pas Pernicious Anaemia Society

Cobalamin News

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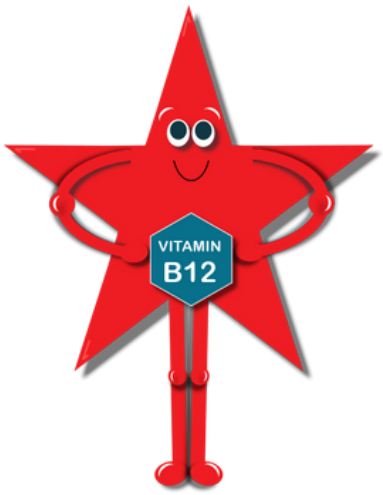


Research Highlight:

An Oxfordshire GP, Willemina Rietsema, is seeking UK-based B12 injection patients or carers for a 4–5 year research project exploring injection frequency and its impact. Volunteers will join Zoom-based Patient and Public Involvement sessions, contributing to survey design, data interpretation, and dissemination. Diversity in age, background is also going to be considered. See the full article under the Research section of this newsletter for the link to sign up

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

Earlier this week, in that moment before I realised that my B12 injection was due and I was again struggling to focus and questioning myself on everything I do and say, I received an email from a member submitting a personal story. I read it through and got a lump in my throat. I sent a thank you reply, saying the story had moved me and started reading it again so I could get it ready for our website when the following message popped up.

"I just wanted to say thank you for your kind email. I had worried about writing my story, but what you said meant a lot to me so thank you"

I'm not going to lie, that message in the corner of my screen sent me over the edge and there were those annoying tears which well up and make you all blotchy like when you watch a John Lewis Christmas advert or a film where the pet dies.

Sometimes I wonder how I got here, leading this team of volunteers and engaging with clinicians, researchers, scientists and government and spending far too many hours talking about vitamin B12. On many occasions I question why and what is the point. It sometimes feels like pushing a boulder up a mountain. I thought it was timely then as we approach the last quarter of the year, to mention that 2026 will be 20 years since PAS was registered as a charity and reflect on why patient advocacy is so important. The following article I wrote first appeared on Substack (more about that later in the newsletter) earlier this month. It perhaps helps us focus on why we are doing what we are doing.

Why Your Voice Matters: The Power of Patient Advocacy and the Patient Voice.
Patient advocacy groups play a crucial role in supporting individuals with misunderstood health conditions, such as rare diseases or conditions with a lack of awareness in the medical community. The Pernicious Anaemia Society has for two decades been supporting patients with this autoimmune condition and campaigning for better research, education and awareness.

The power of patient advocacy lies in its ability to empower individuals and drive systemic change within healthcare. On an individual level, patient advocates may also be a lifeline for those navigating a complex and often intimidating medical system.

Organisations like the Pernicious Anaemia Society help patients understand their diagnosis and treatment options, ensure their voices are heard and try to influence changes in regulations and practice, as well as campaign for and support important research.

As a registered charity, the Pernicious Anaemia Society is fundamentally different from patient-led forums or social media groups. While some groups provide invaluable peer-to-peer support, a sense of community, and a space for sharing personal experiences, some are unmoderated or moderated by other patients without a medical or scientific background. This can lead to the spread of anecdotal advice or misinformation, which may not be ideal.

There is of course a role for many different types of support and groups in helping patients. Where these groups are well managed and moderated, they offer a valuable additional support. We are not all the same and at different times in our life and patient journey we may need access to different information and support.

Collectively, patient advocacy groups and the patient voices are a powerful force for change. We must continue to raise awareness for this misunderstood autoimmune condition and fund and drive essential research. We need to lobby for policy changes that improve access to care, treatment, and funding in every country.
By bringing the lived experience of a condition to the forefront, we can influence everything from the design of research, the development of new treatments and the creation of more compassionate and equitable healthcare policies.

Ultimately, patient advocacy transforms patients from passive recipients of care into active participants and drivers of their own health outcomes and the future of healthcare.
By joining the Pernicious Anaemia Society as a member, you are helping to:

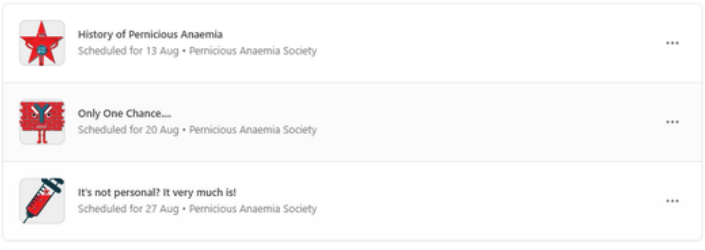
- **Provide a Community and Reduce Isolation:** shared experiences can be incredibly validating and empowering.
- **Provide a Reliable Source of Information:** When a condition is not well understood, there can be a lack of credible information available from the general healthcare system. Accurate, up-to-date, and expert-reviewed information on the disease, its management, and potential treatments is a core foundation of our website.
- **Drive Research and Development:** Patient-led research can be essential for advancing scientific understanding and accelerating the development of new treatments. Pernicious Anaemia Society is the go-to patient participation group for globally renowned researchers.
- **Advocate for Better Care and Policy:** From commissioning the NICE Guidelines on B12 deficiency, providing important feedback to the Guideline as a key stakeholder, being instrumental in setting up CluB-12, Chairing the B12-Alliance and actively taking part in educational seminars and symposia, we are powerful advocates, lobbying for increased funding for research, faster and more accurate diagnoses, and improved access to care and treatment. Through our website, social media and blogs we give a collective voice to a patient community that would otherwise be unheard.
- **Educate Healthcare Professionals:** Bridging the knowledge gap and ensuring that medical professionals are better equipped to diagnose and manage the illness is a fundamental part of the next three-year plan for our Society.
- **Improve Quality of Life:** Beyond medical information, offering practical advice and emotional support, helping patients and their families navigate the daily challenges of living with a misunderstood condition is at the heart of what we do

Substack

Substack is an online platform that combines the features of a blog, a newsletter, and a social media network. It provides a space for organisations like ours to publish our work work and build a direct relationship with their audience.

By following us on Substack, you'll receive additional content delivered directly to your email inbox, ensuring you never miss a new post. It's a way to engage with our work without the distractions of an algorithm-driven feed and to become part of a community that values in-depth content and conversation.
If you don't like the "noise" of social media, and prefer a sense of community, then Substack could be for you.

Click this link here → PAS Substack



Report of the CluB-12 Symposium

Thursday, September 18th & Friday, September 19th - St John's College, Cambridge
By PAS CEO, Katrina Burchell

Education, Education, Education & War

The first day started with ***Patient and Clinician Perspectives*** chaired by PAS CEO and Chair of the B12-Alliance Katrina Burchell. We focussed on patient stories and the plans of the B12-Alliance to continue to raise awareness and education of health care professionals. A talk by Heather Hardie and Asim Naviq gave insight into some patient journeys, particularly on B12 deficiency in mother-child dyads, and Sally Harling gave her own personal account of her journey with her son. Then, Rachel Howard, a pharmacist prescriber from the Isle of Wight, gave both her personal and patient perspective, including some case studies, and explained the valuable work she is doing to enable patients to self-inject. Katrina then updated those present on the progress of the work of the B-12 Alliance and with NHS E-Learning for Health and the upcoming healthcare training programme.

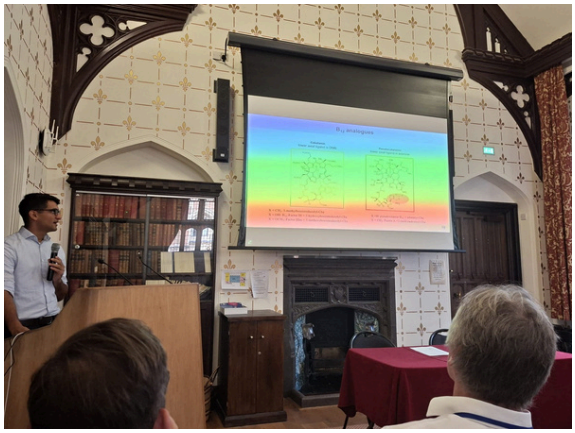
The afternoon session focussed first on ***Diagnosis, Treatment, and Nutrition***, chaired by Willemina Rietsma. Agata Malefora talked about the challenges of using laboratory biomarkers to evaluate vitamin B12 status. Alfie Thain, the PhD student supported by PAS, then spoke about his research paper on *Addressing gaps in the 2024 NICE Guideline for better recognition, diagnosis, and management of Pernicious Anaemia*. The afternoon session was completed with Nicola Ward's presentation on *The impact of the new NICE Guideline on clinical practice and research needs regarding different therapy types (oral, subcutaneous, intramuscular).*

Our upcoming seminar on 11th October will provide further detail and presentations from Alfie and Nicola with the opportunity for patients and members to ask questions about these areas of research.

Session 3 was focused on **Nutrition**. Chaired by Mary Ward, we heard about *Interactions of B12 with other micronutrients, malnutrition in children, and maternal B12 deficiency.*

B12 deficiency and patient advocacy was discussed by Petra van Houten-Ruijters from the B12 Institute with moving case-studies of young adults whose lives had been changed by their symptoms and ultimately restored by getting treatment. Mary Ward's presentation on *Riboflavin (B2) deficiency* generated a great question and answer session. Isabel Iglesias-Platas finished the series of lectures for this day by covering her work on *Serum folate in pre-term infants*.

In the evening a dinner for attendees and some guests took place in St John's College. This room is where the poet William Wordsworth lived (in less lavish style than enjoyed today) while an undergraduate at the College in the 1780s.



On day two, Martin Warren chaired the session on Sourcing of B12, B12 Analogues and Microbiota with a very interesting discussion on Evolutionary perspectives and potential of vitamin B12 in algae by Dr Kostas Papadopoulos which was fascinating.

Martin Warren and his PhD student Freya Hartshorn, from the Quadram Institute in Norwich, then covered Biofortification of plants with vitamin B12 and Bioengineering for enhanced vitamin B12 production in E. coli, which included a very interesting overview of how B12 is currently manufactured and the challenges that faces. Lisa di Zanetti from the University of Ghent then spoke about her interesting PhD work Micronutrient biofortification in rice and the nicotiana plants at Ghent University.

Following the CluB-12 AGM, the Keynote Presentation "***Vitamin B12 Markers: Past – Present - Future***" was given by the esteemed Prof. Ebba Nexo. This reflection on Ebba's extensive experience in diagnosing and testing was a highlight of the symposium. Her views on what needs to be focussed on for the future also generated a healthy debate which continued during the sandwich lunch and as people were leaving to catch trains and planes to various destinations.

Key insights for our audience at PAS: The value of CluB-12 continues to grow as this unique mix of patient advocacy, researchers and clinicians come together to share research, best practice, and case studies. Networking and generating ideas for future research and projects to ultimately help the patient could be heard and seen at every coffee break. The passion with which those involved in the vitamin B12 community continue to search for reasons and answers is very palpable at these meetings and much appreciated by those with a B12 deficiency, whatever the underlying cause.

PAS Support Survey

One of the key objectives of the Pernicious Anaemia Society is to provide help and support to our members and prospective members.

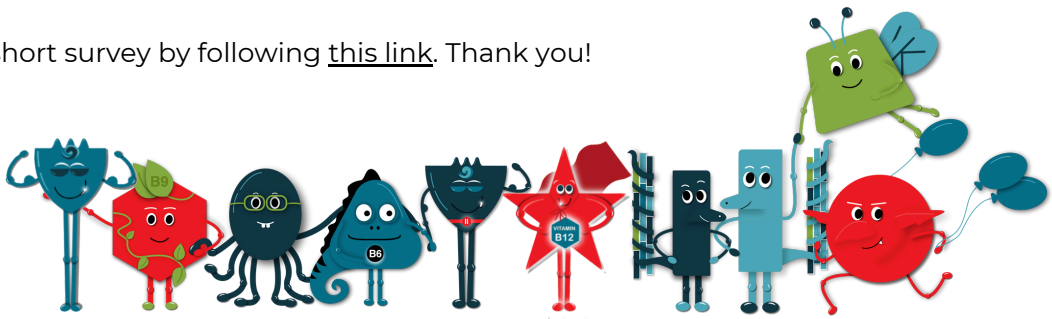
We do this in a number of ways including our helpdesk, helpline, forum, website, social media and seminars. However, the world is changing in terms of communication and we need to make sure that the services we provide are well utilized and wanted.

We are also a much more global organisation now and want to ensure we cover the needs at different times of the day.

We are very fortunate in having been granted funding from the Foyle Foundation to seek third party services to carry out a survey and analyse the results on this topic.

We think the questions in the survey are important ones for PAS to focus on to ensure we plan to use the charity resources wisely in the future.

Please take part in this short survey by following this link. Thank you!



Research

Would you like to collaborate on research about the frequency of B12 injections?

Hello everyone. I'm an Oxfordshire GP, and planning a PhD research project about the frequency of B12 injections and the effect this has on patients – e.g. symptoms returning between injections, quality of life being affected.

I need about 10 patients with B12 deficiency (or carers for a patient) to help me with Patient and Public Involvement (PPI). You need to:

1. Live in the UK.
2. Get B12 injections prescribed by your NHS GP (whether for PA or other cause of B12 deficiency)
3. Be available at least for a 2-hour Zoom call every 2-3 months. You can be more involved if you wish. The project will run for 4-5 years, and your involvement can run for that length of time. Of course, you can stop earlier if you need to.
4. You don't need any special skills. I will provide training where needed.

Your involvement can include input into planning the research, being a co-applicant for funding applications, planning and road testing online surveys, helping with the interpretation of data from surveys and interviews, co-authoring papers, dissemination of findings to conferences, patient support groups, etc. You can decide how much they would like to be involved with or not.

At the moment, I have no funding, therefore, I can't pay you for your help. As and when I do get funding, there normally is a component to pay members of a PPI group. But please do not expect anything before funding is confirmed.
I need a group to be diverse in age, sex, ethnic background, patient, parent or carer of someone on B12 injections, some who are happy on 2-3 monthly injections and some who need more frequent injections (whether you get them or not) or who top-up with B12 tablets. The more diverse the PPI group, the greater the range of experiences and viewpoints, the better the group's input can be.

If you would like to get involved, please send me an email on w.rietsema@icloud.com, briefly telling me about yourself: first name, age bracket, gender, ethnic background (this is because it's important for the research to involve people from diverse backgrounds), how often you get injections, and whether you top up with injections or any oral or sublingual B12 you buy from outside of the NHS.

It would be helpful if you answer the following questions in your email:

- Age in 5-year brackets: < 16, 16-19, 20-24, 25-29, etc.
- Gender
- Reason for B12 injections/ cause of B12 deficiency (or no cause found)
- Receiving B12 injections yourself or care for a child or other relative who receives them
- Frequency of injections
- Topping up yes or no, if yes – injections or tablets/other
- Briefly what motivates you to help with the research
- Something about your background/ previous experience with research etc (optional)

If there are more responses than I need, I will need to select people to form as diverse group as possible. Please note this email address is only for this research project, not for any other purpose.

With many thanks,
Willemina Rietsema

PAS Day & Annual Seminar

PA day is on the 12th of October, and our Annual Seminar will take place on **Saturday 11th October 2025**, at **10:00**.

As well as an opening address from the PA Society CEO, Katrina Burchell, we have three guest speakers:

- **Nicola Ward** - Nicola is an *Associate Professor in Pharmacy (Teaching and Learning), DMU Teacher Fellow,* Leicester School of Pharmacy, De Montfort University. Nicola will be joined by **Adrian Rogerson** a Senior Lecturer in Pharmacy Practice at the School of Pharmacy. They will be discussing what impact have the NICE Guidelines had on people living with Pernicious Anaemia and Vitamin B12 deficiency.

- **Alfie Thain** - Alfie is a Postgraduate Researcher at the School of Biosciences at the University of Surrey. Alfie will be talking about Symptom tracking; tackling Iron deficiency; and testing self-injection: research updates from my PhD.

- **Rachel Barnes** - Rachel is also a Postgraduate Researcher at the Quadram Institute, Norwich University. Rachael will be talking about "Could urine be the answer?".

Get your ticket in our shop.

Recycle 4 Charity

PAS would like to say a massive thank you to the 69 donators – you know who you are! – who have been recycling their ink cartridges through Recycle 4 Charity and who have chosen us as their charity.
All the money raised goes towards helping us to achieve our mission and vision, of raising awareness, providing support to our members, their families and friends, providing information to professionals and taking part in research into this illness, to name but a few.

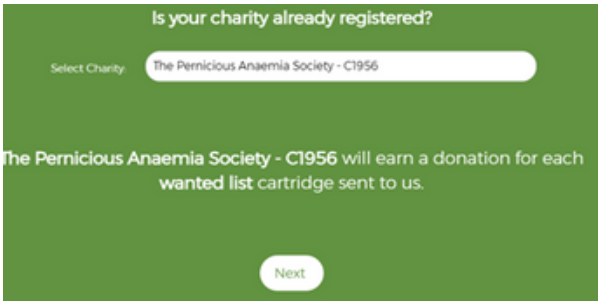
Over the years you have raised a huge £762.90 which includes £11.25 this year, and we thank you all for your support, both to the environment and us.
If you do have any ink cartridges from their list of wanted cartridges below and you feel you can help us, please go to their website to set up an account and return your empties for recycling.

Go to: Recycle4Charity

Choose "**Register your charity**" & type in the Pernicious Anaemia Society, selecting the drop down box.

Click next & enter your email, open your account & return your cartrigdes.

Thank you!



Research

Nutritional Knowledge, Attitudes, and Behaviours and the relationship with fatigue symptom severity amongst United Kingdom adults with Pernicious Anaemia.

A Pernicious Anaemia Society member is currently studying for a Master's in Nutrition and Lifestyle Medicine at the University of Worcester and is seeking participants for a survey. The study aims to explore the relationship between nutritional knowledge, attitudes, and behaviours, and their impact on fatigue symptom severity in individuals with pernicious anaemia — an under-researched but significant topic. The findings could provide valuable insights to shape future nutrition and lifestyle support for those affected by pernicious anaemia.

If you have been diagnosed with Pernicious Anaemia by a healthcare professional, are over 18, reside in the UK, and are not currently suffering from Long Covid, we invite you to participate. The anonymous multiple-choice questionnaire takes approximately 15-20 minutes to complete and can be accessed here: https://app.onlinesurveys.jisc.ac.uk/s/ucw/nkabpas
You can find the Participant Information Sheet with all the information about the study on that link as well. Thank you in advance!

New Address!

We have moved!
Unfortunately, we have had to move out of our offices in Brackla House, Brackla Street, Bridgend as the building was being sold. We would however, like to pass on our grateful thanks to Mike Norgate who so generously let us stay there for over 15 years.

As we no longer have any office space, we would like to advise that our new Registered address is:
The Pernicious Anaemia Society
Connexions
3rd Floor, 159 Princes Street
Ipswich, IP1 1QJ

You can use this address to post us letters and mail, but it will not be possible to make in-person visits. Please note that our telephone numbers and email addresses remain the same if you prefer to correspond with us using those communication methods.

Movement for Good

Fundraising is becoming increasingly difficult for small charities. We rely heavily on donations and membership fees but we are continuously looking for ways we can look for funding from different sources where our members and supporters can contribute at no cost.

The Movement for Good Awards is Benefact Group's annual programme of giving that anyone can get involved in, and again this year they will be donating over £1 million to charities and good causes.
Anyone can nominate their favourite charity or charities for an award of £1,000 – it's one nomination per charity, per person. The more nominations a charity gets, the better their chances of being drawn, so once you've nominated please share with your network, print off the attached poster and put it in your workplace or share the link or QR code which leads directly to PAS on your social media.

Nominations from previous years do not roll over so even if you think you already nominate us, please check and do it again. We'd love to win as we have lots of exciting projects to fund.

Get Cozy with a Good Book This Season and Give Back!

For some of us the days grow shorter and the leaves begin to turn and for others there are longer sunnier days ahead. There's nothing quite like curling up or stretching out with a captivating book. Reading offers a remarkable array of benefits for both mental health and resilience. It's far more than just a pleasant pastime; it's a powerful tool for navigating life's challenges and fostering overall well-being. So now you have the perfect excuse to increase your knowledge, dive into new stories, revisit old favourites, and start thinking about those gifts. We're inviting you to make your reading and gift-giving extra special by supporting our charity and independent booksellers through Bookshop.org.

Why Bookshop.org is Your Go-To This Season

We've partnered with Bookshop.org, an incredible online platform that champions independent bookstores across the UK. When you buy books through our dedicated affiliate link, two wonderful things happen:

- **You Support Our Cause:** A percentage of every sale made through our unique link directly contributes to the Pernicious Anaemia Society. These funds are vital for us to continue our work in providing support groups, raising awareness, education and research.
- **You Empower Independent Bookstores:** Bookshop.org is committed to ensuring that independent bookshops thrive. They give a significant portion of their sales to these local businesses, helping them compete with larger online retailers and remain vibrant hubs in our communities. As the holiday season approaches it is all too easy to go to the big online seller platforms like Amazon who recently stopped their charity giving tool.

So, whether you're stocking up your own reading list or searching for the perfect present, your purchase becomes a powerful act of support for both our charity and the independent book culture we cherish.

There is even another bonus for us! If you are in the UK and access bookshop.org via EasyFundrasing and nominate us as your charity we will get a donation from them too. And this costs you nothing.

Our Bookshelf and Beyond

We have our own bookshelf which you can browse focussing on PA and B12 and tools to support and help. You are welcome to send us your suggestions to add via our contact page on the website. But it isn't just for books on our shelf. Imagine finding that gripping novel for a rainy afternoon, or discovering the ideal children's book that will spark a lifelong love of reading. With Bookshop.org, you can explore a vast selection of titles from the comfort of your home, knowing that every page turned is making a difference. Our CEO also has her own book club recommendations list too which she has shared with us.

The joy of reading and books whether for yourself or giving is amplified when your gifts carry a deeper meaning. A book from Bookshop.org, purchased through our link, is not just a present; it's a contribution to our mission and a nod to the invaluable role of independent booksellers.

Ready to Make a Difference?

It's simple! Just visit our Bookshop.org page at Pernicious Anaemia Society Bookshop UK. Browse their extensive collection, add your chosen books to your basket, and complete your purchase. You'll be enjoying your new reads in no time, and we'll be incredibly grateful for your support.

REMEMBER TO ALWAYS USE OUR LINK ! Thank you for choosing to read, give, and make a positive impact.

Support Group News & Social Media Update

Three online support groups have been held since the last newsletter, one by our volunteer Benita in Sussex, one by Asa our volunteer in Sweden and one by Julie in the USA. Thank you all for organising the meetings!

The next USA meeting is on the 27th September. Register via the link on your membership homepage on the website.

Hopefully, you follow our posts on Facebook and will see there is some excellent information as well as personal stories being shared. We now have over 12,000 followers so we are looking for a couple of people who read our page regularly and who would want to be a moderator for us.

Full guidance/training will be given. Interested? Then do get in touch.

What's on & Key Dates

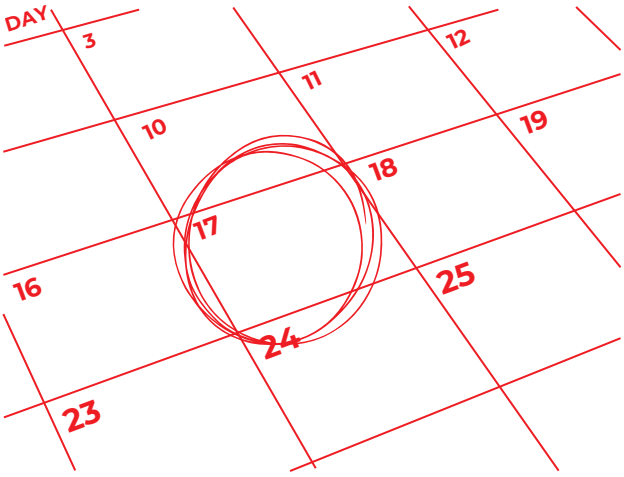
- **4th October 2025** - Do you live near Emneth, Norfolk? If so, a Craft Fair is being held at Emneth Central Hall on Saturday 4th October, between 10:00-16:00, with all proceeds going to the PA Society. Link to event here.

- **11th October 2025** - The Pernicious Anaemia Society Annual Seminar takes place at 10:00. We have really great speakers and I know you will be very interested in what they have to say. Registration is required, and a small fee helps cover our ongoing costs in providing helpine support and other activities. Please see our website.

- **12th October 2025** - Pernicious Anaemia Awareness Day. Can you do something to help highlight the work of the PA society or perhaps raise much needed funds?

Autumn Seminars

We are in the process of organising interesting and educational seminars - keep an eye on our website and social media for news!



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.

Time for Bold Action - The Shift to Prevention

On Wednesday 17th September, I was fortunate to attend an event arranged by The King's Fund called "Time for Bold Action - The Shift to Prevention". The King's Fund is an independent charity whose aim is to improve health and care through research, debate and developing skills for healthcare leadership.

The day long event was attended by representatives of government, the NHS, clinicians, economists, industry and health charities. It was a mix of presentations, question and answer panels and workshops. Discussion focused on how government and NHS can and should deliver the NHS 10 year plan by shifting to a prevention of disease or prevention of worsening conditions ultimately to improve quality of life and reduce the resource burden on the NHS.

Whilst naturally some element of frustration at underfunding for decades came out in discussions, the meeting was an excellent reminder of the passion within the healthcare service to improve. Examples of successful prevention programmes were given including cardiovascular disease, stopping smoking, and vaccination programmes. Honesty and transparency was offered where other areas had not shown hoped for results: alcohol, obesity, diet and nutrition were areas for more work. There was acknowledgement of a changing world and discussion about how individuals, media, early education, and employers need to also take responsibility and accountability.

The advantage of attending was the opportunity to gain a deeper understanding of the ways in which the partner organisations within government and the NHS work together (or don't!). A conversation about ICBs and NICE guidelines and GP practices was particularly enlightening. The workshop I attended gave me the opportunity to talk about Pernicious Anaemia and the need for better diagnosis and treatment.

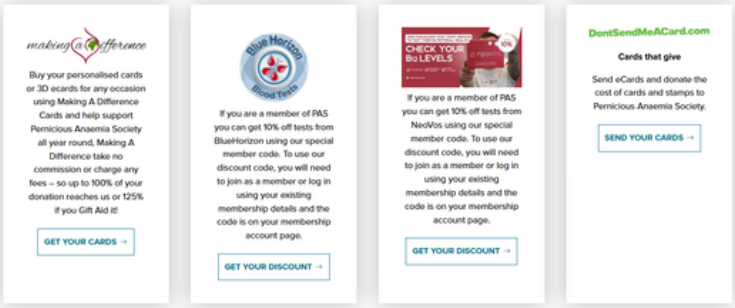
The highlight for me was definitely the last session where the 4 chief medical officers from the devolved nations talked openly, under Chatham House Rules, about the goals and challenges ahead. There is much to reflect on from this event and sone valuable contacts made.
Katrina Burchell.

Professor Sir Chris Whitty, Chief Medical Officer (CMO) for England and Professor Sir Gregor Smith, Chief Medical Officer for Scotland

Our Shop

You can now get your personalised eCards in the shop.

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



Show your face for Pernicious Anaemia

Want to help spread awareness about Pernicious Anaemia?

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

Why your photo matters:

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

How to participate:

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

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

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

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

Personal Story

Kelly Luchtel

I'm not really sure how long I have had Pernicious Anemia because I have been struggling with health issues for years. I have seen endocrinology, cardiology, neurology, and made multiple trips to the emergency room. I wanted to share my story because after learning more about Pernicious Anemia, it seems that it is too common to wait years for a diagnosis.

For me, the health issues came on slowly and I thought it was probably just due to aging and exhaustion from having three young kids. Over the course of a few years, I went from regularly being able to run 50 miles a week to barely being able to make it through a beginner tennis lesson and needing to lay down afterwards. I could see in my lab work that something was not right, but I listened to doctors that told me it was normal to struggle with anemia and other health problems.

Some of the symptoms I had were iron deficiency anemia, unstable blood pressure, extreme exhaustion, brain fog, clumsiness, numbness in my extremities, heart palpitations, and many more that are classic symptoms of Pernicious Anemia. I think one of the reasons my diagnosis took so long is that I was also suffering from symptoms that are not typically associated with pernicious anemia like low cortisol and trouble regulating my blood sugar. If I got sick with a cold, it would sometimes last for months with no explanation. My health was not great but not alarming enough to get the help I needed. I tried to listen to doctors that told me to exercise, get lots of sleep, and eat well but I was not getting better. I was taking an iron supplement but couldn't seem to heal my anemia. I was surviving off on too much coffee, unnecessary medication, and prayer. I felt like I was slowly dying, and I knew I had to do something if I wanted to see my kids grow up and feel like I was actually living again.

I decided to take my health into my own hands and not just blindly trust doctors. I tried a variety of diets, supplements, and health protocols. One thing I tried was going for various vitamin injections at a health spa. I was having some reprieve from illness but was not getting enough regular injections to feel completely well and would end up sick again. After enough trial and error, I was able to make the connection that it was specifically the vitamin B12 shots that were helping. The numbness in my hands started to go away and colors looked more vivid. I took this information to my doctors and was initially dismissed. I had to find new doctors and use concierge health care to convince a doctor to run the blood tests I requested: an intrinsic factor antibodies test and several others.

Finally, I was diagnosed with Pernicious Anemia. I was happy to have an answer, but I was also extremely angry when I got my test results back. I was pushing through an illness that would have eventually killed me without treatment, while doctors convinced me I was just anxious and aging.

Within two months of consistent treatment I had normal bloodwork, something I have not had in years. Pernicious Anemia affects so many systems of the body I think the recovery process really needs more than just treatment with B12 injections. For me the B12 deficiency caused iron deficiency anemia that snowballed into various other health issues. One important part of my recovery has been seeing a holistic doctor. I have found that I have had to educate myself about this disease and to also educate my doctors. Being a rare disease that affects so many bodily systems I have not spoken with a doctor that is familiar with treatment and current recommendations.

Overall, I have been ecstatic with my recovery, but I can also be hard on myself when I cannot meet the expectations I have. My memory is not what it used to be, and I can have fluctuating levels of energy. Sometimes, I am in the position of feeling ill again while I learn how often I need to inject. Like many others with Pernicious Anemia I have found that I need more injections than what my doctor initially prescribed. My diagnosis is pretty recent, and I am still learning how to manage my health but I wanted to share my story so that hopefully someone sees this and will not have to face the years of illness that I did. My advice I would give to anyone with a new or suspected diagnosis would be to trust yourself and advocate for your health, do your own research, switch doctors if need be, and demand answers. Moving forward, I want to advocate for others with pernicious anemia and other rare and invisible diseases. I hope my story will inspire others to get the help they need.

On a final note, I am really grateful to the Pernicious Anaemia Society because if I had not found their website and read the other patient stories I would have not had the information to get my diagnosis. Thank you to them for all that they do!