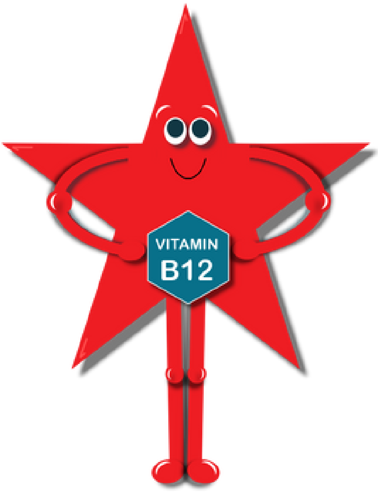
pas Pernicious Anaemia Society

Cobalamin News

Edition 42 Summer 2025 June 2025

Contents



Research Highlight:

CluB-12

A CluB-12 discussion emphasized valuing patient experiences alongside clinical evidence. A 1996 BMJ paper defined Evidence-Based Medicine as combining clinical expertise with the best available research to guide personalized, patient-centered care and improve outcomes. Full article 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-Fri 8:30am-12:30pm*

✉ **support@pasoc.org.uk** - *members who live overseas or prefer emails*

✉ **membership@pasoc.org.uk** - *membership questions*

✉ **info@pasoc.org.uk** - *general questions*

👤 Helpline volunteers: Liz, Kathy, Alex, Karyl

CEO’s Introduction

from our CEO, Katrina Burchell

We are heading towards summer here in the UK and the nice weather always lifts the mood, although for some people the heat affects their fatigue and questions get raised about why some PA patients need more frequent injections than others, why some circumstances such as stress or illness seem to “use up” their B12. Many questions such as these came up in the JLA Priority Setting Partnership work we carried out and we continue to discuss opportunities with researchers and experts and grant funders to try and find ways to research and find answers.

Working with others is important and I'm always personally very thankful to the many scientists and clinicians who willingly give up their time to help and support PAS with their expertise. Did you know for example that we have a team of volunteer doctors and scientists who check our publications, education material and website for accuracy and help us answer some of the more difficult questions we get in our helpdesk. Our membership of CluB-12 enabled me to attend a series of lectures on folate which was incredibly useful and I hope to attend the CluB-12 symposium again in the Autumn.

We also recently thanked our volunteers as part of volunteer week here in the UK. Behind the scenes those that answer the phones and emails, support membership enquiries and keep our finances, office and newsletter going provide an invaluable service.

We have some plans in place for improving our technology and support systems as technology options improve and become more cost effective. We are also starting to prepare for another series of seminars. These were so popular earlier in the year and we have some great ideas and speakers for the autumn sessions and for our annual seminar which will be in October.

As CEO of PAS, I am also a volunteer. I also still work in a paid job although I'm heading towards retirement which I hope frees up more time for myself and my physical and mental health. If like me, and others on the Management Team, you are lucky to have time and the opportunity for a holiday over the next few months, I hope you have a fantastic time.

Regardless of the time of year however, we will continue to make sure that PAS works on its mission for improved diagnosis and treatment through better awareness, education and research.

Katrina Burchell

Remembering Clive Parsons

We are sad to announce that our long-term supporter Clive Parsons sadly died on 13th January 2025, aged 83. Clive became a member of PAS in April 2010, having been diagnosed in 1972 and most likely suffered for a number of years before that. Two years ago, he kindly wrote his personal story for our website to help others who may be suffering from unexplained symptoms. Clive was a staunch supporter of the PA community, including PAS and the Pernicious Anaemia Health Unlocked forum and he will be sadly missed. Our thoughts and best wishes go to his family and friends at this difficult time.

Read Clive’s PA journey in his own words here.

NHS England → 2025/26 priorities and operational planning guidance

In January this year NHS England published their priorities following the damning criticisms of the health care service in Lord Darzi's report.

Two of the key points in the list of priorities will be of interest to people with Pernicious Anaemia or a B12 deficiency requiring regular injections.

The first is to **improve patients' access to general practice**, improving patient experience, note that the access is in bold but not the patient experience. Hopefully this is not an indication that the patient experience is of less value!
Reading the detail of the focus later in the document, it seems to suggest the priority is on dental care but there are requirements for better communication from GPs about access and better coordination with ICBs.

The second point to note is **To live within the budget allocated, reducing waste and improving productivity**. ICBs, trusts and primary care providers must work together to plan and deliver a balanced net system financial position in collaboration with other integrated care system (ICS) partners. This will require prioritisation of resources and stopping lower-value activity. Low Value Activity is described in detail here.
The report states that "Across the NHS we are seeing around 14% more patient contacts than pre-pandemic, but we also have 19% more staff". Most of the cost savings focus on the reduction in use of temporary staff and improving procurement. However, notably there is focus on reducing prescribing costs. Related to this is an interesting report (link here) about the cost reduction in prescribed Vitamin D by sending patients to buy their own or prescribing cheaper variations. Note that in the Open Prescribing report, whilst there is inappropriate glee about the amounts which could be saved, there is no discussion on patient compliance, symptom resolution or the unregulated and non-licensed nature of supermarket and drugstore vitamin supplements.

Another point made is that they should "avoid duplication and low-value activity, including a renewed focus on minimising inappropriate spend against evidence-based intervention (EBI) procedures". Perhaps listening to patients and reading the NICE Guideline on B12 Deficiency about wasting money on unnecessary repeat B12 blood serum tests when PA patients are on injections would be a good starting point. For those willing to do so, training patients to self administer B12 injections would, as PAS proved in their submission to NICE to commission the Guideline, save a significant amount of appointment time and money across the UK. Similarly, reviewing the legislation about Intramuscular and Subcutaneous injection and prescription only injectable B12 could be not only life saving for many patients but would ultimately reduce appointment time, prescription costs and long term health issues for B12 deficiency, regardless of the underlying cause. Attempts to make this point again and again to Karyn Smith MP, Minister of State for Health so far have resulted in her completely missing the point. Her most response is simply that patients should discuss with their clinician who should follow NICE Guidelines. Well, well, well.... We all know how that works out.....

Other interesting points in the document are the priority to **Address inequalities and shift towards prevention**. With the explanation that focus is on causes of morbidity and mortality such as cardiovascular disease and diabetes, the aim is to work together to reduce inequalities and ensure the plans reflect the needs of all age groups including children and young people. Whilst the focus here is largely on two of the major issues for public health, especially cardiovascular, untreated or inadequately treated B12 deficiency and issues related to PA and other autoimmune diseases is, in my view, a public health crisis in waiting.

There are also priorities about moving more to digital systems including electronic prescriptions, referrals, and record access. I feel this has been a priority for focus for many years. Some improvements are already seen and are effective. My GP does electronic prescriptions straight to the chemist, I can select "call back" when I'm in a queue for an appointment, I can fill in an e-Consult if I manage to get one of the limited options each day. I have limited access to my records (they are working on it apparently) and linked information with secondary care appointments is non-existent, but I get a newsletter about what they are doing via text message every 3 months! - CEO Katrina Burchell

Research

Update on our Research for Iron Deficiency in Pernicious Anaemia

Thank you to everyone who took part in our survey on iron deficiency in people with pernicious anaemia (PA). Your responses have provided valuable insights into just how common, complex, and often overlooked iron deficiency is with PA.

Our findings show that iron deficiency affects many people with PA, often starting before they are diagnosed with PA. For around one-third of people, iron deficiency occurred both before and after their PA diagnosis, suggesting it may be an ongoing issue. In fact, over 60% of respondents with a history of iron deficiency said it was a recurring issue.

While most people were prescribed iron tablets (73%), many reported side effects such as constipation, nausea or stomach discomfort, and not everyone found them effective. Only 13% were offered alternatives like iron infusions or liquid iron. Follow-up care was also limited; nearly 3 in 4 people said they were not monitored regularly for iron deficiency.

Interestingly, we found that people who developed iron deficiency at a younger age were more likely to report poor treatment response and recurrence. This could mean that early-onset iron deficiency is a sign of a more persistent or difficult-to-treat condition, and might even appear before B12 deficiency/PA is diagnosed.

Nearly 40% of respondents also found it difficult to distinguish between symptoms of iron deficiency and PA, with fatigue, dizziness, and brain fog commonly reported in both conditions.

Our findings so far highlight the need for better NHS guidance on managing iron deficiency in PA. Including:

- Routine monitoring for ID (including when anaemia is not present)
- Clearer treatment options for people who do not respond to standard iron tablets
- More awareness of how ID can appear before PA and affect symptoms

We are continuing to analyse the data to share with healthcare professionals. Our plan is to put this work into a paper for publication. Thank you again for your essential role in shaping this research. We hope that this work serves as a foundation for meaningful improvements in patient care.

Alfie Thain

CluB-12

At a recent CluB-12 meeting there was an interesting discussion about patient reported symptoms and experiences compared to the "evidence" available for diagnosis or treatment. This resonated with me as I recently gave a talk to one of our B12 Alliance partners about the history and importance of research. PAS is very proud of our involvement and support of research projects and our patient member participation in many key research papers. It is so important to ensure that the patient experience and viewpoint is considered. What is the point of healthcare research if it is not to help the patient? If you are interested in my talk about research and B12 generally, it can be found here.

One clinician member of the CluB-12 group of experts referenced a 1996 paper about Evidence Based Medicine which, despite being 30 years old, perhaps sheds some light on why patient centered studies are so valuable (find the paper here). There are some useful and familiar points in the summary below.

This paper, "Evidence based medicine: what it is and what it isn't," published in the BMJ in January 1996, aims to clarify the concept of **Evidence-Based Medicine (EBM)** amidst both growing enthusiasm and significant criticism.

What is the paper about

The core message is that **Evidence-Based Medicine (EBM) is the conscientious, explicit, and judicious use of current best evidence in making decisions about individual patient care**. It's about combining two crucial elements:

1. **Individual Clinical Expertise**: The proficiency and judgment clinicians gain through experience, leading to more effective diagnosis and compassionate use of patient preferences.
2. **Best Available External Clinical Evidence**: Clinically relevant research, especially patient-centered studies on diagnostic tests, prognoses, and the efficacy/safety of treatments, rehabilitation, and prevention.

What EBM is NOT

The authors address and refute common misconceptions about EBM:

- **Not "old hat" or impossible to practice**: The paper argues against the idea that clinicians are already doing it, citing variations in patient value integration and intervention rates, as well as the overwhelming volume of new medical information. It provides examples of busy clinicians successfully practicing EBM.
- **Not "cookbook medicine"**: EBM is a "bottom-up" approach that integrates evidence with individual clinical expertise and patient choice, meaning it cannot lead to rigid, one-size-fits-all solutions. Clinical expertise is essential to determine if external evidence applies to a specific patient.
- **Not a tool for cost-cutting**: The paper asserts that EBM's goal is to apply the most efficacious interventions to maximize patient quality and quantity of life, which may even increase, rather than lower, healthcare costs.
- **Not restricted to randomized trials and meta-analyses**: While randomized controlled trials (RCTs) and systematic reviews are the "gold standard" for therapy questions due to their reliability, EBM advocates tracking down the best external evidence for any clinical question. This means using appropriate study designs for diagnostic accuracy (cross-sectional studies) or prognosis (follow-up studies), and even basic sciences when relevant.

Conclusion

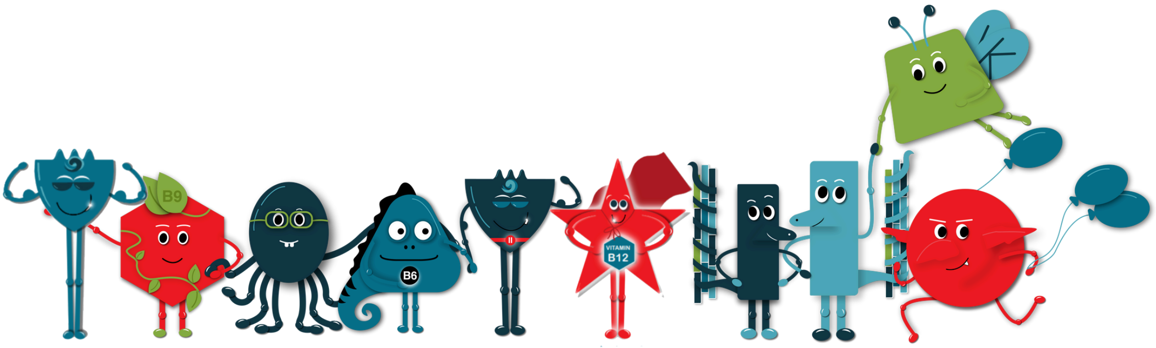
The paper emphasizes that **good doctors use both clinical expertise and the best available external evidence.**

Support Group News

We have held a number of UK online Support Groups recently, but only had a small number of members attended. Whilst we know from speaking with our members the support and information offered via the support groups is considered invaluable, it would be helpful to know how we can help encourage members to join in. Having online groups means that it doesn't matter where you live in the country, you can just hop on to a meeting. If Zoom is a bit scary to you, we can arrange a practice session for anyone who thinks this may help. Just get in touch.

Our support group in the US, however, is thriving and continues to go from strength to strength - thank you Julie!! Julie holds regular support groups so, as ever, keep an eye on the website for dates/times.

Also, our lovely volunteer in Sweden, Asa, will be arranging another online support group in the next few weeks, so do keep an eye on the website and social media for details.



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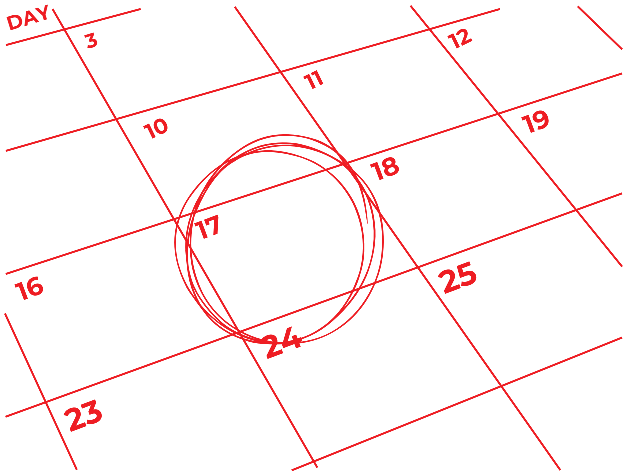
What's on & Key Dates



- **In July**, look out for our upcoming blog post from Julie about the well documented and less well known (and sometimes frankly bizarre) symptoms of Pernicious Anaemia.
- **13th September 2025** - PAS Annual General Meeting - if you are interested in attending, keep an eye on the website and/or your email inbox to get information on how to join.
- **11th October 2025** - PAS Annual Seminar with guest speakers - further details will be in the next newsletter and, in due course, on the website and on social media.
- **12th October 2025** - Pernicious Anaemia Awareness Day.

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

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

PAS Seminar

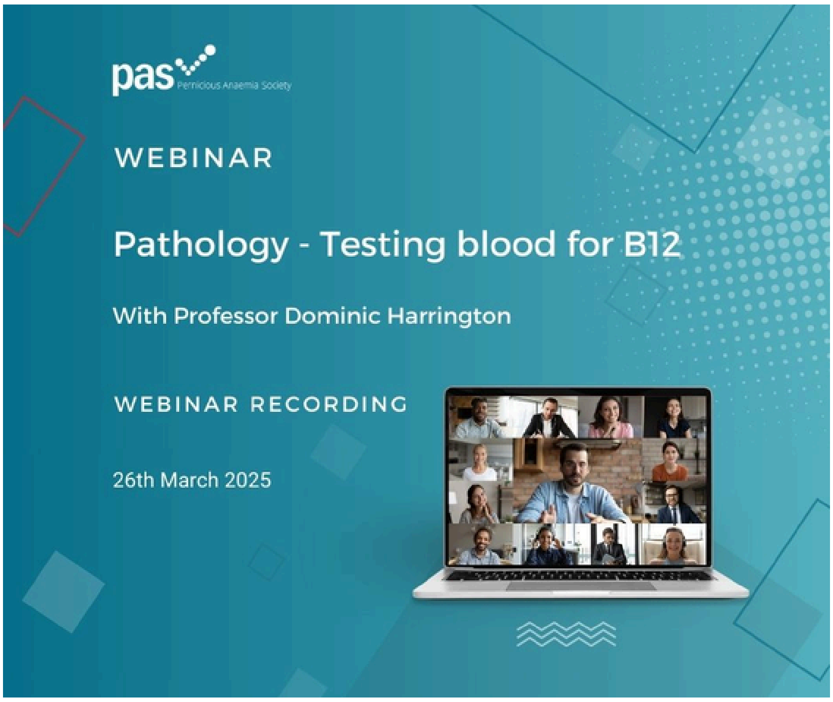
Pathology: Testing blood for Vitamin B12 deficiency

On Wednesday, March 26th, Professor Dominic Harrington, Chief Scientific Officer at Synnovis and Consultant Clinical Scientist, delivered an insightful seminar entitled: “Pathology: Testing blood for vitamin B12 deficiency”. Drawing on his extensive experience since 2017 leading pathology services for South East London, his primary research interest in vitamin status biomarkers, and his numerous publications (over 90 scientific papers and books), Professor Harrington offered a comprehensive overview.

Dominic holds honorary academic positions at King’s College London and the University of Surrey, and is a fellow of the Royal College of Pathologists and a Chartered Quality Professional and has been a long-time supporter and friend of the Pernicious Anaemia Society. Professor Harrington is uniquely positioned to share his in-depth understanding of blood vitamin biomarkers, their applications and limitations; and PAS were delighted to have him as our guest speaker.

Seminar attendees, including patients, clinicians, and researchers, gained valuable insights into the capabilities and limitations of vitamin B12 level blood tests. He clarified why these tests have limited specificity and sensitivity, emphasising the crucial role of considering symptoms alongside results in the diagnostic journey. The audience benefited from an exceptionally clear and well-structured explanation of the factors to consider for accurate diagnosis.

For those unable to attend, this informative seminar is available in our shop for a small donation. All money raised from these seminars goes directly to supporting the Society’s work, including further research into better diagnostic testing and education of health care professionals. Whether you are a patient seeking to understand your test results better, a clinician looking for deeper insights, or a researcher in the field, this seminar will illuminate factors influencing test outcomes, the interpretation of different tests, and provide guidance for clinicians.



B12 Alliance

Through our membership of the B-12 Alliance, (our CEO is currently chair) we continue to raise awareness about B12 deficiency in general, not just that caused by the autoimmune condition Pernicious Anaemia.

As CEO of PAS and Chair of the B12 Alliance, Katrina wrote to the UK government pointing out that the National Diet and Nutrition Survey was two years delayed in publication and asking when it might be published. She also asked that they specifically address vitamin B12 which had been overlooked in previous reports. Delays in the publication were partly Covid related but eventually the NDNS replied to confirm that the report had been published on 11th June 2025. The data does include vitamin B12 for this period and, importantly, the executive report (which focuses on vitamin D, folate and iodine as being of concern to public health) now carries the following statement:

"The absence of commentary for a nutrient does not indicate that there is no public health interest or concern about intakes"

Hopefully, they are now listening more carefully about vitamin B12 especially in the light of some of the results from the survey.

Whilst not directly relevant to those of us whose Intrinsic Factor is missing – diet and nutrition is important to everyone. You may be interested in the full executive summary here, or in Katrina's summary below which reflects that, overall, the report highlights ongoing challenges in achieving recommended dietary intakes across the UK population, particularly concerning fruit and vegetables, fibre, and certain micronutrients like vitamin D and folate, with some disparities observed across income groups.

The National Diet and Nutrition Survey (NDNS) 2019 to 2023 report provides an assessment of the diet, nutrient intake, and nutritional status of the general UK population aged 1.5 years and over. Key findings:

Dietary Habits and Recommendations:

- **Fruit and Vegetables**: Most participants, across all age groups, did not meet the UK government's recommendation of at least 5 portions of a variety of fruit and vegetables daily. Children aged 11-18 years averaged 2.8 portions. Adults consumed 3.3-3.7 portions per day, Consumption for adults and older adults was notably lower than previously reported figures.
- **Saturated Fats:** Average intakes of saturated fats exceeded the recommended limit
- **Fibre**: The majority of the population did not meet the UK government's fibre recommendations
- **Red and Processed Meat**: Average consumption of red and processed meat was below the recommended 70g per day in all age and sex groups. However, about a quarter (27%) of men aged 19-64 years exceeded 90g per day.
- **Sugar-Sweetened Soft Drinks**: Children aged 11-18 years had the highest average consumption (124 ml/day), with the highest consumers in this group drinking 606 ml/day.

Nutritional Status (Vitamins & Minerals):

- **Vitamin D:** Proportions of low vitamin D status were: 10% of children aged 4-10 years, 23% of children aged 11-18 years, 18% of adults aged 19-64 years, and 12% of adults aged 65 years and over.
- **Folate (RBC Folate)**: Low red blood cell (RBC) folate was observed in 12% of children aged 11-18 years, 4% of adults aged 19-64 years, and 2% of adults aged 65 years and over. Notably, 83% of women of childbearing age (16-49 years) had RBC folate concentrations below the threshold for increased risk of neural tube defects in pregnancy.
- **Iodine**: There has been a significant year-on-year decrease in urinary iodine concentration (UIC) since its introduction to NDNS in 2013

Impact of Houshold income:

- Participants in higher income households tended to be closer to meeting some dietary recommendations, particularly for fruit and vegetable intake and fibre intake.
- Folate status for women of childbearing age also tended to increase with higher income.
- For children and adults aged 19-64 years, vitamin D status increased with increasing household income.
- However, where diets failed to meet recommendations, this was broadly consistent across all income ranges.

Fundraising

Chris and Hollie Run the Brighton Marathon

In May, we completed the 42km Brighton Marathon supporting the Pernicious Anaemia Society the whole way !

It was one of the toughest, yet most rewarding experiences we've ever had. The carb-loading the night before was one of the more enjoyable parts, but the nerves definitely kicked in on race morning and during the buildup. As soon as we started running, those vanished thanks to the electric atmosphere, crowds lining the streets, music blasting, cheers and high fives everywhere - That kind of support carries you a long way!

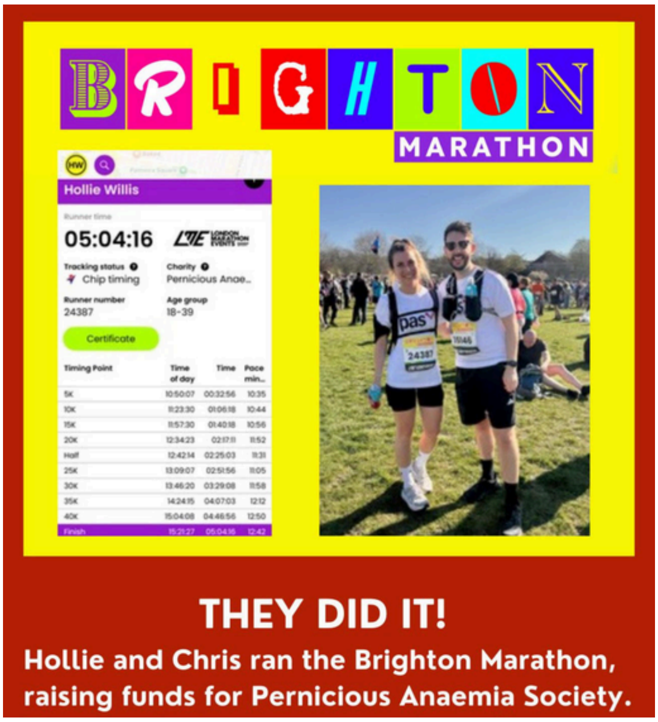
The toughest stretch came just before the halfway mark, heading out of Brighton toward Rottingdean along the seaside cliffs. The sun was unforgiving without a cloud in the sky, the city buzz faded, and the wind hit hard. All we could hear were footfalls and heavy breaths, everyone focusing on their own mental battle - That section was unexpectedly hilly and tested both our legs and mental grit...

We hit the wall around the 33km mark and were in agony, but the crowd and our friends kept us going, shouting and cheering us on! Despite the pain, we couldn't consider stopping (mainly because we feared we wouldn't start moving again!)

When the route finally turned back towards the beach and with just 2km to go, something clicked...our legs found a second wind! We crossed the finish line hand-in-hand both at five hours and 4 mins (our new strava record!). For us it wasn't really about the time, it was the fact that we could now hit the pub and celebrate having survived this grueling challenge, and all the training, early morning runs, and endless doubts, it had all been worth it!

We learned a lot about resilience, mental and physical endurance, and the incredible things you can achieve when you don't let fear or self-doubt hold you back.

Would we do it again? Absolutely... though luckily, and hopefully, not for another year!



Hollie Willis

Runner time

05:04:16

Tracking status: Chip timing

Charity: Pernicious Anae...

Runner number: 24387

Age group: 18-39

Timing Point	Time of day	Time	Pace min...
5K	10:50:07	00:32:56	10:35
10K	11:23:30	01:06:18	10:44
15K	11:57:30	01:40:18	10:56
20K	12:34:23	02:17:11	11:52
Half	12:42:14	02:25:03	11:31
25K	13:09:07	02:51:56	11:05
30K	13:46:20	03:29:08	11:58
35K	14:24:15	04:07:03	12:12
40K	15:04:08	04:46:56	12:50
Finish	15:21:27	05:04:16	12:42

THEY DID IT!

Hollie and Chris ran the Brighton Marathon, raising funds for Pernicious Anaemia Society.

Andy Emerson Story

Camino de Santiago

Me and my friends decided to take on a challenge to do Camino de Santiago one Friday night in September 24. Our group meets roughly 6 times a year, it's a chance to catch up with each other over a couple of pints in a village pub.

At the time, 5 of us had unfortunately lost someone close in 2024, 1 of the guys had always hoped to do the Camino de Santiago with his brother-in-law but unfortunately, he sadly lost his battle with cancer. So the idea to do the walk was born, agreed and over the next month or so all the planning and preparation was put into place.

At the time, I was recovering from a skiing accident which happened in February, in which I managed to rupture my PCL, damaged my MCL and just to make sure I did a decent job, I also had a series of microfractures in my knee. Rehabilitation was tough and long, it required me to wear a metal brace from thigh to calf on my left leg for 6 months. The brace limited the movement of my knee to 45 degrees. Everything was being held in the same place to allow for the ligaments to heel.

The ligaments managed to recover enough to remove the brace in November and I then underwent a programme of physiotherapy. At this stage I could start walking again, a series of regular local walks started straight away, small distances, gradually enabled me to strengthen the muscles and overtime I managed to extend the distances I was covering.

Training hit a peak in Jan, Feb, and March 25, living on the edge of the Chilterns enabled me to do some lovely walks across Hertfordshire and Bedfordshire. The furthest I managed in training was 26 miles, with long walks taking place at the weekend, supplemented by smaller walks in the evenings. The last month before heading to Spain would consist of 60 -100 km per week, so I was confident that I had prepared well, that the knee was in a good place and that I was ready for the challenge ahead.

At the end of March 25, we flew to La Caruna in northern Spain, to do the Camino de Santiago (Ingles), which starts in Ferrol. The reason the English version starts in Ferrol is because pilgrims from the UK and Ireland used to sail to Ferrol due to its port, to start the walk to Santiago.

So, day 1 was a short walk from Ferrol to Neda of 17km, generally quite flat since you hug the coast and walk around bay before arriving in Neda, a small town with a pretty river that runs through it. This part of the journey was picturesque as you have the coastal views, the main challenge was the weather, having to negotiate some torrential sharp cloudbursts which made it all a damp experience.

Day 2, saw us walking between Neda and Pontedeume in constant rain, light drizzle, the clingy type that kept you cool. The journey had you walking through rural villages filled with lemon and orange trees, which was a consistent feature of this walk. Pontedeume was a large town surrounded with hills, realisation started to set in, there was only one way out of town!

We were not disappointed, the climb out of Pontedeume the following morning was without doubt the hardest climb of the walk. At its steepest you had to walk on your toes as you could not place your heel on the ground, and it went on for 1.5 km. We were rewarded with a brilliant view of mists rising from the valley below. Day 3 was longer, 23km in length arriving at Betanzos. The rain had stopped, the reminder of the walk was in brilliant sunshine, around 20 degrees and the blossom was coming through, spring had sprung!

Day 4 was the longest walk from Betanzos to Bruma 28km, which had some long climbs and a sharp hill at the end, which was challenging, but we were rewarded with a nice restaurant which had a cold beer at the top. Hospital De Bruna is a small village with limited places to stay, so a night in a hostel was to follow. They also only have 1 place to eat, they cook and serve 1 meal only, you get what you are given!

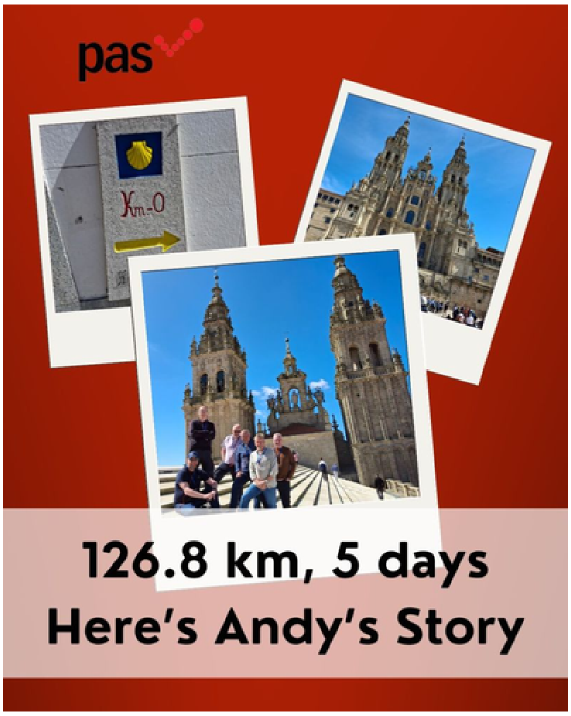
Day 5, another long one – 26km, by this stage the effect of walking each day was beginning to show a little our pace had slowed a little. However doing the longer distances meant when we arrived in Siguero, we were only 18km away from Santiago, the hills had been conquered too, from here on in it was flat.

The final day was quite special, as you walk from town to town alongside other walkers, you tend to get to know groups of people who are doing the same. We met a group of guys from Spain, a couple of people who had walked from France, a group from Venezuela and a priest and his wife from America, amongst others. As we walked into the square in Santiago de Compostela on the final day, with the cathedral on one side and the town hall on the other, we were met by our fellow walkers who cheered and applauded us into the centre of the square. A special moment, which was quite emotional, made by people who had become friends for the week.

The full itinerary was as follows:
1. Ferrol to Neda 17km
2. Neda to Pontedeume 16km
3. Pontedeume to Betanzos 23km.
4. Betanzos to Bruma. 28km
5. Bruma to Siguerro 26km
6. Siguerro to Santiago De Compostela 18km.

An amazing experience, which was made better by the generous sponsorship of people who rewarded our efforts by raising almost £1200 for the Pernicious Anaemia Society. I am overwhelmed by your generosity and would like to say a huge thank you to everyone who donated. The money is much needed, and we at PAS will ensure that we use your donations wisely.

Thank you !



PAS Webinars

On the PAS shop website, you can view our past webinars (some linked below) and also register for upcoming webinars. Please keep an eye out on our social media and website for any upcoming webinars!

Earlier webinars

WEBINAR

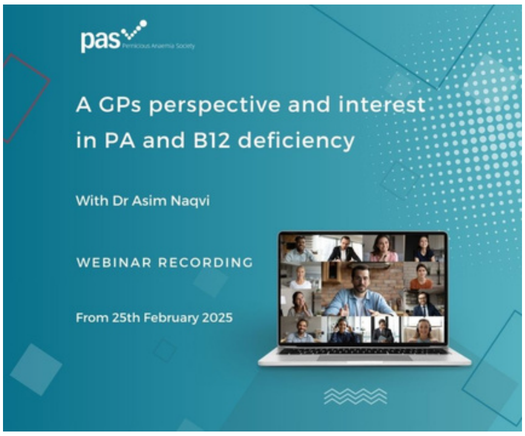
Pathology - Testing blood for B12

With Professor Dominic Harrington

WEBINAR RECORDING

26th March 2025

A changing landscape in B12 testing



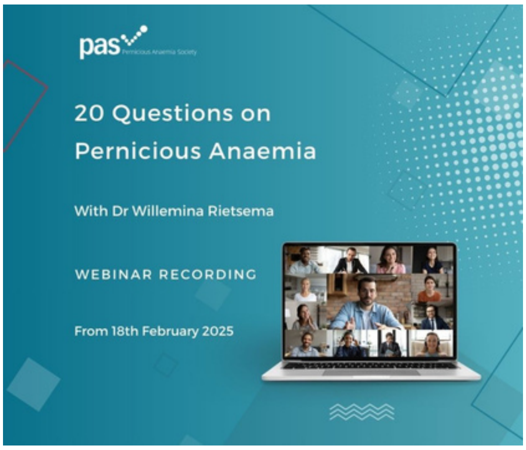
A GPs perspective and interest in PA and B12 deficiency

With Dr Asim Naqvi

WEBINAR RECORDING

From 25th February 2025

A GPs perspective and interest in PA and B12 deficiency



20 Questions on Pernicious Anaemia

With Dr Willemina Rietsema

WEBINAR RECORDING

From 18th February 2025

20 questions on pernicious anaemia

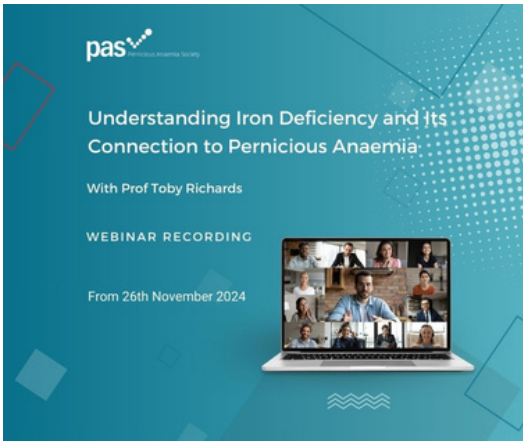
A report and discussion on the need for an international treatment standard for B12 deficiency

With Bettina Borre Buhl

WEBINAR RECORDING

From 21st January 2025

A report and discussion on the need for an international treatment standard for B12 deficiency



Understanding Iron Deficiency and Its Connection to Pernicious Anaemia

With Prof Toby Richards

WEBINAR RECORDING

From 26th November 2024

Autoimmune Gastritis and Pernicious Anaemia – Symptoms, Treatment and Research

Understanding Iron Deficiency and Its Connection to Pernicious Anaemia

With Prof Toby Richards

WEBINAR RECORDING

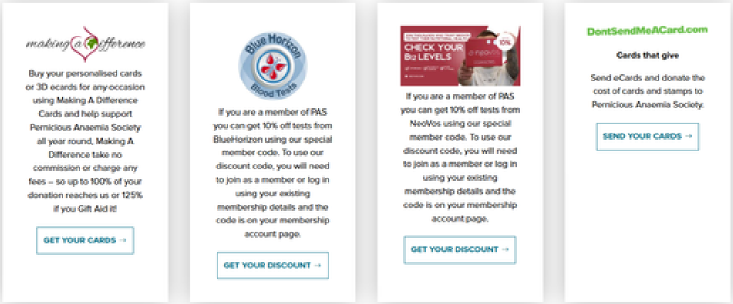
From 26th November 2024

Understanding Iron Deficiency and Its Connection to Pernicious Anaemia

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.



Buy your personalised cards or 3D ecards for any occasion using Making A Difference Cards and help support Pernicious Anaemia Society all year round, Making A Difference take no commission or charge any fees – so up to 100% of your donation reaches us or 125% if you Gift Aid it!

If you are a member of PAS you can get 10% off tests from BlueHorizon using our special member code. To use our discount code, you will need to join as a member or log in using your existing membership details and the code is on your membership account page.

If you are a member of PAS you can get 10% off tests from NeoVos using our special member code. To use our discount code, you will need to join as a member or log in using your existing membership details and the code is on your membership account page.

Cards that give

Send eCards and donate the cost of cards and stamps to Pernicious Anaemia Society.

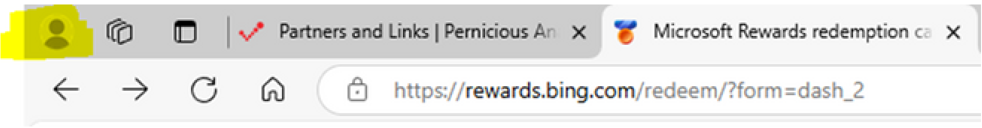
Blog - Making Your Voice Heard: Does contacting your MP Actually make a difference?

This month's blog post is written by CEO of the Pernicious Anaemia Society, Katrina Burchell based on recent correspondence and with the kind permission of active member Sue Childs. Sue's recent experience with her MP sheds some light on why it is valuable to take part in this form of democratic engagement and Katrina outlines how and when making well-reasoned approaches to your MP can help make a difference.

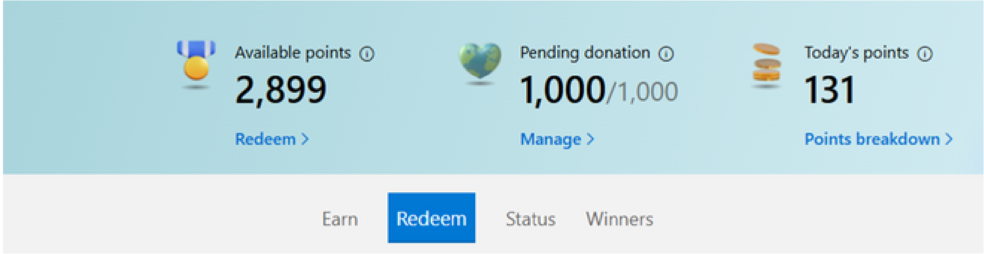
Bing Rewards - How can you and Microsoft help us for nothing!

If you have a UK based Microsoft Account, then please consider helping the Pernicious Anaemia Society with the following free way to donate money to us to help support our cause.

On your computer, when you are logged into your Microsoft Account, you will see your account profile image or a ‘head’ like this:

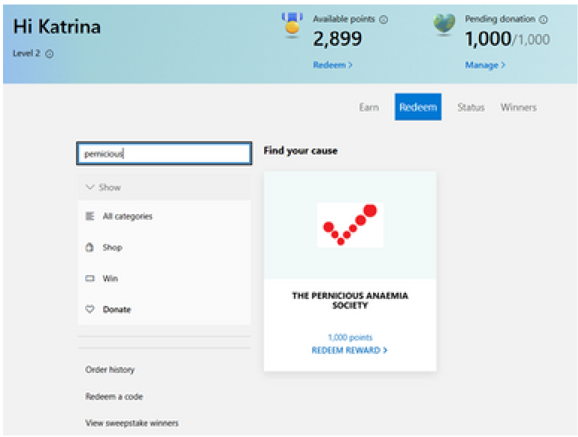


Every time you use the Microsoft Bing search engine to look for something online, points are added to your “Microsoft Wallet”.
These points mount up over time and you can use them to get discounts on online purchases, order gift cards or donate to charities registered with Microsoft. PAS is registered with Microsoft as a UK Charity.



The “Earn” tab will show you ways you can easily add to your points each day with quizzes or links.
The “Redeem” tab will show you ways you can spend the points you acquired just for browsing the web..
If you save up your points you can eventually click on one of the redeem options to get an E-Card such as Marks & Spensers or Tesco E-Gift Card.

But more importantly for us, you can also donate your points to a garity. Go to the Donate page & search for “Pernicious Anaemia”



For every 1,000 points you redeem for PAS Microsoft send us a donation directly through Benevity. It really mounts up over time so please consider doing this if you use Mircosoft Bing at home or work as a search engine.

Using the “manage” option you can nominate how many points to donate and you can even set it up as a monthly regular donation which, providing you have points acquired, will automatically send to us on the 1st of the Month.

We would really appreciate any donations from this source, especially as it doesn’t cost you anything directly.

Why you might be slowly dying - and your doctor is letting you

An excellent perspective and thought-provoking points from Julie Wichlin, our support group co-ordinator in the USA, whose experience undoubtedly will resonate with many whatever your location. Sadly, as Julie also has found, many of us have to advocate for ourselves in the journey through misdiagnosis and adequate treatment. Julie is a great supporter of PAS and her online support groups are well attended and a valuable source of information, support and camaraderie. Details of upcoming meetings can be found on our Events page.

The Silent Epidemic of Pernicious Anaemia and the Medical Blind Spot That's Costing Lives

I spent decades losing my health one misdiagnosis at a time.

There were ER trips, neurologist visits, suspected strokes, unexplained body pain, vision problems, and unrelenting fatigue. My gallbladder was removed. I had nerve conduction studies, MRIs, colonoscopies, and surgeries. There were times I could barely walk. Times I couldn't think straight. Times I thought I might not survive.

And yet, through it all, my doctors told me I was "fine." My bloodwork was "normal." Especially my vitamin B12.

Except—I wasn't fine. And my B12 wasn't "normal." I had Pernicious Anaemia, a life-threatening autoimmune condition that prevents the body from absorbing and metabolising vitamin B12. And I had it for decades—undiagnosed, misunderstood, and slowly destroying my body from the inside out.

The B12 Myth that could be killing you

In conventional medicine, B12 deficiency is considered rare, simple, and easy to treat. In reality, it is common, underdiagnosed, and routinely mistreated. Pernicious anaemia is one of the leading causes of functional B12 deficiency, yet most doctors have little to no training in how it works, much less how to catch it before damage is done.

Here's the kicker: blood serum B12 tests are unreliable, especially in people who have been supplementing (even just with a multivitamin). If you've taken B12 at any point before testing—even a small amount—your blood levels may look "normal" or even "too high." But that doesn't mean it's being absorbed or used properly by your body.

And that's the critical mistake: B12 in your blood does not equal B12 in your cells. Pernicious Anaemia affects how your body absorbs and metabolises B12. If your cells are starving for it but your bloodstream is full of unusable B12, you can still experience severe neurological and systemic symptoms—while doctors tell you to stop taking B12 because your levels are "too high."
It's not just incorrect. It's dangerous.

What B12 Deficiency can look like (Spoiler:Everything:

For me — and for thousands of others — it looked like:

- Widespread nerve pain
- Brain fog and memory problems
- Chronic fatigue and weakness
- Depression and anxiety
- Shortness of breath and dizziness
- Digestive issues like IBS
- Unexplained weight changes
- Vision disturbances
- Balance and coordination trouble
- Burning tongue or mouth
- Suspected autoimmune diseases like MS or lupus

Over time, untreated B12 deficiency can cause irreversible neurological damage, dementia-like symptoms, and even death. And yet, most people are dismissed long before it reaches that point. They're told they're anxious, ageing, depressed, dramatic—or worse, drug-seeking.

The truth? They're metabolically starving—and they know something's wrong.

Why is this still Happening

Pernicious Anemia has been recognized for over a century, yet it remains one of the most misunderstood and under-researched conditions in medicine. Medical schools barely cover it. Most general practitioners don't understand it. And specialists often miss the forest for the trees.

We need better testing—not just serum B12, but also methylmalonic acid (MMA), homocysteine, and holotranscobalamin levels, which offer a more complete picture of B12 function.

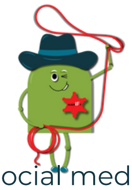
We need better awareness and we need to listen to patients.

What You Can Do

- Trust your body. If you've been told you're "fine" but feel far from it, keep pushing.
- Ask for more comprehensive testing. Especially MMA and homocysteine.
- Join support networks. The Pernicious Anaemia Society is a great place to start.
- Educate your doctor. Many are unaware of these issues—not because they don't care, but because they were never taught.
- Don't wait. Neurological symptoms can become permanent if treatment is delayed too long.

It took me years to uncover the truth. Years to start healing.
But I'm one of the lucky ones — I finally found answers. Many people never do.
If you're struggling with mystery symptoms and being told everything is "normal," consider this your invitation to dig deeper. You are not crazy. You are not alone. You are not fine.
You might be slowly dying—and your doctor may not even know it.
But now you do.

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

Terence Watts

I'm 83 years old, a Fellow of the Royal Society of Medicine, A Member of the City & Guilds Institute and a Freeman of the City of London. I've not got around to retiring yet and teach psychologists around the world via an online platform.

Pernicious Anaemia (PA) crept up on me stealthily at the beginning of 2013, but the symptoms were atypical. I had just an increasing sense of being unwell, a cloud of depression (which was very unusual for me) and a feeling that I was somehow disconnected from my usual self.

My wife and others decided it was 'burnout' after working too hard and too long, and though I disagreed with that, I couldn't define what was wrong. Luckily, I already had a health check booked and when the results came back it showed that my B12 levels were low, and I might be at risk of developing PA.

My doctor disagreed, refused blood tests, and diagnosed age-related depression. Because of the brain fog and memory problems at the time, I only have a jumbled recollection of taking some oral B12, feeling fantastically well, the supplementation gradually failing to work over a few months, more visits to the doctor, more refusal for tests, and increasing depression. And as a psychotherapist, I now knew this was definitely not like any form of depression I had encountered over the years, having worked in the field of psychological therapy since 1989.

By now, I certain I was dying, though I still had no physical symptoms apart from a very slight tingling sensation on the outer two fingers of my right hand, and occasional spells of violent tremors in the back of my thighs which would last for twenty minutes or so. Another visit to my doctor ended with me being told to stop self-diagnosing, that the evident ridges on my fingernails meant nothing, there would be no tests, and I should listen to those who knew medicine.

I've never been good at being told what to do, so I arranged a consultation with a gastroenterologist at a private hospital. It wasn't long, though, before he said my symptoms were not like any form of PA he had ever encountered and there was nothing he could advise, indicating that he thought I had a psychological problem rather than PA. But by now, I had the bit between my teeth and so arranged a blood test for the following week at the same hospital.

The results came back positive for both IF and PC antibodies, and the consultant wrote a letter to the doctor stating that I needed vitamin B12 injections for life (which was quite satisfying, though I never did go back to that particular doctor.)

I decided instead to hang the expense and see a private GP, who delivered loading doses and also taught me how to self-inject – and I was astounded how quickly I started to feel like my usual self again. So, I was one of the lucky ones, since it was only around 9 months from the onset of symptoms to the beginning of treatment, and treatment which worked almost immediately at that. There was a minor setback in that I quickly discovered that Hydroxocobalamin just doesn't work for me, so I have to use Cyanocobalamin, and I also discovered that I need to inject every other day if I am not to start feeling profoundly depressed again.

I joined the PAS in June 2016 and was hugely impressed with the wealth of information and help provided there, though I must guiltily admit to never really getting as involved as I could, my excuse being that 83 I maybe, but I still work over fifty hours a week.

Now, the PA is under control, and I have no permanent damage, though I do have to cope with eczema and psoriasis, as well as issues with cortisol – all autoimmune of course and all manageable. Overall, I certainly feel well enough to continue teaching psychology professionals around the world, which provides a focal point on something far more interesting than the PA!

Your psychological approach to the illness is important and finding something to get engrossed in will definitely make you feel better! It doesn't matter whether or not you're good at it (I'm learning to play the keyboard and I'm rubbish at it!) as long as it gives you an alternative point of focus. Writing short stories or books is also brilliant (I've done that too). If PA is the major focal point in your life, it will drag you down… so, make something else important and the PA loses power – and as a psychotherapist, who has worked with PA sufferers, I can promise you that is a fact!