/initiatives/newborns,

Megaloblastic anaemia is a type of anaemia characterised by the production of abnormally large red blood cells called megaloblasts.

These cells are larger than normal and often have a deformed nucleus. This condition occurs when there is a deficiency of either **vitamin B12** or **folate** (vitamin B9).
A diagnosis of megaloblastic anaemia will usually be made from a blood test including a blood film which looks at the size and shape of the red blood cells.
Iron deficiency anaemia is another type of anaemia characterised by smaller than normal blood cells.

Both types of anaemia can be treated with suitable medication.
There may be an underlying cause which will result in the return of the megaloblastic anaemia and may need further investigation.

Causes

- Vitamin B12 deficiency: This can be due to inadequate dietary intake, malabsorption issues (like the autoimmune condition pernicious anaemia), or certain medications.
- Folate deficiency: This can be caused by inadequate dietary intake, increased folate requirements (such as during pregnancy or rapid growth), or certain medications.
- Other factors: In some cases, megaloblastic anaemia can be caused by other underlying conditions, such as liver disease or certain inherited disorders.

Symptoms

- **Fatigue:** Due to the reduced oxygen-carrying capacity of the blood.
- **Weakness:** A common symptom associated with anaemia.
- **Shortness of breath:** Difficulty breathing, especially with exertion.
- **Pale skin:** A result of decreased red blood cells.
- **Heart palpitations:** Irregular heartbeat.
- **Loss of appetite:** A common symptom of anaemia.
- **Sore tongue:** A common symptom of vitamin B12 deficiency.
- **Nerve damage:** In severe cases of vitamin B12 deficiency.

Treatment

The treatment for megaloblastic anaemia typically involves:

- **Replacing the deficient vitamin:** Either vitamin B12 or folate, depending on the underlying cause.
- **Addressing any underlying medical conditions:** Such as Pernicious Anaemia, Imerslund-Grasbeck syndrome (IGS), selective vitamin B12 (cobalamin) malabsorption with proteinuria or other potential malabsorption issues
- **Monitoring blood count:** To ensure the anaemia is improving.

https://pernicious-anaemia-society.org/articles/megaloblastic-anaemia/

Show your face for Pernicious Anaemia

Want to help spread awareness about pernicious anaemia?

We're looking for members to submit a photo or short video of themselves that we can use on our social media channels. Your participation will help us showcase the diverse faces of pernicious anaemia and connect with more people who may be affected.

Why your photo matters:

- **Real people, real stories:** Pictures of real people resonate with our audience. They help us humanize pernicious anaemia and make it more relatable.
- **Diversity matters:** We want to represent the wide range of people affected by pernicious anaemia, including people of all ages, ethnicities, genders, and geographic locations.
- **Increased engagement:** Posts featuring real people tend to get more engagement on social media, helping us reach a wider audience.

How to participate:

1. **Take a photo or video:** Simply snap a picture or record a short video of yourself. You do not have to use your name if you don't want to. Keep it casual and natural!
2. **Send it to us:** Email your photo or video to karyl@pasoc.org.uk along with your name and a brief description of your experience with pernicious anaemia.

By sharing your photo or video, you're helping to raise awareness about pernicious anaemia and support others who may be going through similar experiences.

We will use the photos and videos on social media or our website.

Let's show the world the faces of Pernicious Anaemia!

Personal Story

Paul Johnson

My name is Paul Johnson in a few weeks' time I will be 70. My story begins over 25 years ago, a business trip took me to Venezuela, a country of polar opposites when it comes to the 'haves' and the 'have nots'. A country under development but as far as I can see nothing has changed, poor people, bad infrastructure, poor sanitation. I contracted a tropical strain of dysentery, there are two types, one you have for 4 days and you die the other one I got, it stayed with me for years. I returned to the UK in the bathroom of a 747!

When my doctor saw me he panicked (it's a reportable disease so no doubt paper intensive, a bit like the journey home eh) within a couple of weeks I developed 9 blood clots in my leg and was prescribed an intensive course of Heparin followed by warfarin (rat poison) this eased my swollen leg somewhat, why am I telling you this? I will come back to that shortly.

My 'condition' deteriorated and close friends were extremely worried that I couldn't string a sentence together, which for a salesman was a tad inconvenient. It got so bad they even talked about a brain tumour (behind my back); my taste buds left home, even my favourite chocolate tasted like vinegar, for the first time in my life people referred to me.....as...well....thin? On top of this the thoughts in my head were equally uncharacteristic, I love people, I love being around them, I began to crave being alone and asleep.

A routine blood test was brought forward, Monday morning 10:20 the nurse visited, 3:55 the same day, a panicked Doctor (another one) was on the phone made me promise to be in his office by 08:00 Tuesday without fail. On arrival he explained that my blood tests had come back by phone (most unusual) with a red flag attached so to speak and I had to have an injection every other day until my B12 levels had come up? I put my best four words together....."what are they now?"....he paused and looked at me and almost whispered 12.

He went on to explain (I said I would come back to it) we are born with an intrinsic factor that allows us to assimilate B12 from our food, the dysentery I contracted was instrumental in starting the demise of this vital factor and then the warfarin which treated the blood clots has seen it off never to return?....."But don't worry we can get you back to normal fairly quickly but you will need injections for the rest of your life."

I saw him every other day for a month, in between numerous tests ensued I asked 'why', clearly still not good with words, said he needed to ensure the intrinsic factor was no more because with levels so low I was probably 3-4 days away from dying and he didn't want that on his conscience (a good man).

I started my lifelong treatment approximately 10 weeks after this dramatic summons to his office by having Hydroxocobalamin injections every 12 weeks, over the years this has become 10 weeks then 8, 6 and now every 28 days, I now self-administer as the district nurse reckoned I was just as experienced as she was .....she trained me.....got permission and now readily supplies syringes in batches of 6, so I see her twice a year for a catch up.

My reasons for adjusting the frequency of injections have always been the same, the original symptoms return, the tiredness/fatigue the inability to taste, I could always identify all of the component flavours in my food (bit of a party piece), but more than this these are all internal, but when family and friends see your face drained and before you've said a word they say "when is your injection due?" you know something is wrong. I have encountered some remarkable people during the last 20 odd years, perhaps one that stands out is the practice nurse where I was first diagnosed. She also lost her intrinsic factor during emergency surgery, she explained to me that the tiredness/fatigue we feel is worse than when she was in her last two weeks of pregnancy....with twins?

We moved house and therefore doctors, and I was asked to go in for a check up.
I was met by my Doctor laying prone in his chair with both feet crossed on top of notes all over an untidy desk:
"morning" I said
he said "i see you are on B12 Injections,,,, we will stop those"
me..."you will will you?....you've read my notes have you?..
him "yes"...me ..
"so you know I have pernicious anaemia and if I don't get them I will die?...
him..cough er legs down glasses on "we will leave that for now"....
me..."yes you will and never bring it up again?"

All was well until recently 2 new surgeries opened up within one minute from my home I tossed a coin and moved....big mistake...same initial conversation same arrogance but this time we will put you back on 12 weekly injections as you are getting too much B12 and that can affect your liver. I commended her for being able to diagnose an overdose of B12 and liver damage from a three minute meeting and a handshake.

I asked her for the reference of the study on liver problems as the Pernicious Anaemia Society would love to review it, further I would produce a report for her to read to update her understanding of the condition, but under no circumstances was she to alter my prescription quantity or frequency without compelling evidence. I left without her saying another word, she followed up this interview by refusing my prescription by text, I put the PAS information together with input from the helpline (10 pages A4 I wanted to be thorough) and returned with two copies one for the practice manager to be entered into my file and one for the Doctor to review at our earliest appointment....3 days...not bad. When I turned up she was unavailable, my wife and I where shown to another office where it didn't go too well.....for him, I asked had he read the information in the report he said no we don't get time to do things like that?

I proceeded to bullet point all of the report
My wife was watching his face as it drained of colour and any sign of arrogance that may have worked in the past, he only interrupted once with the point of cost so I asked him how much one vial of B12 was he said some of his colleagues are charging 3-4 hundred pounds for one I said not how much his colleagues where ripping people off 'how much does it cost" he was astonished when I pointed him to the NICE report which confirms each vial at 83p.
Shortly after we left the surgery with my prescription re-instated (or so I thought) 4 weeks ago I was again refused by text without consultation and with what seemed to be no uncertain terms and no way back.

I moved again, the reception I received could not have been more different, my new Doctor listens, she agreed that she had no knowledge of a report re liver damage and B12, she was uneasy about me self-administering but when I explained how long I have been doing it and after consulting with her partners she was more than happy my prescription was delivered the next day.

There are 2 lessons I have learned when choosing something as important as this. First is don't flip a coin when deciding something as important as your choice of Doctor, coinage is notoriously unreliable under these circumstances
Second is don't assume your Doctor knows as much as you do, with help from the PAS I can confidently attest to the fact that their up to date information will be way ahead of anything your GP has time to read, and when applied under the right opportunities you can be in the position of educator even with the most 'stuck in their ways' GP, I think we would all agree that our health service is under tremendous pressure facilitated by overworked underpaid dedicated individuals that. When presented with the right information you can find someone who will work with you, those that won't....well you can always move.....just not on the flip of a coin.

Being a member of the Pernicious Anaemia Society is an invaluable part of my treatment.

Merry Christmas and Thank You to our Trustees, Members, Volunteers, Colleagues and all who support the Pernicious Anaemia Society.