

Cobalamin News

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Spring 2025

March 2025

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Research Highlight:

New paper on Pernicious Anaemia and the NICE Guidelines

This perspective explores the recent 2024 NICE guidelines on vitamin B12 deficiency, particularly their implications for Pernicious Anaemia (PA). While the guidelines bring some positive changes—such as a shift towards a symptom-based approach to treatment—they also introduce several limitations.



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 needed. 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

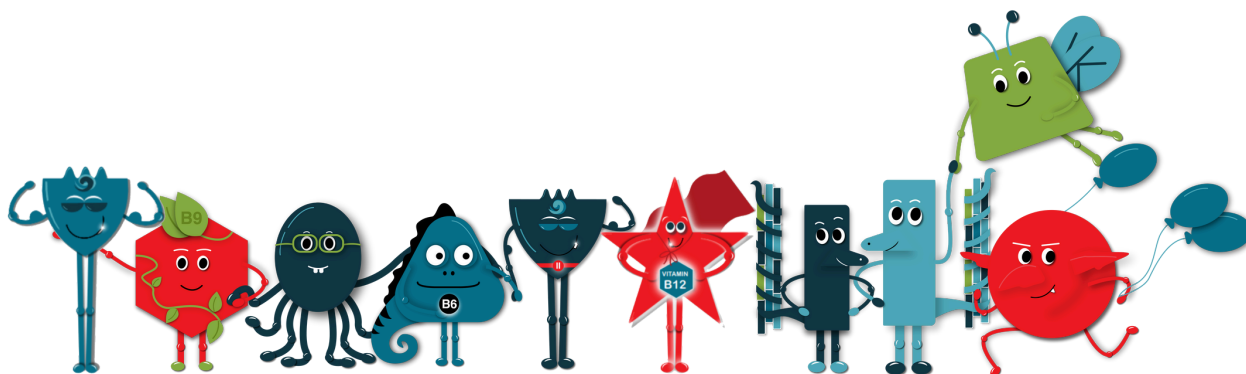
- ☎ **01656 817085** - Mon-Fri 8:30am-12:30pm
- ✉ **support@pasoc.org.uk** - members who live overseas or prefer emails
- ✉ **membership@pasoc.org.uk** - membership questions
- ✉ **info@pasoc.org.uk** - general questions
- 👤 Helpline volunteers: Liz, Kathy, Alex, Karyl

CEO's Introduction

from our CEO, Katrina Burchell

Welcome to our Spring Newsletter. The first few months of the year have been hectic. We have recently moved our physical office twice, still in the same location in Bridgend but first from level 4 to level 2 then now to level 1. We are very grateful to the landlord at Brackla House who makes sure we have office space and these moves have given us the opportunity to think about future meeting space requirements, storage and the potential sale of furniture and equipment we no longer need. It also highlights to us the very real need to improve our telephone system to support our helpdesk and general enquiries, something that we will need to look for funding for in the coming year. Our series of seminars has been hugely popular both live and for people purchasing access via our shop if they are in a different time zone or not available on the day of the event. We are indebted to the speakers who freely gave up their time to share their expertise and to you the audience for your support, attendance and thoughtful questions and debate. We have more seminars for the year in planning and of course will hold our research review annual seminar on 11th October 2025.

Our work with the B12 Alliance, CluB-12, various universities and other organisations continues. In February I wrote to the Chief Medical Officers and Chief Nursing Officers about the lack of education and awareness in primary care and particularly highlighting many examples of personal stories and concerns raised by our members about their journey even after the NICE Guideline publication in 2024. Thanks to additional support from Claire on our social media campaigns we now can be more responsive to topical issues alongside Hollie and Becca who support us with our social media strategic posts. The impact of our voice in social media should not be underestimated so please encourage your friends and colleagues to give us a like, follow or repost on Facebook, Instagram or LinkedIn.



New paper on Pernicious Anaemia and the NICE Guidelines

By Alfie Thain

We are pleased to share that our perspective paper, titled “Addressing the Gaps in the Vitamin B12 Deficiency 2024 NICE Guidelines: Highlighting the Need for Better Recognition, Diagnosis, and Management of Pernicious Anaemia” has been officially published in the European Journal of Clinical Nutrition.

This perspective explores the recent 2024 NICE guidelines on vitamin B12 deficiency, particularly their implications for Pernicious Anaemia (PA). While the guidelines bring some positive changes—such as a shift towards a symptom-based approach to treatment—they also introduce several limitations.

One of the key issues is the renaming of PA as Autoimmune Gastritis. While PA develops as a result of autoimmune gastritis, these two conditions are not interchangeable. PA is a distinct condition characterised by intrinsic factor deficiency and lifelong B12 malabsorption, requiring specific management. The concern is that renaming it may cause confusion in diagnosis, treatment, and patient care.

Additionally, our paper highlights that diagnosing PA remains challenging, as many commonly used tests such as intrinsic factor and parietal cell antibodies have poor accuracy. Some tests lack sensitivity, meaning they fail to detect PA in many cases, leading to missed diagnoses. Others lack specificity, meaning they can detect but cannot confirm PA specifically, as they may also be positive in other conditions such as autoimmune thyroid disease. This makes it difficult for clinicians to rely on these tests for an accurate diagnosis. We also emphasise that only 9% of PA patients are currently offered gastroscopy at diagnosis, despite its importance in confirming the degree of atrophy in the stomach.

On a positive note, the new guidelines acknowledge the need for individualised treatment approaches, including adjusting B12 frequency based on symptoms rather than fixed intervals. However, as we know, many patients still find it difficult to access more frequent treatment when needed.

The perspective calls for better diagnostic pathways, long-term monitoring plans, and clinician education to ensure those with PA receive the correct treatment and management.

This publication is a step forward in raising awareness about PA management and advocating for improvements in clinical practice. We are grateful for the continued support of the Pernicious Anaemia Society and hope that this paper will contribute to ongoing discussions about improving patient care.

If you would like to read the full perspective, you can access it here -

<https://www.nature.com/articles/s41430-025-01583-4>

Exploring Iron Deficiency in Pernicious Anaemia – Preliminary results

By Alfie Thain

We recently conducted a study on iron deficiency in PA, in collaboration with the Pernicious Anaemia Society, to better understand how it is diagnosed, treated, and monitored in individuals with PA.

Why is This Important?

Iron deficiency is common in PA patients, but there are currently no formal guidelines for screening or management. Iron deficiency can present with or without anaemia, single-occurrence deficiency, or recurrent deficiency, which can pose unique management challenges. Many experience deficiency before or after their PA diagnosis, and it can be difficult to distinguish symptoms of low iron from those of PA itself.

Key Preliminary Findings

Of the 202 completed responses (Please note these results may change once we analyse additional responses):

- 33% of survey participants reported experiencing iron deficiency both before and after their PA diagnosis.
- 41% of those with recurring iron deficiency said their condition was not well managed.
- Iron tablets were the most common treatment (71% of participants), while 9% received iron infusions.
- 59% of participants reported that their iron levels improved after treatment, but 42% continued to experience symptoms despite treatment.
- One-third of participants (33%) had no follow-up blood tests after iron treatment.
- Nearly 80% had no regular monitoring for iron deficiency.
- 43% of respondents found it difficult to differentiate iron deficiency symptoms from PA symptoms.

What's next?

Since these preliminary findings, we have received additional survey responses, which we are currently analysing. These new data will help us better understand the full extent of iron deficiency in PA and support our efforts to advocate for improved iron deficiency screening and management.

We want to thank all PAS members who participated in this survey! We look forward to sharing more updates as we continue our analysis.

If you have not yet participated but would like to, you should have received an email from PAS with details on how to take part.

Support Group News

In order to reach as many of our members as possible, we have been holding our Support Groups online, via Zoom.

Having online meetings means any member can join in regardless of where they live.

If you would like to join an online meeting but are not very sure of Zoom, just get in touch and we can help you with this.

Our Support groups are a great way to meet others who understand what it is like to live with Pernicious Anaemia and is a great way to swap information and strategies.

If there is anything you would like to know about the Support groups, just let us know and don't forget, you can also suggest the discussion topic. Check out the website for all support group dates/times

You must register in advance for the meetings if you wish to join. After registering you will receive a confirmation email containing information about joining the meeting.

Scotland

On Sunday 9th March, our volunteer, Karen Seex, held an online support group. which was attended by 6 people. The topic of discussion was 'Sharing real life strategies - tips from fellow members on what has helped them feel better'.

Karen is holding her next group on **Sunday 6th April** at 16.00. Note - you need to register to attend the support group and you can do so by clicking [here](#).

Topic: Speaking to your GP and advocating for yourself

Chicago

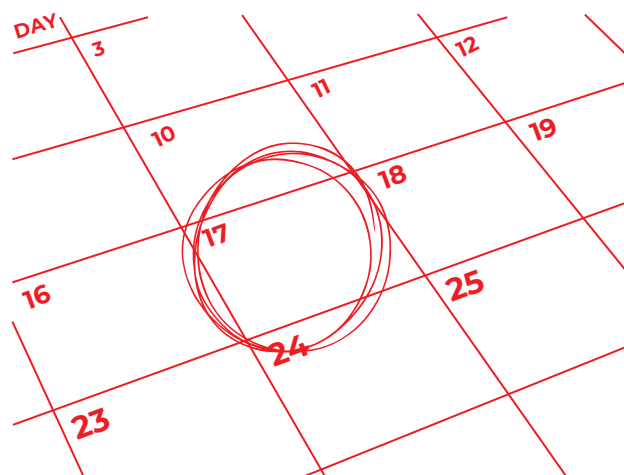
On **Saturday March 22nd**, our Volunteer Julie will be holding an online group at 13.00 Chicago time. Julie has a very successful group with a regular group of attendees and some of the subjects discussed include 'Celebrating small victories - how little changes can make a big difference' & 'Sharing real-life strategies'. You can register [here](#).

Sussex

On **Sunday 30th March** at 11am, our Sussex-based volunteer Benita Johnson will be holding an online Support Group Meeting. If you would like to attend, please [click the link](#) to register.

What's on & Key Dates

- **22nd March** 2025 - Chicago Online Support Group with Julie
- **26th March** 2025 - Seminar with Professor Dominic Harrington - A Changing Landscape for B12 Testing
- **30th March** 2025 - Sussex Online Support Group Meeting
- **6th April** 2025 - Scotland Online Support group with Karen
- **13th September** 2025 - PAS AGM 2025
- **4th October** 2025 - Craft Fair with Nicole
- **11th October** - PA Day and our Annual Seminar



Sign up for the seminars via our shop
<https://shop.pernicious-anaemia-society.org/>

Sessions are also recorded and made available for sale in our shop after the event.



PAS Webinars

A Changing Landscape for B12 Testing - 26th March 6.30pm

Professor Dominic Harrington, Synnovis, will share his knowledge about Pathology: Testing blood for vitamin B12 deficiency. Dominic has been Chief Scientific Officer at Synnovis, who provide all pathology services in south east London, since 2017, and is a Consultant Clinical Scientist. His primary research interest is in the development and application of biomarkers for the assessment of vitamin status. Dominic has published more than 90 scientific papers and books and has an honorary academic position at King's College London and is a visiting professor at the School of Biosciences and Medicine, University of Surrey. In addition, Dominic is a Fellow of the Royal College of Pathologists and a Chartered Quality Professional.

If you are a patient, clinician or researcher, this talk is for you. Even if you think you already know about blood tests, come along and hear about blood samples, what can affect the test results, what needs to be understood about the results, what do the different tests look for and tell the clinician and how should they be interpreted? [Get your ticket here.](#)

PAS Webinars

Autoimmune Gastritis and Pernicious Anaemia – Symptoms, Treatment and Research

On 18th December Professor Lori Taylor gave a presentation on Autoimmune Gastritis and Pernicious Anaemia – Symptoms, Treatment and Research. In this talk Lori explained in detail about how gastritis leads to damage of the parietal cells and intrinsic factor and ultimately Pernicious Anaemia. Her passion for the subject was transparent not only as a patient but as a clinical dietitian, educator, and researcher. The seminar was attended by nearly 50 people all of whom were engaged in the topic and which resulted in a lively question and answer session which was supported by Dr Willemina Rietsema. The extensive and detailed slide deck and the huge amount of information shared by Lori on the science and potential solutions was incredibly helpful and appreciated by all. Luckily the recorded session is available for all who attended to re-listen and if you were not able to attend the live event, it is still available to purchase in our [Shop](#)

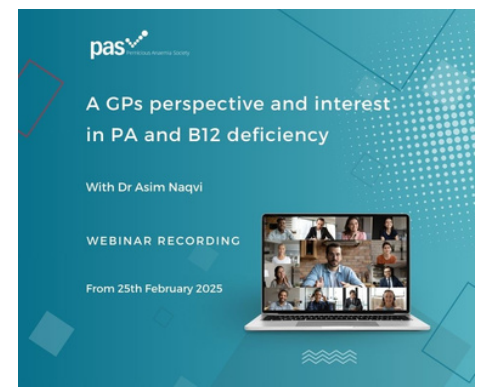


A GPs perspective and interest in PA and B12 deficiency - with Dr Asim Naqvi

On 25th February at 18.30, Dr Asim Naqvi gave his perspective on being a GP and running his own private clinic for patients with B12 deficiency. His own interest in Vitamin B12 and his role with PAS in the James Lind Alliance process, as well as his involvement with other organisations like the B12 Society and CluB-12, give him a unique insight into this topic. Dr Naqvi is well aware however, that the number of GPs who have up to date knowledge of Pernicious Anaemia and B12 deficiency is limited in the UK and wants to share his knowledge and experience of patient management and his understanding of B12 deficiency with the wider health care professional network.

Throughout his very informative seminar, Dr Naqvi shared his views that after 20 years of clinical practice, he had become aware of the importance of vitamin B12 deficiency, the insidious illness that is Pernicious Anaemia, and the failings of current medical care in the management of this. The clinical presentations are widespread and often misdiagnosed leading to significant unnecessary morbidity. Dr Naqvi spoke passionately and strongly feels a scientific approach is required to confirm what he has found in many clinical cases such that guidelines are updated in patients best interests.

Dr Naqvi's seminar was recorded and is available to purchase [in the shop](#) on our website.

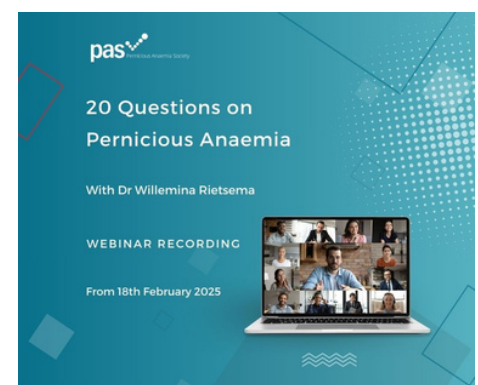


20 Questions on Pernicious Anaemia - with Dr Willemina Rietsema

On 18th February at 18.30, using her experience as a GP, GP assessor, former member of NICE committee for the B12 deficiency guideline and co-founder of CluB-12, Dr Rietsema was invited to address some of the thorny issues associated with Pernicious Anaemia.

Dr Willemina Rietsema looked at the many questions sent in by our members as well as those questions that are frequently asked on our telephone and email help-desks. Throughout her presentation and notwithstanding the guidelines, it is clear that there are still vast areas of knowledge that needs to be disseminated to the doctors and nurses and primary care, and that greater empathy is needed for people struggling to get a diagnosis and adequate treatment for Pernicious Anaemia. The Pernicious Anaemia Society's goal in raising awareness and education is to help the informed patient and doctor have constructive discussions about their health and their autoimmune condition. We still have a long way to go in changing mindsets and attitudes of many healthcare professionals.

The PA Society is very grateful to Dr Rietsema for giving such an informative and useful seminar and for the work she does to help the Society and our members. The seminar was recorded and can be purchased [via our shop](#) on our website.



A report and discussion on the need for an international treatment standard for B12 deficiency - with Bettina Bore Buhl

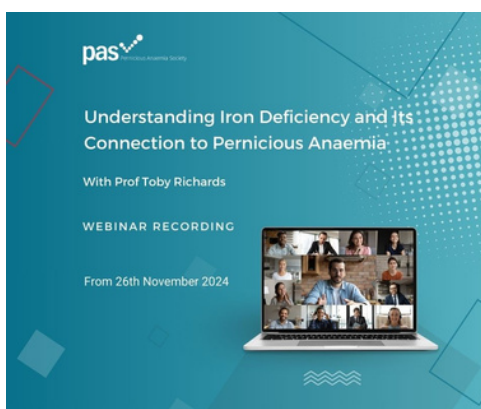
On 21st January, patients, clinicians and researchers gathered to hear Bettina from Denmark describe her personal journey with b12 deficiency and pernicious anaemia and what she has been doing personally to help patients in her clinic in Denmark and to improve awareness through education. In 2024 she co-authored a paper on the need for an international treatment standard. Pointing out that existing treatment standards are based on research which in many cases is decades old but that the conclusions are still clear – treatment needs to be lifelong and must treat symptoms not serum results. Bettina's personal reflection that Each patient is unique and deserves a thorough evaluation, personalized treatment, and to be met with compassion.

is one a proposition that we all support. Her extensive experience has led her to work in Denmark, where she helps others with B12 deficiency and contributes to critical research. During the seminar, Bettina provided an insightful breakdown of the research paper she co-authored, captivating an engaged audience eager to learn more.

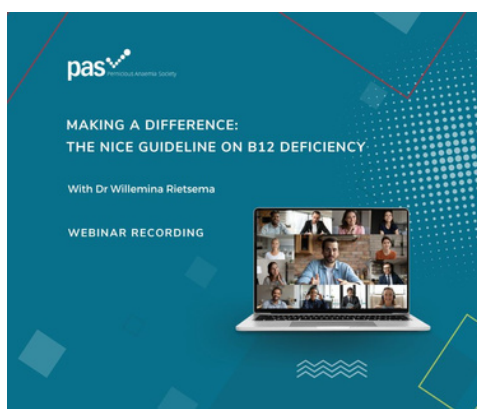
For those who couldn't attend the seminar, the recording is available [in our shop](#), providing an opportunity for our global community to access this invaluable knowledge. Every purchase helps support the Pernicious Anaemia Society's ongoing mission to raise awareness, advocate for better care, and promote further research.



Earlier webinars



Understanding Iron Deficiency and Its Connection to Pernicious Anaemia – Recording of the webinar from 26 November 2024 with Prof. Toby Richards



Making a Difference – The NICE Guideline on B12 deficiency – Recording of the webinar from 23 April 2024 With Dr Willemina Rietsema



Annual PAS Seminar – Recording of the webinar from October 2024 with Alfie Thain, Clara Plattel and Katrina Burchell

Andy Emerson's Camino de Santiago Challenge

One of our Trustees, Andy Emerson is about to embark on the Camino de Santiago (Ingles) 126.8 km walk from Ferrol to Santiago in Northern Spain. Breaking the walk over 5 days rather than 4 (23rd March to 27th March) will hopefully alleviate some of the challenges that Andy and his friends will face. Andy has been a trustee of the Pernicious Anaemia Society for the last 18 months and would like to take this opportunity to use the walk to fundraise for PAS with the aim of supporting our current projects and future activities of the charity. Andy will be posting regular training blogs over the next few weeks and updates during the walk on the Pernicious Anaemia Social Media Accounts and Andy's social media accounts.



Any donation in these difficult times is warmly welcomed from those who can afford to give. If you are a company and would like to adopt the Pernicious Anaemia Society as your organisation's charitable cause, please contact our CEO at ceo@pasoc.org.uk

Support Andy with a donation
Click [here](#) or scan the QR code.



Socials

Follow along on Andy's [Facebook](#) & [LinkedIn](#)



Chris and Hollie Run the Brighton Marathon

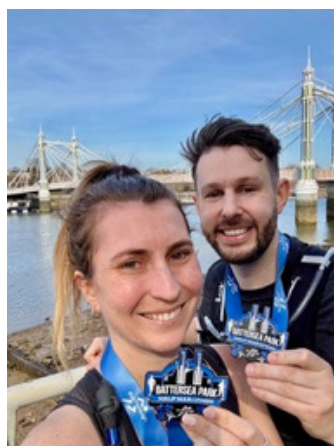
Chris, 31, and Hollie, 30, both architects living in London, are running the Brighton Marathon on the 6th of April for the Pernicious Anaemia Society to raise awareness of the condition and its impact on people's lives.

Hollie, who has Pernicious Anaemia, faces daily challenges due to B12 deficiency, but she refuses to let her condition define her or limit her passions. Her resilience and determination have inspired Chris to join her in tackling this gruelling 42km challenge, along with the months of training and preparation. They enjoy many sports, including regular parkruns with their friends and dogs at Battersea Park, and love going on extreme hiking trips in South America, such as their five-day hike to Machu Picchu in Peru, seasonal skiing holidays in the Alps and the Pyrenees, and month-long adventures, most recently travelling the length of Japan. They have just completed the Battersea half marathon (21km) on Saturday the 8th of March and are in full training for next month's marathon.

Hollie's unwavering spirit remains determined to not allow her condition to prevent her from keeping up with Chris on their travels and in life. They hope this marathon will not only raise awareness for those living with pernicious anaemia, but also support vital advancements in treatment. Thank you to everyone who supports this meaningful cause.

Support them with a donation:
Click [here](#) or scan the QR code.

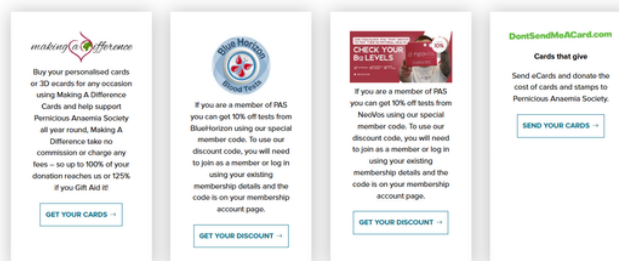
Chris and Hollie Run the Brighton
Marathon for Pernicious Anaemia's
JustGiving Page



Our Shop

You can now get your personalised eCards in the shop.

- **Personalized:** eCards can be customized with unique backgrounds, media, and messages, making them feel more personal than a generic paper card.
- **Environmentally** friendly: eCards are a paperless alternative to traditional cards, reducing waste and saving trees.
- **Convenient:** eCards can be sent instantly and from anywhere, making them a great option for last-minute greetings or when you can't be there in person.
- **Cost-effective:** eCards are often free or less expensive than traditional cards, making them a budget-friendly way to show you care.
- **Long-lasting:** Unlike paper cards that can get lost or damaged, eCards can be stored digitally and viewed repeatedly.
- **Fun and interactive:** eCards can include animations, videos, and other interactive elements that make them more engaging than traditional cards.
- **Easy to share:** eCards can be easily shared on social media or through email, making it simple to spread the joy.



Fundraising

Slimming World & Weight Watchers

Did you know that Slimming World and Weight Watchers (WW) groups choose a charity to support? If you are a member of one of these groups, we'd be so grateful if you considered nominating The Pernicious Anaemia Society as your group's chosen charity.

Every little contribution helps us continue our vital work, and it's an easy way to support a cause you care about while working towards your own goals. If your group needs any more information to consider us, just get in touch here - karyl@pasoc.org.uk - we'd love to hear from you.

Also, many crematoriums in the UK participate in metal recycling schemes, where metals remaining after cremation - such as orthopaedic implants and metals from coffins - are respectfully recycled with the consent of the deceased's family.

One prominent initiative is the Institute of Cemetery and Crematorium Management (ICCM) recycling of Metals Scheme. Since its inception in 2007, this scheme has raised over £19 million for more than 700 charities across the UK.

Do you know or could you find out for us if your crematorium (or local authority) participates in a metal recycling programme and, if so, the process for nominating charities?



Bing Rewards

PAS are now set up as a charity that can receive donations through the Bing Rewards programme.

If you use Bing as a search engine and you have a Microsoft account, you get points every time you search for something on Bing, play games or shop. Once you have £1000, you can choose a charity to donate to or you can even set up automatic donations.

If you are on Bing.Com you can go to rewards.bing.com to learn more and see your own points!

Thank you Emma & Paul

We would like to say a huge thank you to Emma and Paul who got married on 8th December 2024 and who nominated PAS as one of their chosen charities to receive donations. We are very grateful to them and their friends and family who have so kindly donated to their nominated causes.

Emma suffers from symptoms of PA daily and has advised that PAS supported her when she first became ill and enabled her to live a relatively normal life. Emma got the opportunity to meet the founder of Pernicious Anaemia Society at their head office and was interviewed on how her condition affects her and this in turn has helped to support other sufferers. It was whilst she learnt about all the research they fund to develop new treatments and the free support they provide to other sufferers.

Emma and Paul had set a target to raise "250 for PAS but have exceeded this and more!! They have raised £408 for PAS to date which, with Gift Aid, becomes a massive £506.88!

Once again, we send you both our huge thanks and offer congratulations on your wedding and all the best wishes for a healthy and happy future together



Research

An update from Rachel Barnes on her PhD:

Whilst Rachel is still waiting for ethical approval for her lab work, we are happy to confirm she has been granted the data sets needed to move forward but is awaiting approval to download them. We are really excited about Rachel's work and will continue to give you updates as things progress.

Wren Project

We are pleased to confirm our relationship with The Wren Project. The Wren Project exists to bridge the gap between a life-changing autoimmune disease diagnosis and access to mental health support.

Founded by people living with autoimmune diseases, The Wren Project understands the huge impact a diagnosis has on your mental and emotional health.

Many of our Wrens, people we support, have experienced a long wait for a diagnosis. The impact of living with unexplained and worsening symptoms, to receiving a diagnosis and then managing medications and appointments, is life-changing. We believe that by harnessing the power of deep listening, we can reduce feelings of grief, loneliness and helplessness. We create spaces where our Wrens feel heard and validated in their experience.

Here, you can talk openly about how you are feeling, without the time constraints of a medical appointment and to your trusted volunteer.

Click [here](#) to contact The Wren Project for support



The
Wren
Project

Tracking Symptom Changes and Treatment Responses in Pernicious Anaemia

We are happy to share findings from our symptom tracking study in Pernicious Anaemia, conducted in collaboration with the Pernicious Anaemia Society. This study aimed to better understand how PA symptoms vary day-to-day and how treatment and different treatment frequencies impact symptom relief.

Why is This Important?

Current PA treatment guidelines recommend B12 injections every 2–3 months, but many report needing more frequent injections to manage symptoms. However, little research has been done to track how symptoms fluctuate over time and how patients respond to different treatment schedules.

Our study used daily symptom tracking to capture how B12 treatment affects symptoms like tiredness, muscle pain, and concentration difficulties. This approach helps us better understand individual treatment needs and the potential for more personalised care strategies.

How did we conduct the study?

To better understand how PA symptoms fluctuate and respond to treatment, we conducted a three-month symptom tracking study. Participants self-reported their daily symptoms (such as tiredness, muscle pain, and poor concentration) using an online survey and recorded any B12 treatments received. This allowed us to track how symptoms changed over time and how different treatment frequencies affected symptom relief.

Key Findings from the Study

Tiredness (97%), muscle pain (85%), and poor concentration (82%) were the most commonly reported symptoms. Treatment frequency varied among participants, with 44% receiving B12 injections every 2–3 months, 26% receiving monthly injections, 15% receiving weekly injections, and 15% receiving more than weekly injections.

Symptom severity decreased after treatment, but the degree of improvement varied between individuals and symptoms. While some participants experienced complete symptom resolution, for others, certain symptoms did not respond to treatment at all.

For some symptoms, more frequent injections were linked to greater improvements. For example, tiredness improved by 61% in those receiving weekly injections, compared to 46% in those receiving injections every 2–3 months. However, for other symptoms like word finding difficulties, treatment frequency did not appear to impact symptom relief.

Additionally, participants had different response times to treatment. Some reported immediate symptom relief, while others experienced a delayed response, ranging from 1.6 to 5 days.

What's Next?

We have now completed data collection and are analysing the results in more detail. We aim to publish a full study soon and hope this research will help shape future discussions on personalised treatment approaches for PA.

Future research should explore wearable tracking tools, such as smartwatches, to enable real-time symptom monitoring and help improve individual treatment strategies.

We are incredibly grateful to all PAS members who took part in this study. Your contributions are helping drive research forward and improve understanding of PA. We look forward to sharing more findings soon!

Alfie Thain

Blogs

February

The NHS Delivery Plan for Access to Primary Care

In the UK, one of the most common complaints we see from our members is about access to doctors and nurses in primary care. Not just for diagnosis but for their ongoing treatment with injections as well. The experience seems to be the same in the USA and in other countries where we have members.

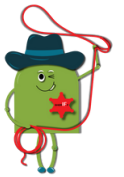
In October 2024 the NHS updated their website page on the delivery plan for recovering access to primary care. This plan was initially published in May 2023 and perhaps many of our readers will not be aware of the goals and progress in this area. Read the full post [here](#).

March

Taking Control of Your Health: Accessing and Understanding Your Medical Records

This month's blog post is about accessing your medical records to help you advocate for yourself. We know advocating for yourself can be difficult when you feel unwell but maybe some of the points in the blog post will help build confidence to meet the challenges. Understanding your medical history is a powerful tool for taking control of your health. You can also access 'A Practical Guide to Accessing your Medical Data in various countries' as a PAS member. [Read the full blog post on our website.](#)

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

Megan Healey

I am a 24-year-old from Worcestershire who got diagnosed with pernicious anaemia in March 2018, at the age of 17. I have been a member of the pernicious anaemia society since the start of 2018, when my GP first noted my deficiency in B12, but it was a long road to get to that point!

I also want to introduce myself as a volunteer for the Pernicious Anaemia Society. I have been assisting some behind the scenes operations, with the most recent and continuing project being the newsletter format which was introduced in December 2024. I am extremely grateful to have been given the opportunity to help PAS who, as you will read below, provided essential support in the journey to my diagnosis of Pernicious Anaemia.



July 2017

I had just finished my GCSEs & I was packing for a once in a lifetime experience for which I had fundraised more than £2,000 over the 12 months prior; a Girlguiding trip to British Columbia, Canada. At the time of packing my mum and I both noted how tired I was but put it down to the exams finishing, so we continued to try and fit 2 weeks' worth of clothes in a rucksack!

It was not until the connecting flight from Vancouver to the town where the jamboree was being held that my health took a turn for the worse. I had a severe pounding headache, it was more than a migraine, I still am not sure how to describe it other than absolute agony. I tried to cover my head, leaning on the tray table in front of me. I had some sips of fruit juice and biscuits as I had also started to feel dizzy. The plane was chartered for the camp, so when we landed some of the camp leaders told my group to wait so I could leave the plane slowly.

When I stood up, I felt extremely weak, I struggled with my balance & my dizziness. My heart was racing, and I felt just very unwell. We made it through the small airport & onto the coach transporting us to camp. I am still unsure if I collapsed or what exactly happened, but I have absolutely no memory of this 20/30-minute journey.

That night I joined in with the opening ceremony, struggling still to hold myself up, feeling weak & extremely dizzy. I decided it was time to head back to the tent & get some sleep, settling in at around 9pm. It wasn't until 9am, not the next morning, but the morning after that, that I stirred. I did initially feel so much better – I was hungry, thirsty and I felt much more energised.

Less than 1 hour later I started to feel much more how I had previously felt – I spent the day resting in our communal area on camp chairs, before being escorted to the first aid tent for a lie down later in the day. This continued for another day before they decided to transfer me to the camp hospital. This was exactly as it sounds – a barn with camp beds down two sides & about 12 chairs as a mock up waiting room. I was placed in a camp bed away from the other guides as unfortunately there was a sickness bug going round and the doctors there knew, whatever it was that was wrong with me, that certainly wouldn't help.

That evening, I was drifting in and out of awareness, with my most vivid memory being my pillow and hat falling on the floor. A nurse came and picked it up and sat with me for a while, comforting me which I really appreciated. Before sunrise I was moved over to the other section where an intravenous drip was given to me – 2 x 2l saline bags. By lunchtime I felt 80% better. I was so, so hungry! I went back to my group for dinner & I was able to enjoy the last 2 evenings with my group which I am so grateful for.

Unfortunately, at this point it was the end of the camp, which I had been looking forward to for many months. I wasn't able to do the activities I had booked, but I was feeling better, and I was close to seeing my parents again, which were the two things I was focusing on at that stage. I was able to enjoy the sights of Vancouver before coming home to a very emotional embrace with my parents who had gone through an equally horrible time here, unable to help and with very minimal information being provided to them. We felt utterly in the dark, so we sought advice from who we thought would help – the GP.

August – October 2017

I had several GP & A&E visits throughout the following few months. My symptoms came back around 2/3 weeks after coming home from Canada and progressively got worse. In this period the most concerning periods included when my face dropped & my left arm felt weak, which was one of the few A&E visits. The doctors confirmed it was not a stroke but equally did not know what had caused the episode.

Unfortunately, this became a theme, with each GP from my practice telling me to call an ambulance if I felt unwell. Each A&E visit concluded on one of three things: some kind of post viral fatigue; attention seeking teenager; avoidance of education and even possible drug misuse was mentioned. I felt absolutely helpless. I was, and still am, a very determined academic person who just wanted to get back to school and live my life. I wanted to learn to drive, I wanted to start to gain that independence but instead I was in and out of medical appointments every week. One doctor even told me he didn't believe me when I said I liked studying.

During this period, I also started to suffer symptoms affecting my vision, including photophobia and double vision. I went to my family opticians who urged my parents to get an MRI of my head as he was extremely concerned. So, with the long waiting lists, my parents found a private clinic, desperate for answers – but yet again we got none.

November 2017 – February 2018

This is where things took a dramatic turn downhill. On the morning of 1st November 2017, I woke up paralysed from the waist down. I couldn't feel or move my legs, with the only sensation being in what I described as "a penny being dropped on my big toe". My dad went to the GP to tell them what was happening & they said a doctor would come round soon. Almost 5 hours later a doctor arrived, in shock saying "you actually can't walk? Most people say that because they can't be bothered to come into the practice". He was quite obviously concerned & pulled my mum into a different room to talk to her.

I was admitted into hospital, finally getting to my ward at around 9pm. I was placed on geriatrics as no one knew where I belonged. Over the next few weeks, I went through what I can only describe as hell. On my second night a lady sadly passed away, I had to buzz the nurses as they hadn't noticed this happen. I was 'forgotten' one afternoon in the loo and waited for over 2 hours to be taken back to bed. And the worst moment was when the consultant told me "It's in your head just stand up". I felt utterly invisible, it's a feeling I hope I never have to experience ever again.

After a week I had managed to stimulate some muscles in my leg & I was able to discharge myself. We managed to get some Physio sessions through a local university. Over the next few months, I had 2 more episodes of paralysis, and I hardly went to school, completing my work from home where I was able to.

March 2018

By this point my parents, and I, had quite honestly had enough of being passed from pillar to post with no answers. The decision was made to move GP surgeries in hope of some answers. Instantly the doctor we saw said she thought she knew what was wrong, but that she hadn't seen it in anyone young, so wanted to run some more tests to check before she confirmed.

The tests she ran were blood tests. They showed that my B12 was around 140 and my folate was <0.1. That's when my doctor confirmed that all of this has happened because of a B12 & Folic acid deficiency which we needed to understand. She looked back at my notes and said my b12 had been low on a previous test and had been falling over a few months. She wasn't sure how I was even functioning considering the levels of my blood but was keen to get a treatment plan in place straight away. After explaining a few things, my mum confirmed that I take multi-vitamin tablets with b12 in (I had been doing so since I was born as I was premature) and that I had a very healthy diet. The doctor confirmed that this therefore must be being caused from malabsorption and was certain it was due to pernicious anaemia. She prescribed 6 x hydroxocobalamin injections over 2 weeks with a review after the 2 weeks of my symptoms. After the 2 weeks had passed, I was still struggling with weakness, double vision, brain fog & many other symptoms. She then prescribed a further 6 injections over another 2 weeks, with 1 injection every month following this, along with folic acid tablets.

July 2018

By this time, we had found the Pernicious Anaemia sSociety, and I had signed up as a member. This became absolutely crucial when my doctor retired & I had my 3-month check-up. The doctor claimed I didn't need injections every month but instead every 12 weeks as my b12 levels were over 2000. We protested this explaining that he wasn't correct, and we provided him with several pieces of material from the PAS website, with a follow up appointment booked for a week's time.

At that appointment he apologised, after reading the notes, he agreed I did need the injections once a month. He asked the nurse to show me how to do this myself so that I could self-inject and ever since he has continued to prescribe me injections when I have needed them over this 1 per month dosage.

Since then

It's been a very busy 6 years since then. With the injections, I was able to treat the majority of my symptoms, with some weakness re-occurring from time to time & heart palpitations remaining. However, the treatment has allowed me to continue to live what I would describe as a fulfilled and 'normal' life.

I sat and passed my A-Levels in July of 2019, achieving grades which allowed me to start my accounting and audit apprenticeship in September 2019. I worked hard over the next 4 years and sat my exams for the ACA qualification with the ICAEW, becoming a member of the ICAEW in July 2024. I have worked hard throughout this time, working my way up to being an Assistant Manager within audit gaining some amazing experiences with my current firm – recently including audit visits to clients in Spain.

I am extremely fortunate that I have been able to regain my life and independence, knowing how unwell I was. I have come away from this experience with a changed attitude, a much more positive and confident attitude to many things.

One of my main ambitions that has derived from this experience is to help the Pernicious Anaemia Society and others like me. Those who feel invisible and ignored by those we trust to help us when we are in need. By sharing my story, not only here but throughout several stages of my life since I got diagnosed, I continue to explain what happened, hopefully making people aware of the b12 deficiency & pernicious anaemia and its possible effects.

I still continue to learn more about b12 deficiencies, pernicious anaemia and many other factors around these; both in respect of my own body and general research. I am nervous about how this may continue to impact me throughout my life, growing up and possibly raising my own family in the future, but I remain positive & hopeful.

My main advice would be to believe in your gut feelings. If you know something is not right, don't give in to doctors & other people telling you there is nothing wrong. Seek out the help and advice of those around you, including those at PAS. Nobody going through this should feel alone as many others have gone through or are going through similar experiences.

Healthwatch England

Healthwatch England are asking for your thoughts by completing a short survey. In just three minutes, you can make a difference by sharing your views on health or social care services.

Healthcare England wants you to tell them what works and what needs improvement. Just click on the following link - <https://www.healthwatch.co.uk/have-your-say>

REQUEST FOR HELP FROM THE NIHR - VITILIGO

The NIHR (National Institute for Health Research) is asking those who are interested in health and care research to give feedback on a clinical trial for Vitiligo. As we are sure you are aware, it is not uncommon for **Vitiligo** to co-exist with Pernicious Anaemia.

THE DETAILS

The NIHR is pleased to share an opportunity for members of the public who have lived or caring experience of Vitiligo to be involved in a discussion of a commercial trial.

We are working with a company to help them improve their research. Our partner is looking for people who are willing to share their experiences and insights in an online group discussion. This will help them to make sure that their study is focused on the needs of the patient, their family, and their community, and that information about the study is clear, understandable and shared in the right places.

Who is the NIHR looking for?

This opportunity is for 8 adults (aged 18 or over) who:

- Live in the UK
- Have lived experience, as a patient or carer, of Vitiligo that was diagnosed at least 3 months ago
- Can access and use an online video calling platform such as Zoom
- Are happy to discuss their lived experience in a group.

The company would especially like to hear from people with darker skin.

What do I have to do?

If you are interested in taking part, please complete the application form linked below. If you are successfully selected for the session, we will invite you and the other public contributors to take part in an online group meeting which will last for 2 ½ hours.

The meeting will be hosted by the NIHR PECD Team, together with the company we are supporting. The session will involve:

- Hearing about the impact your health condition has on your life
- The company talking to you about their research
- Sharing your thoughts and feedback on the research and how the study information is shared with the public

The NIHR PECD Team will support you throughout the session and will ensure that you have access to any information or guidance you might need to allow you to participate fully.

When will the meeting take place?

A date has not yet been set for this activity, but it is likely to take place in mid-March 2025. Timings of the session can be flexible, such as evening or late afternoon to allow for working hours and will be agreed in advance by participants and the company representatives. The activity will last for 2 ½ hours, including a short break.

Will I get paid?

The NIHR, on behalf of the company we are working with, will reimburse you £67.50 for your participation. This will be paid by bank transfer, usually 6 weeks after the activity has taken place (although it can occasionally take a little longer). You can find information about payment for research involvement activities, and the impact this may have on your tax and national insurance [here](#).

What happens after the session?

The NIHR PECD team will write an anonymised report for the company, summarising the session's discussions. The company will use this report to review their plans and make changes to their study based on the group's feedback.

A few months after the activity, the PECD team will send an update from the company to all contributors detailing how the insights were used to improve the study.

How do I apply or find out more information?

If you would like to take part in this opportunity, please complete this application form:

<https://forms.office.com/e/9Z6fegdztX>

If you have any questions about the PECD Service or the planned activity or have any difficulties completing the application form, please contact the NIHR PECD Service Coordinator by emailing pecd@leeds.ac.uk

Deadline for applications: Wednesday, 5th March 2025.