pas Pernicious Anaemia Society

Cobalamin News

Edition 44 Winter 2025 December 2025

Contents

Highlight:

PAS education programme for healthcare professionals launched!

We are really delighted to be able to report that after significant work and investment the Pernicious Anaemia Society education package aimed at clinicians and health care professionals has been launched.
Read more on page 5.

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-Thu 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 Annual Review Introduction: Reflecting on 2025

from our CEO, Katrina Burchell

As your CEO, it gives me immense pleasure to introduce our Annual Review for 2025. This has been a year of significant progress, strategic groundwork, and inspiring collaboration. We have woven every achievement throughout these four quarters directly into the fabric of our core **Business Plan, focusing intently on Raising Awareness, Education, Patient Support, Engagement, Membership, Funding, and Research.** Katrina Burchell, Chief Executive Officer December 2025

Quarter 1: January to March - setting the pace for progress

The first quarter was marked by a strong focus on **Education** and **Raising Awareness**. We hosted highly successful webinars, including Professor Dominic Harrington's session on *Pathology - blood testing in B12* and Willemina Rietsema's "*20 Questions*" session addressing commonly asked questions via our helpdesk. We also held a seminar in February from Dr. Assim Navqi, giving us a GP's perspective of PA, and *A Report and Discussion on the need for an International Treatment Standard for B12 deficiency* by Bettina Borre Buhl.

These seminars, and others we have held, are all available in our shop. We took part in the Global Anemia-thon via social media, strongly **Raising Awareness** that **anaemia** is not solely about iron deficiency.

On the **Funding** front, we secured a grant that allowed me to dedicate an additional two hours of my own time each week to undertake the six-month Fundraising Everywhere digital online course, significantly enhancing our future fundraising strategy and capabilities. In terms of **Patient Support**, an initial discussion with the Wren Project led to an immediate collaboration, resulting in a valuable link on our website providing additional listening support services. More exciting developments with the Wren Project will follow in 2026. Details about our support services, including our partnership with the Wren Project, can be found here: Partners and Links. Note that whilst we are open help anyone struggling with or getting a diagnosis for PA or B12 deficiency, some of our helpdesk and helpline services are available only for members so we encourage you to join to get full access.

We significantly pushed our **Research** agenda, holding various meetings with Alfie Thain, the PhD student we proudly support at the University of Surrey. Initial discussions with Rachel Barnes, another PhD student we are supporting, this time at the Quadram Institute, had us all really excited for future developments. We worked with De Montfort University, Leicester, who reviewed patient and clinician perceptions following the NICE Guideline publication. All of these projects and their updates can be found on the research page on our website.

Furthermore, a new collaboration was agreed upon with Louise Twedell from Worcester University on her nutrition research, and many members took part in her survey and we continue to provide support to bring the results to publication. To further our **Raising Awareness** and **Research** goals, I spoke, alongside Heidi Seage, at a Lunch Byte session at Cardiff Met University. This session successfully highlighted the need for specific research following the James Lind Alliance PSP and NICE Guideline recommendations, engaging new departments, students, and the public, inspiring them to join key areas of research.

Quarter 2: April to June - Strategic Building Blocks

This quarter was defined by key advancements in **Education** and **Engagement**. I was appointed Co-Chair of the annual CluB-12 Symposium, and I immediately began working with Luciana Hannibal from the Laboratory of Metabolism, Medical Center, Freiburg, to plan the September conference's topics and speakers. Our regular **Engagement** continued through my blog posts and those of the guest contributors I organised. Our social media quarterly reviews focus on what topics are most in demand by our followers and commentators and each month I plan, propose topics and draft posts which are polished into shape and published by our wonderful social media team, Hollie and Sara at Elements-OBM and our volunteer Claire.

In a major step toward **Raising Awareness** at a governmental level, and following a joint wish from the B-12 Alliance members and CluB-12, I put forward a proposal for a working party to look into holding a Parliamentary reception or round table in 2026. This working group is now fully up and running, with plans underway for a significant campaign and reception next year**.**

Our **Funding** strategy gained momentum with focused meetings involving our trustees, Tara and Andy. Based on the management team's needs, they proactively applied for grants where we were eligible. Despite the difficult field for small charities, we were delighted to secure Foyle Foundation funding to carry out our support group survey. Although a second application was unsuccessful for more core support funding, that foundation provided invaluable feedback, encouraging us to try again.

The cornerstone of our **Education** strategy was completed this quarter: the PAS education programme for healthcare professionals. We finalised the content with expert input and worked closely with the NHS eLearning team to ensure it met their criteria. Thanks to another successful grant application, we partnered with (and are hugely grateful to) Luke and Mark at Konnectis to host the programme on both the NHS website and our own, enabling us to reach a wide domestic and international audience. More about this impactful launch will follow in 2026 but we are already communicating with clinicians in the UK encouraging them to complete the 12 module training programme to improve their knowledge and understanding of PA and follow the NICE Guideline. I continue to support the B-12 Alliance and CluB-12 education package with input to content and reviews and hope that this will similarly be finalised and published early next year.

Quarter 3: July to September - Media Reach and Political Movement
This quarter saw a surge in **Raising Awareness** through media. I was invited to write an article for Occupational Health, and my personal story was published again by The Telegraph, generating broader media interest from many different countries and leading to opportunities to share more member stories and speak with TV doctors and online clinicians. Personal stories remain really valuable support and persuasive evidence material and as we move forward into 2026 we will be building more on story telling by video and audio to reach a wider audience.

Crucially, the persistent work and **Engagement** with the Royal College of General Practitioners (RCGP), some key pharmaceutical companies and consulting organisations, and the Medicines and Healthcare products Regulatory Agency (MHRA) began to pay dividends. Letters to the Chief Medical Officers (CMOs) and Chief Nursing Officers (CNOs) elicited responses, causing what I describe as deep rumblings. It is not yet an avalanche of change, but it confirms we are pushing in the right direction and bringing influential others with us.

A significant global moment came in July when Aalto University in Finland contacted me, starting a chain of events that culminated in the student team winning a gold medal in the iGEM competition—a full story you can read elsewhere in this newsletter. Our **Membership** and governance were strengthened at the AGM in September, where we welcomed two new trustees: Andrew Axford, who had been observing throughout 2025, and Julie Wichlin from the USA, marking our first step towards having an international board oversee the management committee's activities and moving towards making a global impact.

Quarter 4: October to December - Sustaining Growth & Legacy
The final quarter focused on reinforcing our foundations for the future. **Research** meetings continued, particularly those centred on communicating valuable published papers and developing ideas for new research funding applications.

In a poignant and crucial development for our long-term **Funding**, we were fortunate to be the recipient of a couple of legacy donations this year, alongside very generous one-off or ongoing standing order donations from long-term legacy members. These funds are vital as we look to continue supporting PhD students and **Research** projects, and to grow our **Patient Support** activities in different formats.

October 11th saw our well-attended annual online seminar, which reviewed exciting research; the recording is available in the shop if you missed this fascinating event. October 12th was PA Day. We had great Engagement initiatives, including the second craft fair from Nicole in Norfolk, UK and two potters in Wales offering free pot making in return for a donation at an event in November (see more about these events later in this newsletter). Carrie-Anne Carr reinvigorated her fundraising with a birthday JustGiving campaign so do head over there at this link to add your contribution as she has now joined our parliamentary reception working group, with her support kicking off our campaign.

In November, we expanded our shop merchandise and added links for other ways to raise donations, such as buying books via Bookshop.org and greetings cards via Making A Difference. The continued support from Blue Horizon and Neovos is also greatly appreciated. They offer discount codes for visitors to our website on their tests.

The Constant Thread: Alliance and Support

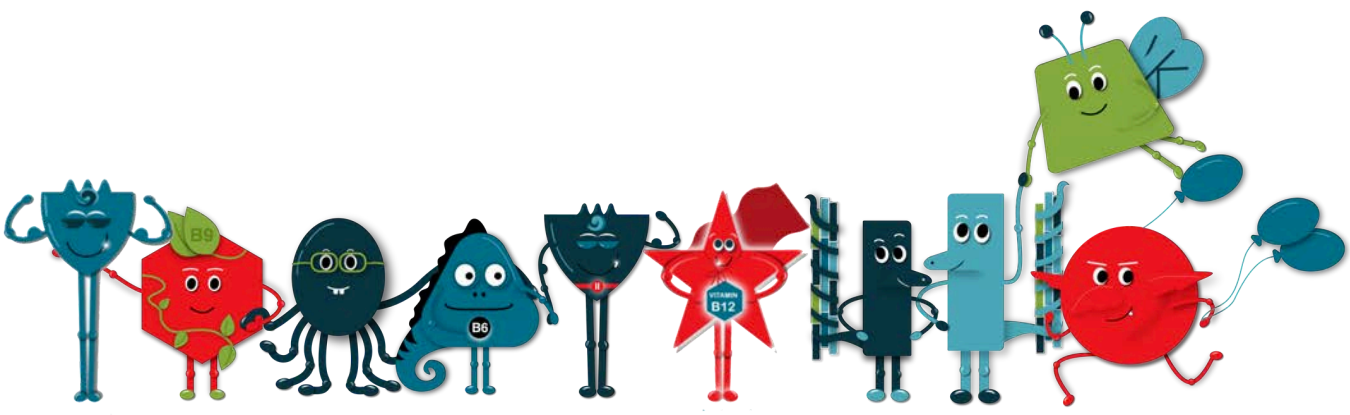
Throughout all four quarters, a constant has been the B12 Alliance meetings. The **B12 Alliance** is an international collaboration of organisations, researchers, and experts dedicated to raising global awareness and improving the diagnosis and treatment of B12 deficiency. I am currently privileged to serve as the Chair and our monthly meetings focus on education and awareness.

Our commitment to **Patient Support** is demonstrated by the success of our support groups, such as the one in the USA, which is consistently well-attended. However, we have also started frank discussions between the management committee and Trustees on why attendance and commitment to support groups elsewhere has been dropping off, an area we will focus on improving. We carried out our Support Group Survey and a full report and our action plan is covered in this newsletter. Grateful thanks to Tony Burchell who gave up his time to design the survey and analyse the results.

Finally, while these high-profile activities dominate this review, I want to acknowledge the unsung, weekly work of the management committee and volunteers: the constant updating of the website, the diligent preparation of monthly and annual accounts, the regular social media posts, answering countless telephone and email helpdesk enquiries, and ensuring we remain legally compliant through policy updates, safeguarding, and GDPR training. Our **Membership** is steadily growing, even as we carry out a significant review of our legacy and charter members and make plans for a more modern database.

Looking Ahead to 2026

Next year, 2026, marks 20 years since PAS became a registered charity. We have adopted the rallying banner: **This is The Year Things Change**. Thank you for your continued support to date. Whether you are a new member or have been around for some time, I look forward with confidence to what more we can achieve together with your help and support in the future.



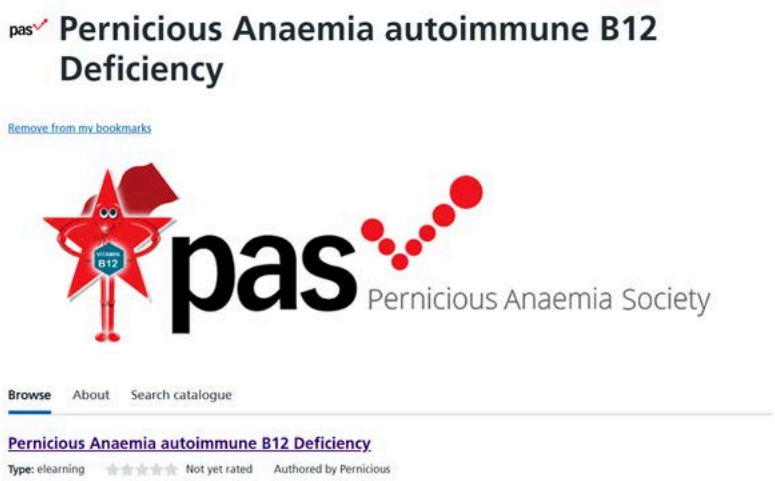
PAS education package for clinicians

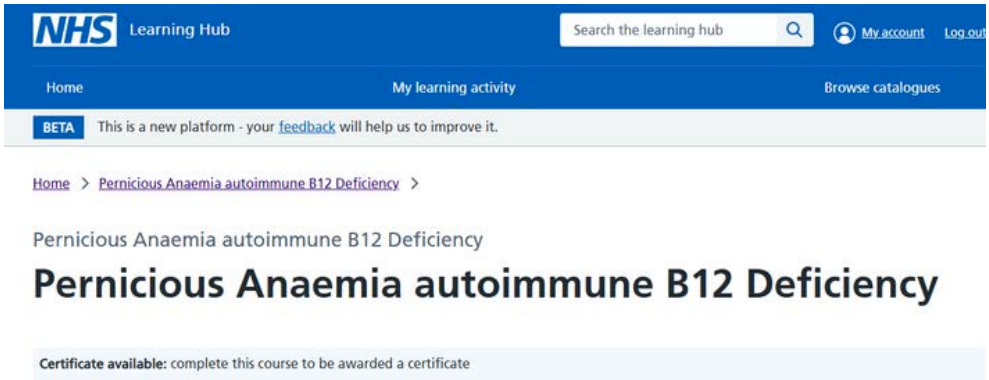
We are really delighted to be able to report that after significant work and investment the **Pernicious Anaemia Society education package** aimed at clinicians and health care professionals has been launched.

This package was designed with the help of ZS Consultancy and written and reviewed by healthcare professionals. Then with the help of eLearning specialists Konnectis and the NHS eLearning for Health Team it has come to life and is now available on the NHS eLearning website. For others who do not have access via the NHS site or an international audience access can be made through the PAS Website.

This is a significant step forward in our plans to make 2026 **The Year That Things Change** and our focus for the coming months will be on communicating to health care professionals and encouraging them to take the modular course and get their certificate, contributing to their ongoing professional development.

The course has been written with a UK health care audience in mind focussing on NICE Guidelines and published research but is also suitable for any clinician, anywhere, wanting to learn more about this autoimmune condition. As patients you can certainly let your doctor or nurse know that this approved training is available to them FREE via NHS Learning Hub.





Research

Ongoing research into PA & B12 deficiency

Two recently published papers are summarised below for your interest. Ongoing research into PA and B12 deficiency is a vital part of the Pernicious Anaemia Society's mission and our engagement with CluB-12, where papers such as these are discussed.

An Extreme Case of Pernicious Anaemia Underlines Need for Better Diagnosis and Care

Pernicious Anaemia (PA) is a condition where the body can't absorb enough vitamin B12 due to a lack of intrinsic factor (IF), a protein made in the stomach. While often presenting as anaemia (low red blood cells), B12 deficiency can also lead to serious neurological and psychiatric issues.

A recent case study published in the American Journal of Case Reports brings into sharp focus just how severe and misleading PA can be, especially when it affects vulnerable patients with pre-existing mental health conditions.

A Life-Threatening Crisis and Unexpected Links

The report details the case of a 51-year-old woman with a history of schizophrenia who was admitted to hospital with extreme weakness and breathlessness. Her initial test results revealed a critically low haemoglobin (Hb) level of 2.5 g/dL, which is considered life-threatening. She was quickly diagnosed with PA based on a very low vitamin B12 level, and extremely high levels of markers for B12 deficiency (specifically, methylmalonic acid, or MMA, at 34,920 nmol/L). The definitive PA diagnosis was confirmed by the presence of IF-blocking antibodies. The case was unusual for several reasons:

- Extreme Severity: An initial Hb level below 2.5 g/dL is incredibly rare, and the patient required multiple blood transfusions along with B12 replacement therapy to stabilise.
- Extreme Cell Changes: Her blood smear showed an unusually high number of abnormally large, multi-lobed white blood cells called hypersegmented neutrophils, some with as many as 8 to 10 nuclear lobes. These cell abnormalities disappeared completely within two weeks of B12 treatment.

Dramatic Improvement in Psychiatric Symptons

Perhaps the most compelling finding was the impact of the treatment on her mental health. After daily intramuscular B12 injections, the patient not only recovered physically—regaining strength and mental clarity—but her long-standing symptoms of schizophrenia also dramatically improved. Within two months of treatment, she reportedly no longer needed her psychiatric medications and showed no signs of mental disorder. The paper notes that while it's unclear whether the B12 deficiency directly caused her schizophrenia or simply exacerbated an underlying condition, the link is too significant to ignore.

A Call for Greater Awareness & Research

This rare, severe case serves as a powerful reminder for patients, caregivers, and clinicians:

- Consider PA: PA can present with symptoms ranging from mild tiredness to life-threatening anaemia and psychiatric symptoms. In our view, clinicians must "rule out B12 deficiency" in all patients presenting with unexplained anaemia or psychotic symptoms, as neurological damage can occur even before anaemia develops.
- The Power of Diagnosis: Early and accurate diagnosis of PA (which affects about 0.1% of the general population) is crucial. There are limitations in existing diagnostic tests but clinical presentation of symptoms is a key.
- Lifelong Treatment: Confirmed PA requires lifelong B12 replacement therapy to prevent debilitating and irreversible complications.

This case underscores the need for further research into the complex relationship between vitamin B12 deficiency and psychiatric health, ensuring that patients receive holistic care and an accurate diagnosis that addresses all their symptoms.

The second paper we report on here concerns **Autoimmune Gastritis: Why This 'Non-Rare' Condition Deserves Our Attention**

A recently published position paper by the Autoimmune Gastritis Italian Network Study Group (ARIOSO) provides critical insights into Autoimmune Atrophic Gastritis (AAG), which they use to describe the underlying cause of pernicious anaemia (PA). The paper aims to improve the diagnosis and management of this often-delayed and misdiagnosed condition.

The report offers several key takeaways that are vital for patient advocacy: AAG is not rare, its clinical scope is much wider than just anaemia, and timely diagnosis is essential to prevent severe, life-long complications. The UK NICE Guideline refers to Pernicious Anaemia as Autoimmune Gastritis. For reasons PAS has explained before we are concerned by this attempt to rename the condition without proper considered debate in the UK and the research community. Our view is supported in various research papers and is potentially detrimental to patients already diagnosed. In this paper the Italian team use the term pernicious anaemia to refer to one symptom (actual anaemia). Whilst the terminology in this paper is not consistent the underlying message is of course very important. In Italy, pernicious anaemia as we understand it is called Anaemia di Biermer (Biermer's Anaemia).

1. AAG is Not a Rare Disease

For years, AAG was considered an uncommon condition, perhaps confined to specific populations. The ARIOSO paper challenges this, stating that AAG should not be considered a rare condition.

- Global Prevalence: The paper cites an estimated global prevalence of 3.8% for AAG.
- Widespread Impact: It has been described in all populations, regardless of age, sex, or ethnicity, citing series from Europe, Japan, China, Africa, and South America.
- Gender Skew: It appears more common in females, with a ratio of approximately 2:1.

The prevalence of the later-stage manifestation, Pernicious Anaemia, is also significant, with reports showing it affects 2% of individuals over the age of 60.

2. Pernicious Anaemia is Only Part of the Story

A critical point for awareness is clarifying terminology. The paper explicitly states that Pernicious Anaemia (PA) should not be used as a synonym for AAG.

- AAG is the Cause: AAG is the underlying immune-mediated disorder that destroys the stomach cells needed to absorb vitamin B12.
- PA is a Symptom: PA is only one, usually late, manifestation of AAG—characterised by macrocytic anaemia (large red blood cells) due to severe vitamin B12 deficiency.

The clinical spectrum of AAG is much broader and often includes:

- Iron Deficiency: Impaired gastric acid secretion often leads to iron malabsorption and iron deficiency anaemia.
- Neurological/Psychiatric Issues: Patients can experience mood alterations, paraesthesia (pins and needles), dementia, and other psychiatric manifestations due to B12 deficiency.
- Increased Cancer Risk: AAG is a progressively worsening condition that carries an increased risk of developing Type 1 gastric neuroendocrine neoplasms (t1-gNENs) (up to 10–15% of patients) and, less frequently, gastric cancer (GC).

3. The Importance of Timely Diagnosis

The ARIOSO group stresses that AAG patients are frequently misdiagnosed or diagnosed with a substantial delay. This lag in diagnosis can have severe consequences due to persistent micronutrient deficiencies and neoplastic complications.

- Silent Cases: Up to 30% of patients may be completely asymptomatic at the time of diagnosis, often being discovered only during screening for other conditions or autoimmunities.
- Lifelong Progression: AAG is a progressively worsening condition where gastric atrophy advances from mild to severe stages in virtually all cases.

The paper strongly advocates that all newly diagnosed AAG patients must be screened for associated conditions, including micronutrient deficiencies (like B12 and iron deficiency anaemia), as well as other autoimmune diseases such as autoimmune thyroid disease and coeliac disease.

This position paper confirms that AAG, and the resulting pernicious anaemia, is a major health concern that requires a more vigilant and comprehensive diagnostic approach.

Putting Patient Voices First: Landmark Study Drives Future Pernicious Anameia Research

The struggles faced by people living with Pernicious Anaemia (PA) and vitamin B12 deficiency are often invisible to the medical community, but a recent, large-scale study published in BMC Primary Care has captured these patient-reported experiences to demand change.

The article, **"Patient-reported characteristics of pernicious anaemia: a first step to initiate James Lind Alliance Priority Setting Partnership driven research,"** confirmed what many of our members already know: there is a significant gap between patient needs and primary care delivery.

Key Findings and Patient Experience

Based on a survey of thousands of individuals across the UK, the research highlighted widespread dissatisfaction and feelings of being 'let down' or stigmatised by the healthcare system. The most common issues reported include:

- **Treatment Access Difficulties**: Many participants reported problems securing appointments for essential injections, as well as instances of having their treatment stopped or the frequency reduced by their healthcare provider.
- **Safety Concerns**: Disturbingly, many patients perceived primary care as less safe and reported not feeling treated with dignity, respect, or involvement in decisions regarding their condition.
- **The Rise of Self-Medication**: The study found that four in ten people (40%) chose to **self-medicate via injection (SMVI)**. The two primary reasons for this were a desire to **improve their quality** of life (80%) and dissatisfaction with their prescribed **treatment frequency** (67.8%). While most would prefer to be treated under medical guidance, they felt they had no choice but to take matters into their own hands to regain their health.

The Next Step: Patient-Led Research

Crucially, this research is not just about reporting problems—it's about setting the future agenda. The study was initiated to establish a **James Lind Alliance (JLA) Priority Setting Partnership (PSP)** for Pernicious Anaemia.

The JLA PSP is a collaborative effort that brings together patients, carers, and clinicians to identify the top 10 unanswered questions about a specific health condition. By using this powerful patient data, we can ensure that future research funding is focused entirely on the issues that matter most to the PA community.
This is an exciting and essential step in making sure the patient voice drives meaningful change and research that truly addresses the challenges of living with Pernicious Anaemia.

Patient-reported characteristics of pernicious anaemia: a first step to initiate James Lind Alliance Priority Setting Partnership driven research | BMC Primary Care

Works like this would not be possible without the hard work of the team from the University of Surrey and in particular Alfie Thain who is the PhD student that the Pernicious Anaemia Society has supported for the last 4 years. By building a long lasting and strong relationship with Alfie we hope that further investment in quality research like this will be secured to continue to answer the important questions raised by in the James Lind Alliance PSP. We are working hard to ensure that this article in the BMC Primary Care publication reaches health care professionals

Watch a short video update from PhD student, Alfie Thain, in which he summarises what we found, why it matters, and how the repository will support future studies aimed at improving diagnosis, treatment, and quality of life for everyone with PA on our website research page.

Watch this short video update from Alfie in which he summarises what we found, why it matters, and how the repository will support future studies aimed at improving diagnosis, treatment, and quality of life for everyone with PA:

PhD Update

Exciting update to report from my recent trip to Norwich. I was able to use the laboratory facilities and take six urine samples for analysis.
The working hypothesis implies that less-responsive patients are more likely to have significant cobalaminuria. In that those patients who require treatment at four weeks compared to those who are happy with the interval of 12 weeks.
Six samples taken, three of those on the four weekly treatment regime and three of those on the 12 weekly treatment regime. The samples were subjected to being filtered and injected potassium cyanide (KCN) to the samples to convert all B12 forms into the stable cyanocobalamin. So that this could be detected in the samples, two rounds were completed to show repeatability in the test.
Excitingly the results agreed with the hypothesis showing very sample numbers (15-17mmols) in the patients at three monthly intervales compared to (127-130) in those at four weekly intervals.
It was great to see that the idea of losing more B12 in the urine in those patients experiencing symptoms, was evident in the research.
This now leads onto a much larger scale study – numbers to be confirmed!
I will update you again soon

Many thanks,
Rachel Barnes

Blog

When it's not just in your head - November 2025

You go to therapy because something feels wrong. You're tired, but it's more than that. You're anxious, but you don't know why. Some days you cry for no reason. Other days, nothing touches you at all. You think maybe you're just burned out or overwhelmed. Maybe this is depression. Maybe you're simply bad at coping.

So you try the usual routes. You talk it through, follow the advice, take the medications, do the breathing exercises. You want to believe it's going to help. But part of you knows something else is happening. You're doing the work, but your brain still feels off. You still don't feel like yourself.

See our website for this blog post.

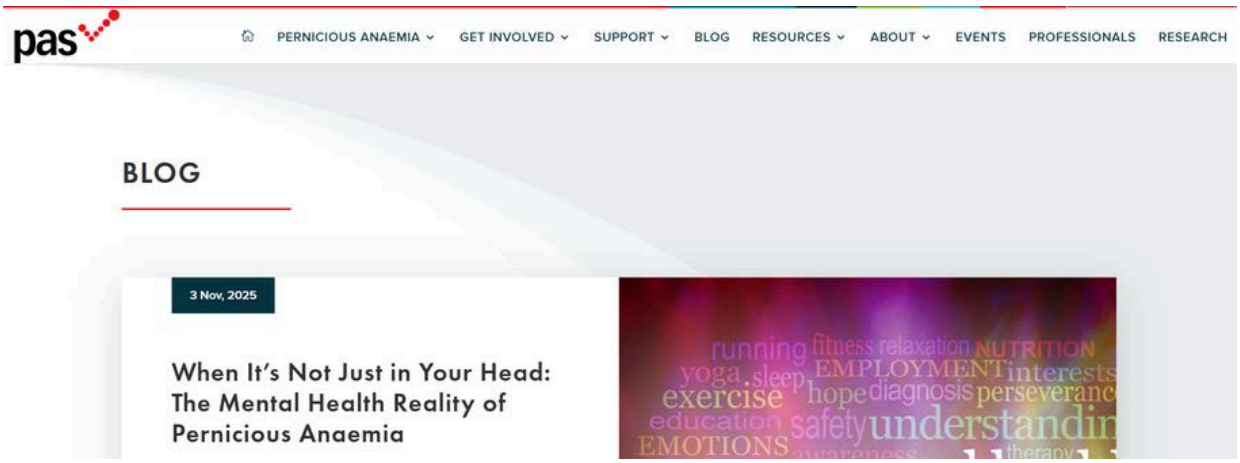
Artificial but not intelligent - December 2025

December's blog is by Prof. Bruce Wolffenbuttel, a long time supporter of PAS and previous popular blog post contributor. At the end of the year and before PAS enters into its 20th year in existence, Bruce reflects on the persistent problem of outdated and inconsistent medical knowledge regarding B12 deficiency treatment. Bruce tests various AI systems with a key clinical question—how often to measure serum B12 in an asymptomatic patient with pernicious anaemia on regular injections—his findings and comparisons with the correct response that routine monitoring is unnecessary, underlines the established but poorly followed clinical guidance.

See our website for our this blog post.

Upcoming: Why Your Vitamin B12 Injection Remains Prescription-Only in the UK - January 2026

For thousands of people in the UK living with Pernicious Anaemia (PA) and other B12 deficiency disorders, the need for regular Hydroxocobalamin injections is a lifelong reality. But why does this vital medicine remain strictly a Prescription-Only Medicine (POM), and what is the path to better treatment for patients? The regulatory status of injectable B12 is a source of frustration for many, particularly those advocating for greater patient autonomy. Here, our Chief Executive Officer, Katrina Burchell breaks down the legal and clinical reasons behind the current classification and highlights the crucial work being done by the Pernicious Anaemia Society to improve care.



Fundraising

Carrie-Anne's Final Push - Fundraising for PAS!

For over twenty years, the fight against **Pernicious Anaemia (PA)** has been a deeply personal mission for me. Diagnosed in my 20s, I know firsthand the life-changing impact of this condition, which, as I've seen too often, can be deadly if left undetected and untreated. I'm eternally grateful for my own diagnosis and treatment, which gave me the chance to advocate for the **Pernicious Anaemia Society (PAS)** from the very beginning.

My journey has included everything from lobbying "the powers that be" to helping countless others achieve their own vital diagnoses.

A Renewed Commitment
A few years ago, the sudden loss of our dear friend Amanda to cancer, followed by my Dad the next year, spurred me to make an even bigger push to raise funds for the PAS—to help where it truly matters. We decided to channel our grief into joyous remembrance, hosting two incredible "Celebration of Life" parties: a fantastic **Vintage Theme** event and a brilliant '80s Theme bash. These events brought everyone together to have fun, catch up, and raise money for an essential cause.

We've Almost Reached the Summit!
Through those wonderful parties and further fundraising efforts, we have collectively raised a **whopping £7,700!**
We were tantalisingly close to our £10,000 target and it would mean the world to me if I could reach that goal.

Here's the Pitch: Let's Hit £10k by Christmas!
As we just needed £2,300 to reach the goal, I decided to make one final, heartfelt push between my birthday on 30th October and Christmas.
If you've ever considered donating, now is the time!

- **Could you** spare even just a £1 donation? Every single pound genuinely helps.
- **Cardless Giving**: Consider donating what you might have spent on a birthday card, Christmas cards, and postage this year for friends and family.
- **Saying Thank You:** If I or one of other amazing volunteers in this community has helped you on your own health journey, a small donation is a wonderful way to say thank you.

Whatever your reason or the amount you can afford, please be 100% confident that every penny will go directly towards projects within the PAS that I believe will have the most significant impact.
Collectively, we have already proved we can move mountains. Thank you for your continued support over the years—we are eternally grateful.
Here's to our final push—we can do this!
Best wishes and Health to you ALL,
Caz xx

Donate to Carrie-Anne's fundraiser here.

Festive Fundraising

A Festive Feast for the Senses Raises £325 for the PAS!
We are absolutely delighted to share the wonderful news of a generous community donation that will significantly support the work of the Pernicious Anaemia Society this winter.
A fantastic total of **£325** was raised at the recent **Festival of Senses** in Llandeilo, South Wales, a popular, vibrant pre-Christmas event that celebrates local Welsh artists, independent shops, and community spirit.

The funds were raised through the brilliant efforts of two talented potters, **Jacky John** and **Mick Morgan**, operating under the banner of **Crafts Alive**. During the festival, Jacky and Mick invited visitors to literally get their hands dirty by offering the chance to 'have a go' at making their own pot in exchange for a donation to the Society. This unique and engaging activity proved a huge hit, raising the impressive sum through the kindness of the local community.

An Impact That Ignites All the Senses
This incredible generosity will be put straight to work, helping us raise vital awareness of Pernicious Anaemia, expanding our essential education programmes, and ensuring our support desk remains fully operational to assist those who need us most.
Our Chief Executive Officer, Katrina Burchell, expressed her heartfelt gratitude: "This generosity will mean so much to us. Thank you, Jacky John and Mick Morgan, and everyone at Crafts Alive, for thinking of us and providing such invaluable support to the Pernicious Anaemia Society. We are thrilled to be able to feature your amazing fundraising effort in our newsletter!"

Thank you Nicole!

We would like to say a huge thank you to Nicole for arranging a local autumn craft fair again this year. The fair, held on 4th October, had a variety of stalls each selling different goods with lots of ideas for Christmas presents – even some for our four-legged friends!

Nicole had set up an additional tombola stall specifically for PAS and great fun was had by all who attended it, some coming back for more tries!
Our thanks also go to our PAS volunteers who gave so generously of their time to support Nicole:

- Barbara who encouraged all passers by to try their luck to win on the PAS tombola
- Paul and Andrew who made the teas and coffees for stall holders and shoppers and who did an amazing job of up selling the cakes and pastries
- Our Treasurer Nicola who supported before the event and attended in person.

And of course, thank you to everyone who attended and made the day both great fun and a huge success. We are very grateful for the £560+ Nicole has raised this year!

2025 Support Survey: High Value and a Clear Mandate for the Future

The 2025 Support Survey, completed by 315 members of our community, confirms that the Pernicious Anaemia Society (PAS) Support Services are highly effective and valued. Users reported strong satisfaction levels, ranging from **83%** to **94%** across all utilised channels, including the Help Desk, Email Support, and Support Groups. This feedback is a powerful affirmation of the hard work done by our volunteers and team. However, the survey also provided a clear mandate for where we need to improve. The primary challenge is not service quality, but awareness and accessibility.

Key takeaways & focus areas

1. **A Call for Clarity**: Only 10% of respondents were fully aware of the breadth of our services. Our most immediate goal is to work on a **Service Clarity Campaign** to ensure every member knows the full range of support and how to easily access it.
2. **The Thirst for Knowledge**: The community continues to express a strong desire for detailed, easily accessible information that provides greater control over their condition. We will maintain our focus on **Knowledge Empowerment**, developing self-advocacy tools to assist with primary care interactions and newly diagnosed patients.
3. **Local and Emotional Support**: There is a demand for more **localised support groups** (nationally and internationally) and dedicated resources for the **emotional and psychological aspects** of living with pernicious anaemia. To address this, we need to **increase our volunteer workforce**, something that all small charities are struggling with in current times.
4. **Bolstering International Capacity**: To address international time zone enquiries and **bolster Help Desk capacity**, we will explore ways to extend availability and deepen our team's expertise for complex and non UK queries.

The survey shows our services are critically valued; now, we must ensure they are easily found and accessible to everyone who needs them.

Aalto-Helsinki iGEM Team 2025

Finnish Flair and Synthetic Biology:
PAS Supported Collaboration with Aalto-Helsinki Sweeps the iGEM awards!

The **Pernicious Anaemia Society (PAS)** is delighted to announce the remarkable success of the Aalto-Helsinki student team at the prestigious 2025 **iGEM** (International Genetically Engineered Machine) competition in Paris this October. Here is the story of how PAS supported the team from the University of Helsinki and Aalto University and how they achieved outstanding recognition, including a **Gold Medal** and multiple special awards in this prestigious competition and what it means for people with Pernicious Anaemia and B12 Deficiency in the future.

Why we backed the Finnish Innovators
The iGEM competition is the premier worldwide student competition in synthetic biology, tasking interdisciplinary teams to design, build, test, and measure a system using engineered biological parts (BioBricks) to solve a real-world problem.

PAS was proud to collaborate with the Aalto-Helsinki team because they focused their concept on addressing a challenge faced by the **Pernicious Anaemia** patient community. Crucially, the idea to approach the solution from a completely **"different angle"** came from the students themselves after engaging with PAS and discussing the issues that arise from poor diagnosis and undertreatment and the plight of many of our members worldwide.

Our role was to provide essential **human practices** support—connecting the students with patients and experts, offering real-world perspective on the condition, and generally supporting their journey. This collaboration was a joy for us, bringing huge hope and enthusiasm from the next generation of researchers dedicated to the vitamin B12 field. The students' detailed work, covering lab design, safety, security, ethics, and societal impact, is documented on their official iGEM wiki page. https://2025.igem.wiki/aalto-helsinki/.

While iGEM is primarily an educational competition for students, the Overgrad division, composed of Master's students, consistently produces projects that are near the level of preliminary academic research.

The research done by graduate (Overgrad) teams in the iGEM competition is generally considered to be of **high utility and increasing accuracy**, often contributing directly to the field of synthetic biology.

A golden success in Paris
The hard work of the multidisciplinary team paid off handsomely at the Grand Jamboree in Paris. The Aalto-Helsinki team not only secured a highly coveted **Gold Medal**, but they also "swept the board" with several specific achievements that highlight the quality and innovative nature of their project.

The team shared the fantastic news with PAS leadership upon their return:

"We are very happy to share that our team won a **gold medal**. We also received the special prize for **Best Measurement** and for **Best Sustainable Development Impact**, and we were nominated for **Best Therapeutics Project (Overgrad).** It was an unforgettable experience, and your help played a strong part in getting us there."

The recognition for **Best Measurement** speaks volumes about the rigor and scientific excellence of their lab work, while the **Best Sustainable Development Impact** award affirms that their synthetic biology solution was designed with a mindful, long-term global perspective. The nomination for **Best Therapeutics Project** in the Overgraduate division places their innovative approach among the world's elite biological solutions for medical treatment.

This success underscores the value of patient-advocacy groups like PAS collaborating directly with cutting-edge academic teams. Our CEO, Katrina Burchell said "I was so impressed with the enthusiasm, creativity and diligence of this team and I hope that they will continue their careers in research hopefully with a focus on vitamin B12 and Pernicious Anaemia."

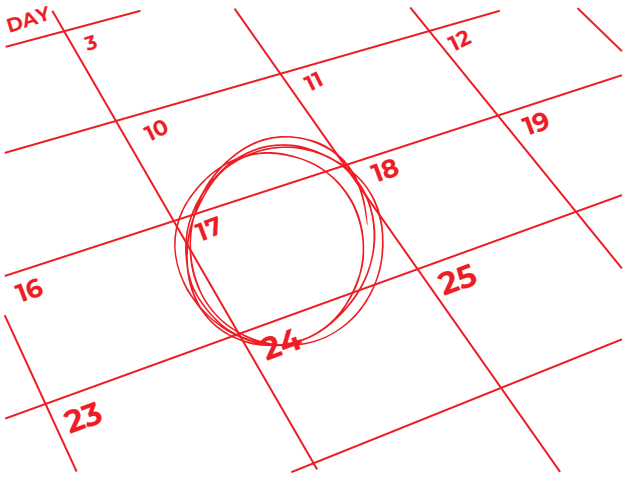
Whilst this is primarily a competition, PAS really hopes that it will act as a **Catalyst** in the same way other successful iGEM projects have done. The work the team did serves as a prototype for valuable areas of research which could mean so much for the future diagnosis and treatment of B12 deficiency whether caused by autoimmune Pernicious Anaemia or other causes. PAS will continue to offer their support to the team and the individuals that took part if they wish to follow up on the topics explored as part of their future career. By sharing this information with existing research teams via organisations such as CluB-12, we also hope that new research will be inspired by the Aalto-Helskinki team's success.

What's on & Key Dates

Office Closure
The PAS Office will close on **Friday 19th December 2025** and re-open on **Monday 5th January 2026**

US Support Group Meeting
January 3rd 2026 at 1pm Central.
To join in, register via the link on your membership homepage.

Wren Project
On th**e 27th January 2026** there is a seminar with The Wren Project



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.

Our Seminars

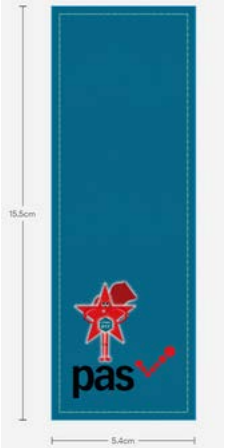
Our seminars have proved extremely popular and continue to do so, with members and non-members still purchasing previous seminars and reporting how much they have learned from them. All of our seminars are recorded and are available in our shop at just £5 for members.

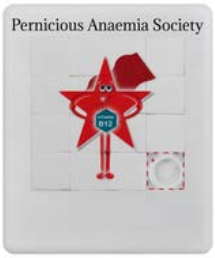
On Saturday, 11th September, we held our **PAS Annual Seminar** with speakers **Alfie Thain, Nicola Ward and Adrian Rogerson, and Rachel Barnes.** Alfie spoke about his research into Symptom Tracking; tackling Iron deficiency, and testing self-injection, as well as research updates from his PhD. Nicola and Adrian spoke about their research on the impact the NICE Guideline has had on people living with Pernicious Anaemia and vitamin B12 deficiency. Rachel, who like Alfie is a post graduate researcher, had a very intriguing title to her speech: 'Could urine be the answer?'. You can read more about Rachael's and Alfie's work in this newsletter.

Our most recent seminar was held on 19th November and Support Group Volunteer, **Julie Wichlin**, was our guest speaker. Julie's talk was entitled 'Breaking the Silence, Building Community Living with Pernicious Anaemia and Advocacy in the U.S'. Julie, who lives in Chicago, spoke about what it is like to live under a cloud of mystery symptoms for years and made observations on how PA is diagnosed and treated in the U.S., and how it compares with experiences in the UK and elsewhere in the world. Julie stated that the case for why the patient voice matters - from personal journeys to global awareness. The seminar is now in our shop and available to both members and non members.

On the 27th January 2026, we will be holding our next seminar and this time, we will be hearing from **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, they understand the huge impact a diagnosis has on your mental and emotional health and provide a listening ear. It is going to be a very interesting talk. Keep an eye out for the details on our website and on our social media pages.

New Shop Items for sale now!





Go to the shop >

Legacy & Memorial

We extend our sincere condolences to the family of the late Patricia Lambourn and our deepest gratitude to Mr Alan Homes, a lifetime member of the Pernicious Anaemia Society. Both left generous legacy donations in their wills, for which we are truly thankful.

Legacy gifts are a vital source of funding that helps charities like PAS continue into the future. These contributions make a significant difference to our work, enhancing the quality of life for current and future members, supporting vital research into the diagnosis and treatment of pernicious anaemia, and strengthening awareness and education.

We know that this is a delicate subject and that leaving a gift in a Will is a very personal choice, so we strongly recommend that you consult a professional when making such an important decision. If you do decide to leave a legacy to a charity, please consider PAS, or if you are looking for further information including what information a solicitor may require, please go to our website at https://pernicious-anaemia-society.org/legacies/ where we have more information and FAQs.

Support Group News

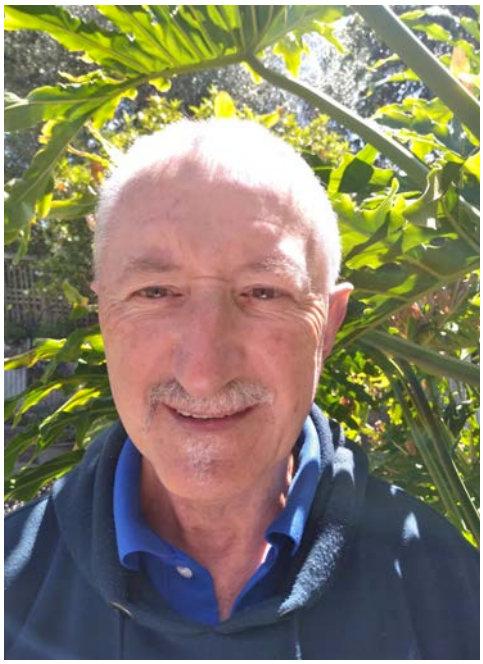
On Sunday 26th October, our Support Group Volunteer, Benita, held an online support group. We had 23 people register to attend, although on the day, there were a few less in attendance. Nevertheless, it presented a great opportunity to have a get together with all reporting it was a very positive experience. Benita showed everyone how to access the resources page on our website and many topics arose that will form future support group discussions.

On 8th November, our Support Group Volunteer, Julie, held an online support group where the topic was Living and Working with Pernicious Anaemia. It gave a good opportunity for the attendees to share how they manage their symptoms and adapt their routines when working, amongst other things

On 6th December our Support Group Volunteer (and Office Manager) Karyl, hosted an online group where she provided an update on the reasons behind our office closing (due to the landlord selling the building) and our support group survey. Our CEO was present to announce the news about the launch of the Education Programme and the work we are doing to ensure it is communicated in primary care.

Personal Story

Anthony, Australia



My name is Anthony, I'm 71 years of age, I'm a retired Chartered Accountant and I live in Adelaide, South Australia.

I've always regarded myself as being quite a healthy person. So, you can imagine my shock when I woke up one morning in mid-July 2025 with a tingling / pins and needles type feeling in my fingers and toes. I didn't know much about pins and needles but what I did know is that it never ended well. I had never heard of Pernicious Anaemia (PA) or vitamin B12 deficiency (B12d). There was also possibly some loss of taste, some breathlessness and some brain fog. I say possibly because I contracted a nasty virus at roughly the same time, and these latter symptoms are also common to viruses.

The virus and these symptoms have now passed. Fortunately, my residual neuropathy symptoms in my hands/fingers and feet/toes are not painful although perhaps slightly uncomfortable occasionally but come with an awareness that something is not quite right. I do not look or act differently and so my family and friends are generally unconcerned although they probably do not really understand anything about PA and/or B12d.

So, the first thing that I did was to Google pins and needles Very quickly it seemed obvious that I had a B12 deficiency and possibly also PA. Next, I made an appointment to see my local GP. During my consultation I told my GP my symptoms as well as my internet assisted self-diagnosis. He tended to agree with me but arranged for me to have a blood test to confirm our thoughts. The blood test results duly confirmed our diagnosis. My total B12 level was a very low 109 pmol/L (recommended range is between 130 and 855) and Intrinsic Factor antibodies (IF Ab) and Gastric Parietal Cell antibodies (GPC Ab) were detected. These antibodies confirmed my PA.

The initial treatment recommended was B12 injections on a frequency of 3 weekly, (a total of 6) then quarterly thereafter. This sounded quite reasonable to a naive me at that time. I continued to search the Internet, and this is when I came across the Pernicious Anaemia Society (PAS) website. What a revelation! It was amazing! What I found most fascinating were the personal stories of medical/health challenges, great suffering, poor diagnoses (if at all) and undermedication over periods of years, if not decades. I will never forget the difficulties in getting GPs to, firstly, understand the PA problems and, secondly, to change their medical diagnoses in a proactive manner. With these stories ringing in my ears, I realised that my GP recommended injection treatment schedule could be grossly inadequate.

I started to become stressed and anxious about the thought of needing to discuss this with my GP in the hope of getting him to listen to my concerns and then to adjust the B12 injection protocol. Nevertheless, I quickly made another appointment with my GP. Fortunately, my concerns were unwarranted as he listened patiently and then altered the injection protocol to 3x per week. What a relief! I must have sounded very impressive as I quoted the PAS treatment recommendation for PA with neurological impairment not to mention the lessons learnt from the personal stories.

Around this time during my internet searches, I stumbled upon an Artificial Intelligence (AI) application (Microsoft Copilot). Wow, it was incredible! It didn't matter what questions I asked or how I asked them, the responses were prompt, detailed and seemed medically logical and well researched. I learnt so much about the biological, neurological and functional aspects of PA and B12. But the biggest surprise was the ability to model various scenarios. I included in my questions my blood test metrics, intramuscular injection frequency and treatment timelines/milestones. The responses were very detailed and included in tabular form predicted levels of total and active B12, methylmalonic acid (MMA) and homocysteine as well as the progress of nerve regeneration and nerve functional recovery. Every scenario could also be compared to each other. My biggest issue with PA, apart from the disease itself, is not knowing when the active treatment will end and the life-long maintenance treatment commences. The scenario modelling gave me a good idea about this and showed the impact of the tapering of injection protocols. As a result, I am very wary of tapering too soon as symptoms may remain longer and may become irreversible – an outcome that I wish to avoid at all costs. When I asked, both GPs that I have been seeing admitted that they had never treated a PA case before.

From what I have seen so far, it is my opinion that in the future the PAS website could consider including some AI functionality. The result could be an incredibly powerful resource tool.

So, after 12 weeks (21 injections), I feel that my treatment is going well. I'm sure that my symptoms have improved even though the improvement is not linear or consistent and can be very frustrating. I want to maintain my aggressive IM injection protocol so that my tissue and neurological pathways are saturated with B12 as this will optimise nerve regeneration and recovery. After 9 weeks (12 injections), my active B12 was >128 pmol/L (recommended level is >35) – so I knew that I was on the right track. Overall, I think that I am lucky(?) as my symptoms seem quite mild. My philosophy has always been that the earlier that treatment commences, the better the outcome. As far as I know, there has not been any history of PA in my family although, in hindsight, I am wondering whether some of the symptoms displayed by some relatives may have been due to PA and/or B12. My GP is starting to talk about tapering the frequency of injections, but this worries me a little. I'll have to have a discussion with him to see where this goes.

At this point, I would like to sincerely thank PAS, the PAS website and their dedicated volunteers for providing valuable information, support and guidance. I would certainly be in a far worse place without them. I would also like to thank the medical fraternity (researchers, scientists, specialists, doctors and nurses) who both treat and endeavour to find a cure for PA.

I'm hoping to update this story in 6-9 months by adding some good news regarding my recovery. I'm hoping for a full recovery. I would also like to pass on my best wishes to all PA sufferers and hope that their respective journeys meet their expectations.
I've chosen to write my personal story because I was inspired by all the other personal stories that I read, and I hope that it will help others on their journey.

This personal journey highlights the potential of AI as a supplemental tool. However, we strongly caution readers that artificial intelligence generated information does not replace the crucial expertise, judgment, and care provided by human experience, knowledge, advocacy support and guidance from doctors and medical teams.