pas Pernicious Anaemia Society

Cobalamin News

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Contents

Highlight:

Why Patient Voices Matter

Understanding the lived experience of people with pernicious anaemia is essential for improving both clinical practice and patient-centred care. Research that explores symptom burden, daily functioning, and the broader impact on wellbeing helps illuminate the often-under-recognised challenges patients face throughout their diagnostic and treatment journey. By deepening insight into how current treatment regimens—particularly the frequency of injections—affect quality of life, such work supports the development of more flexible, responsive, and personalised care pathways. Ultimately, studies like this play a crucial role in shaping services that better align with patient needs, preferences, and long-term outcomes.

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 Introduction:

from our CEO, Katrina Burchell

This first quarter of 2026 has been a whirlwind of activity. We started the 20th year of the Pernicious Anaemia Society ramping up our social media activity including reels looking back at our 10th year anniversary conference. Reflecting on how far we have come and how far we still have to go has been both exciting and challenging but helped us confirm our resolve to make 2026 a year that things change.

Our social media exists to raise awareness and educate about PA and we are active on Facebook, Instagram and LinkedIn as these meet our target audience of patients, prospective members and professionals in medicine and research. Unlike other FB groups, the role of our social media is not to answer specific queries and questions should be directed to our help desk email or telephone line. We also host the HealthUnlocked forum where patients can talk to other patients about their experiences. There is often confusing or misleading information online and we strongly recommend that you seek support from reliable sources.

As you will read in this newsletter, our online Support Groups provide a free and open space for members to discuss their journeys through diagnosis and treatment and we know from feedback that many find these a great way of “normalising” how they feel, I whether that is with specific symptoms or challenges faced with their health care providers. Taking feedback from the survey about our support services, we are working on updating our activities and would love to hear from any members who are interested in running an online support group, anywhere in the world.

Part of our mission to raise awareness is to create materials in different forms and aimed at different membership categories. Here in this newsletter you will read about our new *First Diagnosis Leaflet* aimed at the start of the journey. Our blog posts are more in-depth explorations of topical issues and in addition to the one reported on in this newsletter, there are blogs from me and from guest bloggers, including posts about *the Wren Project*, *Nobel Prizes*, *Oral Implications of PA* and *Why injectable B12 is prescription only at the moment in the UK*. Talking of the Wren Project, this autoimmune listening charity gave us a talk in February. This is now available in our shop free for all members to listen to.

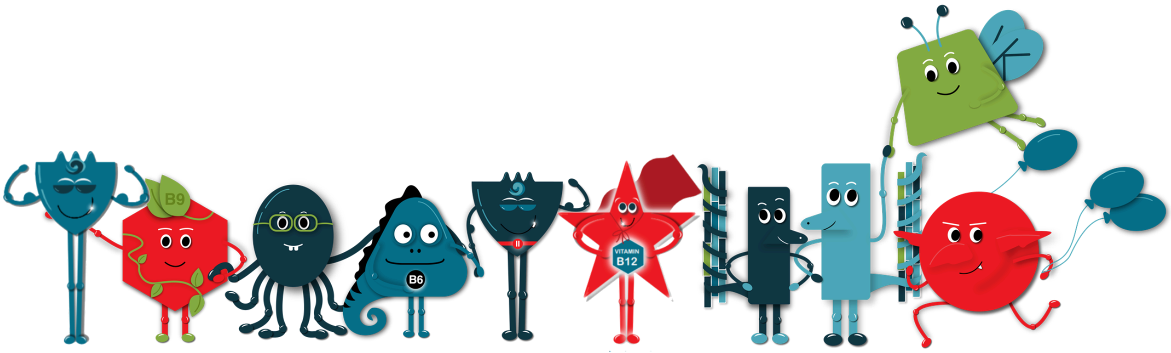
If the blog posts are too long or contain too much information for you at this stage of your journey, then you may like our Substack which is an online magazine where we share some more general ideas and thoughts about Pernicious Anaemia. Substack is an online platform that allows independent writers and creators to publish newsletters directly to subscribers. You dont have to be a member to follow us on Substack but we hope that those that enjoy our articles and find them useful, will sign up to PAS as a member to help support the work we do.

All of this work on social media and the articles in blog posts and on Substack are initiated and created by our small team of volunteers. Although we have the support of a professional team for social media graphics and uploading, the hard work of the team behind the scenes and our helpdesk really makes a difference in raising the profile of the charity. From this launch pad we can open doors to working with high quality research institutes, the NHS, the MHRA and clinicians who understand and want to help improve diagnosis and treatment.

We have a number of exciting research projects in their infancy, some which have started - see the request from De Montfort in this newsletter - and some that we are looking for funding for. This gives me the opportunity to thank all of those that gave so generously at the end of last year to our general cause and to research projects, and to those who set up or continue their standing orders to donate monthly. And also to those who support us by buying from our shop, whether it is seminars, merchandise or using the links to post eCards or buy books from our dedicated bookshop link.

Our next big project will be working with the B-12Alliance to bring **a Parliamentary Lobbying Reception** to life and there will be more about that soon in emails, social media and a dedicated B-12Alliance website. Although it is not officially launched yet, you can help us get ahead with our plans and activities by donating on the JustGiving page here.

For now I am off to prepare for our upcoming Trustees meeting where we will be discussing fundraising ideas and support, the next three year "business plan" for the charity, and some exciting new projects on research and our website materials. Our treasurer will be preparing the end of year accounts and working with our auditors to get ready for our AGM later in the year. The management team and our other volunteers will continue to work on the lengthy "to-do" list of ongoing projects and upcoming ideas.



Research

Update by Rachel Barnes, PhD student, Norwich:

After encouraging results from my pilot-study, I am currently recruiting patients for the next step of my project. I will be looking at 40 patients with four urine samples at timed intervals of 24 hours pre-injection, the day of the injection and 24 hours after, then 72 hours post injection. The hypothesis is that that this will show that patients need individualised treatment plans. I am also correlating the CPRD data
(a database collecting anonymised patient data) which provisionally shows approximately half a million patients have received B12 in the preceding 10 years across England, showing the scale of the issue we all face.
I hope to have updates for you all soon regarding further CPRD data and the next trial.

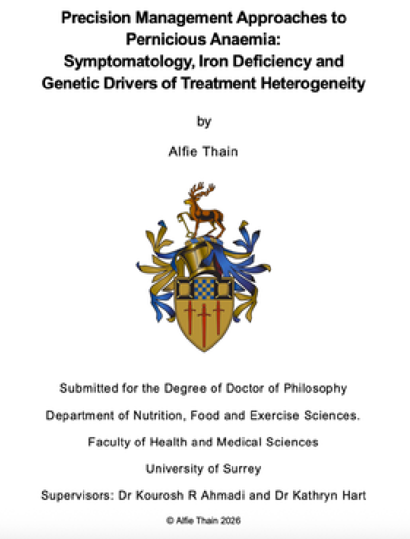
Research

By Alfie Thain

PhD Thesis Update

I am very pleased to share that I have now submitted my PhD thesis. My viva examination is scheduled for the end of April.

I would also like to sincerely thank the Pernicious Anaemia Society, and in particular Katrina Burchell, Karyl Carter and Petra Visser, for their support, collaboration and commitment to advancing research in this field. Their enthusiasm for improving the understanding of Pernicious Anaemia has been instrumental in making this research possible. I am especially grateful to the many members of the Pernicious Anaemia Society community who generously shared their time, experiences and data by participating in the studies included in this thesis. I hope that this work contributes, even in a small way, to improving understanding of this often-overlooked and under-researched condition and to supporting better recognition, treatment, and management for those living with Pernicious Anaemia.



Precision Management Approaches to
Pernicious Anaemia:
Symptomatology, Iron Deficiency and
Genetic Drivers of Treatment Heterogeneity

by

Alfie Thain

Submitted for the Degree of Doctor of Philosophy

Department of Nutrition, Food and Exercise Sciences.

Faculty of Health and Medical Sciences

University of Surrey

Supervisors: Dr Kourosh R Ahmadi and Dr Kathryn Hart

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What was the research about?

Pernicious Anaemia is often treated as a simple B12 deficiency with a standard treatment approach. However, many people report ongoing symptoms, differences in treatment response, and challenges with diagnosis and management.

My research aimed to better understand these differences and to explore the development of more personalised approaches to Pernicious Anaemia care.

What did I find?

1. Symptoms vary widely between people

One of the most important findings from this research is that Pernicious Anaemia does not affect everyone in the same way.

People experience a wide range of symptoms, including neurological, cognitive, and gastrointestinal symptoms, and these can differ greatly between individuals. Importantly, symptoms often return or worsen before the next vitamin B12 injection, suggesting that current treatment schedules may not fully meet everyone's needs.

Many of these patterns will be familiar to people living with Pernicious Anaemia. However, an important part of this research has been to provide evidence of these experiences, helping to demonstrate to clinicians that these patterns are consistent.

We are currently preparing this work for publication, and one important finding is that different symptoms respond differently to treatment. Some symptoms improve quickly after an injection, while others take longer to respond or may not improve consistently. This challenges the common assumption that people feel better immediately after an injection, which, for many individuals, is not the case.

2. Different "response types" to treatment

Another key finding is that people appear to respond differently to vitamin B12 treatment. Some individuals experience clear improvement in symptoms following injections, while others report more limited or inconsistent benefit.

This suggests that there may be different “response patterns” or subtypes of response to vitamin B12. This is important because it challenges the idea that a single treatment approach works equally well for everyone.

Better understanding these differences in symptoms and response is key to improving treatment and ensuring that care is better tailored to individual needs.

3. Iron deficiency is very common, often recurrent, and not well managed

The research found that iron deficiency is very common in people with Pernicious Anaemia, affecting more than half of the participants in the study.

Despite its high prevalence and impact, iron deficiency is not always routinely investigated, monitored, or effectively managed in clinical practice. Many individuals reported limited follow-up after treatment, and some did not receive further testing to confirm whether their iron levels had improved.

In addition, while oral iron is commonly prescribed, it is not always well tolerated or effective. Some individuals reported ongoing symptoms despite treatment, and relatively few were offered alternative options such as iron infusions when initial treatment did not work.

Overall, these findings highlight an important gap in care and suggest that iron deficiency is an under-recognised contributor to ongoing symptoms in people with Pernicious Anaemia.

4. Many people have other autoimmune conditions

Pernicious Anaemia often occurs alongside other autoimmune diseases. In this research, a large proportion of participants reported at least one additional autoimmune condition, such as autoimmune thyroid disease or vitiligo. This supports the idea that Pernicious Anaemia is part of a broader autoimmune picture rather than an isolated condition.

Having multiple autoimmune conditions can make diagnosis and management more complex, as symptoms may overlap and different conditions may influence each other. It may also mean that people require more coordinated and individualised care across different areas of health.

Future work should aim to explore whether management approaches should differ between those with Pernicious Anaemia alone and those with additional autoimmune conditions.

5. Genetics may help explain differences between people

The PhD also explored genetic factors that influence the development of pernicious anaemia. Findings suggest that genetic differences play a role in both the risk of developing the condition and how individuals respond to treatment, including how frequently vitamin B12 injections may be needed.

In particular, we found that individuals with a genetic tendency towards lower vitamin B12 were more likely to require more frequent injections. This provides evidence that differences in treatment needs are not simply subjective experiences but may have an underlying biological basis.

What does this mean for people with Pernicious Anaemia?

Overall, this research suggests that Pernicious Anaemia should not be viewed as a simple vitamin B12 deficiency and that a standard treatment approach is not appropriate for everyone.

Instead, it appears to be a more complex autoimmune condition that varies between individuals in terms of symptoms, treatment response, and is associated with other health conditions, and long-term management needs.

Across this research, clear differences were seen in how people experience symptoms, how these symptoms change over time, and how individuals respond to treatment. In many cases, these patterns were consistent within individuals.

Importantly, these findings also highlight that ongoing symptoms may not always be explained solely by vitamin B12. Factors such as iron deficiency and other autoimmune conditions may also play an important role and should be considered as part of a broader picture.

There was also evidence that longer delays before diagnosis may be linked to greater long-term treatment needs, highlighting the importance of earlier recognition and diagnosis.

Together, this suggests that current “one-size-fits-all” approaches to diagnosis, monitoring, and treatment do not fully reflect the reality of living with pernicious anaemia.

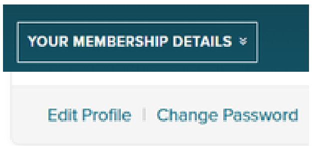
This highlights the need for:
- More personalised and flexible treatment approaches
- Better recognition and validation of ongoing symptoms
- Improved investigation and monitoring of related conditions, such as iron deficiency
- Greater awareness of pernicious anaemia as a complex autoimmune condition among healthcare professionals

What happens next?
This PhD represents a starting point rather than an end. Future work will focus on improving treatment approaches, including exploring more personalised vitamin B12 regimens and developing new models of care, such as supported self-injection.

Important: Update your membership information!

As part of our commitment to keep your account details up to date, and to ensure you continue to receive our newsletters and updates, we regularly review our records. We ask that you carry out the following steps as soon as possible, but no later than 28th March 2026.

- log into your account on the website
- choose the option “Your membership details”
- Choose the option “Edit Profile”
- Review your personal details
- Make any changes



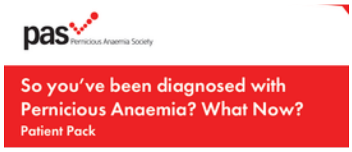
This is even more important if you are one of our many generous donors who gift aid their payments as it is essential we provide the correct information to HMRC.

Please also tell us (by email) if your tax status changes and we can no longer claim gift aid on your behalf, or if you would like to make your membership fee gift-aided if you have not done so before.

If for any reason you are unable to update your information online, please send the changes to us at membership@pasoc.org.uk

PAS Patient Tools

The First Diagnosis Pack



pas Pernicious Anaemia Society

So you've been diagnosed with Pernicious Anaemia? What Now?

Patient Pack

New on Our Website: The First Diagnosis Pack for Newly Diagnosed Pernicious Anaemia Patients

We're pleased to announce the launch of our brand-new **First Diagnosis Pack**, now available on our website. This dedicated resource has been created especially for new members and individuals who have been recently diagnosed with Pernicious Anaemia—a moment that can often feel overwhelming and confusing.

Why We Created the First Diagnosis Pack

A diagnosis of Pernicious Anaemia frequently comes with a flood of unfamiliar information, medical terms, treatment options, and lifestyle considerations. Many newly diagnosed patients tell us they feel unsure where to begin, especially when they're already coping with significant symptoms such as fatigue, cognitive difficulties, or physical discomfort.

The First Diagnosis Pack is designed to address this need by offering:

- Clear explanations of what PA is and what causes it
- An overview of current treatment approaches
- Guidance on managing this lifelong condition
- Helpful tips for navigating your journey
- Reassurance and support from credible resources

Our aim is to empower patients with reliable, accessible, and easy-to-understand information from the moment they're diagnosed.

A Valuable Tool for Healthcare Providers

We know that time during clinical appointments is limited—and that patients often leave feeling uncertain about next steps. To support better communication and continuity of care, healthcare providers can now download and share the First Diagnosis Pack directly with their patients via our website.

It's an ideal resource to give to individuals who may:

- Be trying to process a large amount of new information
- Have questions they forgot to ask during their appointment
- Need extra support understanding what their diagnosis means
- Want guidance they can take home, revisit, and share with family members

Where to Find It

The First Diagnosis Pack is now available to all members on our website. We encourage newly diagnosed patients, established members, and healthcare professionals alike to explore and download the pack.
If you—or someone you support—has recently begun their journey with Pernicious Anaemia, we hope this new resource brings clarity, confidence, and comfort.

Support Group Update

Our wonderful volunteer, Karen, held an online support group on Friday 19th March and 18 members registered to attend; I think that's a record!

They also looked at our new First Diagnosed Pack and thought it was a great resource, not only for those who are newly diagnosed, but they also felt it served as a good reminder for those already on their PA journey.

Discussions were held on a number of topics including going back to work after being signed off mainly due to PA. How can you ensure an employer has sufficient information to make suitable adjustments, if needed? We were able to share our leaflet:

Employers and how they should deal with workers who have PA or B12 deficiency.

Also, members asked for tips on how to deal with travel, injections and insurance, and wanted to ensure they were covered in all sorts of areas.

We hope to address travel information very soon, so keep an eye on the website and keep an eye out for dates of forthcoming online support groups.

Don't forget, it doesn't matter where you live, all members are welcome to all support groups.

Research

April Blog Post - Research by Heidi Seage

This month our CEO, Katrina Burchell, takes a look at the recently published research led by long time friend and colleague of PAS, Heidi Seage and reflects on the importance of patients being given more control over their long term care.

The "Half-Life" of Pernicious Anaemia: Why Patient Voices Matter
A new study published in the Journal of Rare Diseases shines a much-needed light on the lived experience of Pernicious Anaemia (PA). For many in our community, the findings won't come as a surprise, but they provide vital academic validation for the daily struggles we face.

The research, led by Heidi Seage at Cardiff Met University, used in-depth interviews to map the "symptom journeys" of patients in the UK. Here is what the study tells us about the reality of living with PA:

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1. The Long Road to Diagnosis
Participants described a "prolonged diagnostic uncertainty" that often lasted years. Before being heard, many were told their symptoms—ranging from unrelenting fatigue to "real fog" in the head—were simply psychological.

- Misattribution: GPs frequently defaulted to labels like depression or anxiety.
- Invisible Burden: Patients felt "disconnected" and "unheard," struggling to explain that they weren't just tired, but fundamentally ill.

2. Treatment Isn't Always a "Cure"

While the UK standard of B12 injections (hydroxocobalamin) generally reduces symptom intensity, it often fails to eliminate them.

- The Treatment Gap: Many patients reported that symptoms return or intensify towards the end of their 8 to 12-week treatment cycle.
- Permanent Damage: For some, like "Elizabeth" in the study, delayed diagnosis led to irreversible nerve damage and chronic pain that persists despite treatment.

3. Taking Control through "Illness Literacy"

Faced with suboptimal treatment, the study found that patients are becoming "experts" in their own care.

- Self-Management: Up to 40% of patients may be self-medicating with non-prescribed injections to achieve better symptom control.
- Lifestyles Adjustments: Living with PA requires a "lifelong negotiation". Participants described having to reduce social activities, exercise, and work commitments just to function.

"You can't convey that to someone who's never had it... being so emotional and so angry about the way you're feeling and not being able to do anything about it." — Helen, study participant

The Bottom Line for Advocates

This research underscores a clear need for patient-centred care. We are not just numbers on a blood test; we are individuals managing a complex, fluctuating condition.

The study concludes that healthcare models must move beyond just "medical management" and start supporting the broader psychosocial impact PA has on our lives. It’s time for shared decision-making regarding injection frequency and a genuine recognition of the patient as the expert in their condition.

This is why PAS, through our CEO who is currently chair of the B-12Alliance, is driving forward the UK parliamentary reception which will be held later this year to turn the focus on empowering patients with the flexibility to self-administer B12 injections. By allowing patients to reclaim control over their health and tailor treatment frequency to their unique symptom patterns through a shift towards supported self-management, we can significantly improve a patient's quality of life while reducing the administrative and clinical burden of routine appointments on the NHS.

However, true empowerment must be grounded in patient-centred care, ensuring that everyone—regardless of the cause of their deficiency—retains access to professional monitoring and the expert guidance necessary for safe, long-term health outcomes.

Research Project - Children with PA

A team of researchers at De Montfort University, Leicester, are conducting a study to explore the experiences of parents with a child or children that they suspect or know has vitamin B12 deficiency of any cause, including Pernicious Anaemia. They hope to gain an insight into any challenges that parents have faced as they have approached healthcare professionals to explore a potential diagnosis, testing and accessing treatment for their child.

They are looking for UK residents aged 18 years or older with a child or children that you suspect or know has vitamin B12 deficiency or Pernicious Anaemia to complete a short online survey, which should only take 10 minutes to complete. Further information about the study and the survey itself can be found via the link below:

Vitamin B12 deficiency in children: Exploring the experiences of parents – Take part

They are also looking for a small number of people who would be willing to participate in a short online interview (maximum 30 minutes) to discuss their experiences in more detail. If you would like to learn more about this please email Dr Nicola Ward at n.ward@dmu.ac.uk and she will respond with further details. Making contact does not commit you to taking part.

Participation in this research is entirely voluntary and all responses will be fully anonymised.

If you have any questions about this study please contact Dr Nicola Ward directly n.ward@dmu.ac.uk

Digital Health & Care

In January our CEO, Katrina Burchell, attended a two day event in Edinburgh organised by Holyrood Connect.

This conference, in its 17th year, brought together Scotland's top political voices, NHS leaders, and tech innovators to move beyond policy talk and focus on "ambition to impact." Discussions focused on the imminent Scotland wide rollout of the Digital Front Door programme and the Shift Toward Preventative Care. Case studies were shared and focused on citizen and charity sector led design to reduce administrative bottlenecks and ensure patient inclusion in the design of new technology-based services. Ideas like automated note taking, Apps for pre-surgery important preparation steps, virtual headset games to improve mobility, apps for tracking and monitoring symptoms and updating GP records directly were all ideas that PAS could take away to study further on how we can work with the NHS and our membership to offer solutions towards better diagnosis and treatment. The conference included big picture thinking about a digitally confident workforce as well as honest debate about infrastructure and funding. During the "Designing for Prevention" panels, there was a specific emphasis on **Data-Driven Innovation.** This aligns with PAS interest in a move toward "personalised and preventative care" aims to use longitudinal data to flag nutritional deficiencies—like B12, folate and iron—much earlier by identifying subtle patterns in blood results over time. These events are valuable for PAS to attend for networking purposes as well as learning. Many of the research experts that we work with or are keen to work with were present to discuss ideas with during the coffee breaks. Our CEO returned with a notepad full of thoughts and ideas and a diary of follow up meetings and calls. We are very grateful to Holyrood Connect for arranging this meeting and to the sponsors for enabling a PAS to attend this event.

Stronger Together: Highlighting the Overlap Between PA and Iron Deficiency

At the Pernicious Anaemia Society, we believe that understanding the full picture of our health comes from building connections—both in research and within our community. We are proud to highlight the vital work of **Alfie Thain**, a PhD student the **PAS helped fund**, whose recent research has brought a critical statistic to the forefront: **up to 40% of people with Pernicious Anaemia also had iron deficiency at the time of diagnosis**. This significant overlap confirms that for many of us, B12 is just one part of a larger conversation. Because of this common ground, we see the newly launched **IronLife** charity as a natural ally, and we look forward to working closely with them in the future to ensure all patients receive the comprehensive screening they need.

If you would like to dive deeper into this topic and support our work, we have a fantastic resource available in our **webshop**. You can find a recording of an exclusive seminar given to the PAS by **Professor Toby Richards** of **IronLife**, which is an excellent starting point for any members wanting to learn more about the complexities of iron health. Thanks to IronLife for their introduction below:

Introducing IronLife: A New National Voice for Iron Health

A new UK charity, IronLife, was launched on World Anaemia Awareness Day (13 February 2026) to tackle one of the most common and overlooked micronutrient deficiencies: iron deficiency.

Who

IronLife brings together clinicians, researchers and patient advocates determined to improve awareness, screening and early treatment of iron deficiency across the UK. The organisation works alongside healthcare professionals and patient groups to ensure iron deficiency is recognised as a serious but treatable condition.

What

The charity intends to encourage people to recognise symptoms such as fatigue, brain fog, breathlessness, anxiety, low mood, hair loss and to request appropriate ferritin testing. IronLife is also advocating for routine screening in higher-risk groups.

Why

Iron deficiency affects an estimated 1 in 4 women of reproductive age worldwide, and is particularly common in those with heavy menstrual bleeding, chronic illness or malabsorption conditions.

For people living with Pernicious Anaemia, this overlap is significant. Iron can be as important a factor to consider as folate and B6, as many people with PA are also iron deficient. In fact, a recent survey cited by the Pernicious Anaemia Society found that 40% of respondents reported iron deficiency. Due to this high prevalence, it is recommended that all patients with pernicious anaemia are screened for iron deficiency.

Where & What’s Next

Since before launch, IronLife has been reaching out to build partnerships with universities, employers, policymakers, healthcare charities and networks across the UK to drive education and policy change throughout 2026.

You can follow and support IronLife here:
Website
Facebook
Instagram
X
LinkedIn
TikTok

Detect it. Correct it. Empower her.

Looking for information to help you understand more about B12 Deficiency?

In a recent session at the Long Covid Clinic, Dr. Andrew Klein, a consultant anaesthetist and director of the Cambridge Iron and B12 Clinic, shared critical insights into the often-misunderstood world of vitamin B12 deficiency. Whether you are a patient navigating chronic symptoms or a healthcare professional looking to refine your diagnostic approach, this video provides some key takeaways which highlight why B12 is a "missing puzzle piece" in many chronic illnesses.

As we know here at the Pernicious Anaemia Society, it is vital that patients empower themselves by understanding the significant limitations of current B12 testing; a "normal" blood result does not always rule out a deficiency, especially when symptoms are present. For healthcare professionals, the shift must move toward a clinical, symptom-led approach rather than relying solely on laboratory ranges and arbitrary numbers that often fail to capture deficiencies.

To delve deeper into these nuances, we highly recommend watching Dr. Andrew Klein’s full presentation. Although the discussion is framed within the context of Long COVID, the insights regarding the mechanisms of B12, the pitfalls of testing, and the necessity of symptom led treatment are incredibly valuable and directly applicable to those living with pernicious anaemia.

Watch here

A Heartfelt Thank You to Our Community

We would like to extend our deepest gratitude to the families and friends who have recently chosen to support **PAS** through **MuchLoved.com**.

For those who may not be familiar, MuchLoved is an online tribute platform that allows loved ones to create beautiful, lasting memorials while hosting donations in honour of someone special.

We are truly moved by those who nominated us as their chosen charity and to everyone who contributed a gift. These donations make a profound difference, directly contributing to our ability to continue our vital work and support those who need us most.

We want to thank them here for their kindness and for keeping our mission close to their hearts

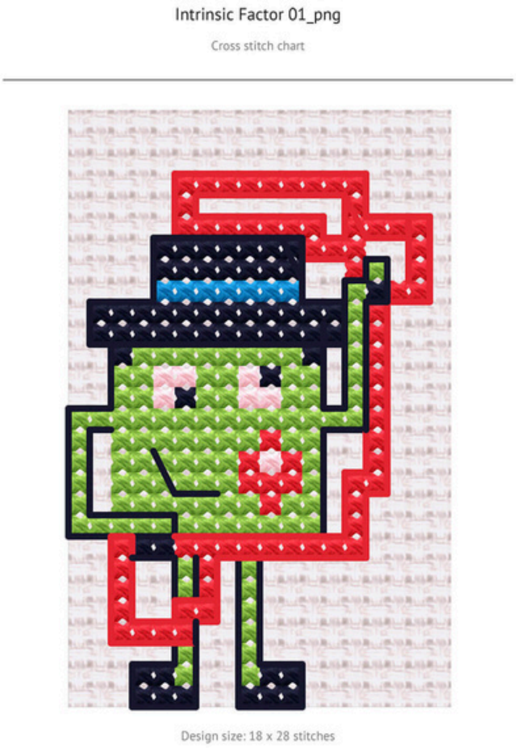
MuchLoved | The memorial tribute platform

Cross Stitchers

Calling all Cross-stitchers!

A little bird tells us that some of our talented members have been purchasing the cross-stitch pattern available to buy in our shop. If you are happy to share, we would love to see the finished results so send us a photo (ideally with you in shot too!) and we can publish it in our next newsletter.

Email your pictures to: info@pasoc.org.uk



PAS SUPPORT GROUPS

Our support groups are now being held online which gives all Members the opportunity to join in regardless of where they live.

On Saturday 14th March, our Volunteer Benita, held an online support group where attendees included members from the UK, Ireland and the USA.
The Support Groups are a great way to ensure members are aware of what's available to them, and at Benita's group they were able to have a look at our new First Diagnosis Pack, which is now available on our website. This led to conversations and discussions about symptoms, treatment, diagnosis and living with PA.
All who attended said they found the group positive and informative.

Our online Support Groups are advertised on our website and on social media, e.g. Facebook, so do keep a look out if you're interested in joining in.

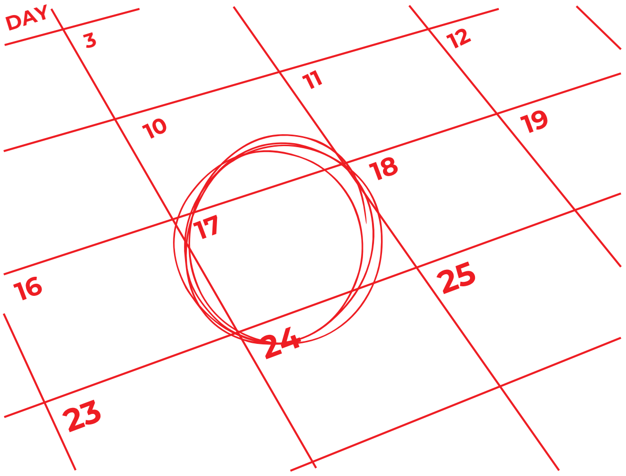
What’s on & Key Dates

10 September: B12Alliance UK Parliamentary Reception

12 September: PAS Annual General Meeting

23 September: Webinar on PA and IBS
with Liane Reeves BSc Nutrition & Dietics TBC

3 October: PAS Annual Seminar



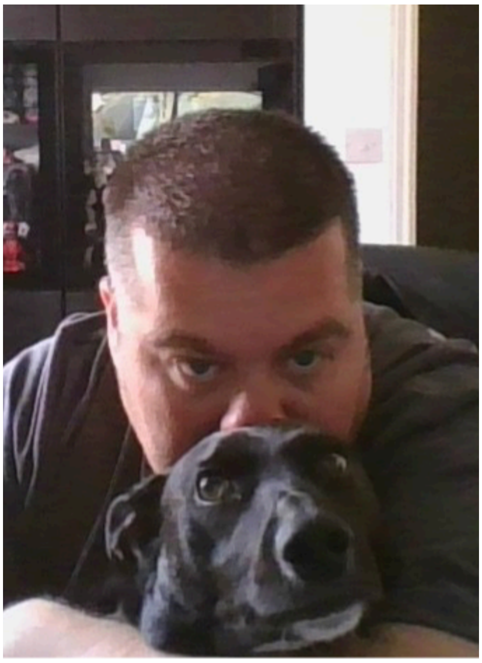
Pernicious Anaemia Society

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.

Personal Story

Andrew, Lincolnshire



I couldn't get out of bed.

Not because I was lazy. Not because I was depressed. But because my body had simply stopped functioning. For two weeks, I lay there, unable to work, unable to think clearly, unable to explain to my employer what was happening to me. My vision was blurred, my hands shook, pins and needles shot through my limbs, and when I tried to walk, I couldn't move in a straight line.

This is what untreated Pernicious Anaemia looks like.

My Story

I'm Andrew, 50 years old, from Lincoln. I work as a Project Manager for an industrial gas turbine manufacturer - a demanding, fast-paced role that requires sharp thinking and constant problem-solving. Today, I'm managing my condition and performing well. But getting here required a fight that should never have been necessary.

A Family Legacy

Shortly after my birth, I had pyloric stenosis and underwent surgery at about 6 weeks old. Apart from that, my childhood was relatively unremarkable. But autoimmune disease runs deep in my family, like a genetic inheritance none of us wanted.

My maternal grandfather had Pernicious Anaemia. One of my brothers has Hashimoto's disease. The other has Hidradenitis suppurativa. A good number of my cousins have PA. We're a textbook case of autoimmune clustering—the kind doctors should pay attention to when taking a family history.

The First Time: When Medicine Worked

I was first diagnosed about 22 years ago. I was working as a sales manager for a soft drink manufacturer, living in Medway and commuting to Gloucester weekly. When I wasn't in the office, I was on the road visiting customers across the UK. Life was good, busy, successful.

Then something shifted. I started feeling tired - not normal tired, but a bone-deep exhaustion that sleep couldn't touch. I became irritable, unable to concentrate. Simple tasks felt impossible. I went to my GP several times. They ran tests. Nothing conclusive came back.

Then my surgery moved to a new medical centre, and I saw a different GP. He did something radical: he actually looked at my medical history. He asked about my family. When I mentioned my grandfather's Pernicious Anaemia, he immediately prescribed loading injections.

Within days, I was back at peak performance.

It felt like a miracle. My serum B12 level was very high after treatment, so they decided I didn't need further injections. For several years, they were right. But that decision would come back to haunt me.

The Second Time: The Fight for Treatment

About 12 years ago, I'd moved to Lincolnshire but was still doing extensive driving - weekly trips to the South London office, plus a national customer base. The symptoms returned, similar to before, but this time they escalated terrifyingly fast.

Tired. Confused. Irritable. No appetite. Vision problems. Tremors. Pins and needles shooting through my body. Ataxia - I couldn't walk straight. My teeth started having issues. The full devastating list of neurological symptoms.

At one point, I went to bed for two weeks because I literally could not function.

Try explaining that to your employer. Try finding the words when your brain is foggy and you can barely string a sentence together. 'I can't come to work because I can't get out of bed' sounds like depression or laziness, not a serious medical condition. The professional consequences of an invisible illness are real and frightening.

My new GP was much harder to convince. Despite my family history - despite my previous diagnosis - despite my obvious symptoms, they tested my B12, found it low, and prescribed tablets and dietary changes.

They did absolutely nothing.

Here's what people don't understand about Pernicious Anaemia: it's an absorption problem. My gut cannot absorb B12, no matter how much I ingest. Tablets are useless. It's like telling someone with Type 1 diabetes to just eat less sugar - a fundamental misunderstanding of the condition.

I had to fight. I had to argue. I had to advocate for myself while my brain was failing me. Finally, I got another course of loading injections. Things improved.

Then the course ended. The symptoms returned.

I had to push for regular injections. First, they agreed to every three months. I relapsed. Every two months. I relapsed again. After writing a letter to the practice manager, I finally got injections every four weeks.

Let me be clear: B12 injections are inexpensive and virtually risk-free. Yet I had to fight, relapse, and write formal complaints to get adequate treatment for a well-documented condition with a family history.

The Absurdity of It All

The solution to my condition costs pennies. A B12 injection is one of the cheapest treatments in modern medicine. There are virtually no side effects. The evidence for its effectiveness in PA is overwhelming. The consequences of under-treatment include permanent neurological damage.

Yet patients across the UK are fighting the same battle I fought. We're questioned, dismissed, offered tablets that don't work, told our levels are 'fine' when we're clearly symptomatic, and forced to deteriorate before we're believed.

Why? What's the reasoning? When the treatment is cheap, safe, and effective, why make patients suffer and fight for it?

Life Now

Today, my Pernicious Anaemia is under control with regular four-weekly injections. I work in a dynamic, demanding environment and I'm performing well. I refuse to use PA as an excuse or let it hold me back.

But 'under control' doesn't mean perfect. I've had other medical issues that I suspect are related to PA - the autoimmune connection, the years of under-treatment, the neurological damage that may have occurred. I can't prove the link, but the pattern is there.

PA is always there in the background. I'm vigilant about my injection schedule. I know my early warning signs. I've learned to recognise when I need to advocate for myself. The condition doesn't control me anymore, but I'm acutely aware of what happens when treatment fails.

What I Wish I'd Known: Practical Advice

You're not going mad. What you're feeling is real, valid, and physiological. The fatigue, the brain fog, the neurological symptoms - they're not in your head. They're caused by your body's inability to absorb a critical vitamin.

Document everything. Keep a symptom diary with dates. Record how symptoms affect your work, your daily life, your ability to function. This documentation is your evidence when you need to advocate for yourself.

Know your family history. Autoimmune conditions cluster in families. If you have relatives with PA, Hashimoto's, Type 1 diabetes, or other autoimmune diseases, tell your doctor. Bring documentation if necessary. This is medically relevant information.

Understand the tests. Request serum B12, active B12, intrinsic factor antibodies, and parietal cell antibodies. Know that a 'normal' B12 level doesn't mean you're not symptomatic - treatment is based on symptoms, not just numbers.

If tablets don't work, say so. PA is an absorption problem. Oral B12 is ineffective for many people with PA. If you've tried tablets and you're still symptomatic, insist on injections. Don't let anyone tell you to 'give it more time' while you deteriorate.

Be prepared to fight. Sadly, many patients have to advocate firmly for appropriate treatment. Be polite but persistent. Ask for things in writing. Escalate if necessary. Your health is worth fighting for.

Find support. Organisations like the Pernicious Anaemia Society provide evidence-based information and community support. You're not alone in this fight. Connect with others who understand.

Don't suffer in silence. The isolation of an invisible illness is real, but there are people who understand, resources available, and growing awareness of PA. Speak up. Tell your story. Help others recognise the signs.

A Message to Healthcare Providers

If you're a GP, nurse, or healthcare professional reading this: please listen to your patients.

When someone presents with fatigue, neurological symptoms, and a family history of autoimmune disease, take it seriously. When someone tells you tablets aren't working, believe them. When someone describes symptoms consistent with B12 deficiency, don't dismiss them because their levels are 'in range.'

Treatment is cheap. Treatment is safe. Under-treatment causes permanent damage.

You have the power to change lives with a simple prescription. Please use it.

Final Thoughts

I'm sharing my story not for sympathy, but for recognition. Pernicious Anaemia is a serious condition that's often dismissed, under-treated, and misunderstood. The medical evidence is clear. The treatment is straightforward. The outcomes with proper treatment are excellent.

Yet thousands of us are fighting the same battles, having the same conversations, experiencing the same dismissals.

It doesn't have to be this way.

If you're reading this and recognising yourself in my story - the fatigue, the neurological symptoms, the struggle to be believed - please don't give up. Keep advocating. Keep documenting. Keep fighting for the treatment you deserve.

You're not imagining it. You're not being difficult. You deserve to be heard, believed, and properly treated.

Your health matters. Your voice matters. Don't let anyone tell you otherwise.