Issue No: 11
June 2025

SUMMER EDITION

This magazine by PEM Friends is for
people in the UK who suffer from
Pemphigus or Pemphigoid
or those who care for them.

PEM LIVES
MAGAZINE

25 Years of Support, Science & Solidarity

25
ANNIVERSARY

PEMPHIGUS AND PEMPHIGOID
PEM Friends
You are not alone

Celebrating 25 Years of Empowerment
Science and Innovation Reports
Exclusive: Voices from the PEM Community
Advocacy and The Future - From Awareness to Action

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Navigating the waters of Pemphigus and Pemphigoid for all

ANNIVERSARY

This year marks a significant milestone for PEM Friends as we celebrate 25 years of unwavering dedication to support, advocacy, and awareness. Keep a look out for our 25 stories which are being published over the course of this year, on our website pemfriends.org.uk/ (#1 is included in this magazine.) For those unfamiliar, Pemphigus and Pemphigoid are rare autoimmune diseases characterised by blistering and sores on the skin and mucous membranes. Living with these conditions can be challenging, but with the right support and resources, patients can lead fulfilling lives.

The journey of advocacy began a quarter of a century ago when a small group of patients recognised the urgent need to raise awareness about the struggles faced by individuals living with Pemphigus and Pemphigoid. PEM Friends was founded on the principle that no one should have to navigate the complexities of Pemphigus and Pemphigoid alone. Over the years, we have grown into a robust community that offers comprehensive support and provides a voice for everyone affected.

As I reflect on the past eight months as the new Chair of PEM Friends, spent advocating for those affected by Pemphigus and Pemphigoid, it is hard to summarise the transformative experiences, connections, and insights I have gained. This endeavor, while challenging at times, has been an eye-opening and fulfilling journey. Living with these diseases can be isolating, and too many feel as if they are alone in their struggles. It is paramount to continue to create a network of support where individuals can share their stories, frustrations, and triumphs. In an effort to combat this isolation, I have organised a disease-specific Zoom meeting. These virtual gatherings served not only as platforms for education and information sharing but also as safe spaces for individuals to discuss their experiences and feelings. The therapeutic benefits of connecting with others who truly understand the journey cannot be overstated. Participants often leave these meetings feeling a renewed sense of hope and empowerment.

I simply cannot overlook the tireless support and contributions of the volunteer Trustees and PEM Council members, who work so very hard. Thank you all! Isobel has laid an incredibly strong foundation for advocacy and support. Her dedication and commitment have inspired us all, and while it may seem daunting to follow in her footsteps, I hope to channel her spirit and resolve as we together, continue this important work.

It is important to emphasise the need for ongoing research into these conditions. PEM Council are constantly on the lookout for studies that may improve our understanding of Pemphigus and Pemphigoid whilst looking out for drug trials. In doing so, we are not just passing through the waters; we are seeking to make impactful waves that bring about change. Each contribution, each participant, plays a vital role in advancing knowledge and developing new treatments.

Furthermore, as I delve deeper into this advocacy journey, PEM Council aims to raise awareness beyond PEM Friends. Increased awareness can lead to better diagnostic practices, more informed healthcare professionals, and ultimately, improved patient care. It is a ripple effect that can benefit so many people who are seeking a diagnosis or better treatments for their disease.

My journey over the last eight months has been, indeed, a dive into the deep blue sea, filled with challenges, learnings, and heartfelt connections. I wholeheartedly believe that support is crucial in managing these conditions, and I commend all who join PEM Friends, in breaking the silence that often surrounds Pemphigus and Pemphigoid. Together, as a community, we are navigating these uncharted waters and ensuring that no one has to feel alone in their fight against these diseases.

In closing, as PEM Friends celebrate this 25-year milestone, we extend our heartfelt gratitude to all the patients, caregivers, healthcare professionals, and supporters who have joined us in this journey. Your dedication and resilience inspire the PEM Council to continue our mission. Together, we will forge ahead, advocating for greater awareness, supporting one another, and remaining steadfast in the pursuit of a brighter future for all affected by Pemphigus and Pemphigoid. Here is to 25 years of progress and the many more to come!

Take good care!

Trina Harris

Trina Harris
Chair, PEM Friends

Key Announcements!

PEM in the Mouth Leaflet Now Available to UCLH Doctors and Dentists

Our PEM in the mouth leaflet (pdf) is now accessible to doctors and dentists in the members-only section of the UCLH website. Roddy McMillan, Consultant in Oral Medicine & Facial Pain at the Royal National ENT & Eastman Dental Hospitals, University College London Hospital NHS Foundation Trust (UCLH) and is also part of our Advisory Group. Roddy has shared this resource with the membership, noting that "trusts are open to utilizing external 'national' society leaflets alongside their local materials. This initiative will further educate healthcare professionals, enhancing their ability to identify PEM in the mouth through our leaflet.

New Advisory Board Member – Welcome onboard Julie Van Onselen

Julie Van Onselen - Dermatology Lecturer Practitioner / Clinical Nurse Specialist - has accepted our request to be part of our PEM Advisory Group of clinicians.
Julie is a Dermatology Lecturer Practitioner; a dermatology clinical nurse specialist with 30 years' experience in primary and secondary care. Dermatology Education Partnership Ltd provides dermatology educational projects and training.

Julie is a health care writer and publishes widely in health care journals; and past editor of the BDNG Journal, Dermatological Nursing. Julie is a PCDS committee member and works on national dermatology projects.
Julie has been involved in developing primary care dermatology services around the UK for over 20 years, Julie is passionate about improving care for people with skin conditions through developing educational initiatives for both healthcare professionals and patients.

Our Work with Dermatology Nurses

Molly Connolly, (via Emma, the events education lead nurse at the British Dermatological Nursing Group) the specialist AIBD Education Nurse, at the BDNG, has invited Trina (Chair PEM Friends) to share her emergency experience with her PV diagnosis. This will involve speaking to nurses about her experience during one of the study days the BDNG will be running in Birmingham on November 11th, 2025. The event will focus on the theme of 'Emergency presentations of skin conditions,' and Trina looks forward to engaging with nurses on this important topic. She will travel to Birmingham on the 10th and stay overnight.

#25yearsofPEMFriends #1 – The Birth of PEM Friends

By Carolyn Blain

An Unforgettable First Meeting

In 2000, the three of us sat having mid-morning coffee in a café near the Eurostar platform at St. Pancras Station. Thanks to the wonderful help from the organization in America (later called the IPPF), I had been connected with two others in the UK—both from the Southeast—who had also reached out for support.

After sharing our symptoms over coffee, we grew comfortable enough to do something rather unorthodox:

- First, the woman stood up and lifted her top to show her lesions (though I can't recall if they were on her front or back!).
- Next, it was my turn—they examined the sores in my mouth and throat.
- Finally, the man rolled up his trouser legs, and we inspected his affected skin.

Only one other table was occupied the entire time. Realizing how bizarre we must have looked, we burst into laughter, I'm sure those strangers dined out on that story for years! Even now, it still makes me smile.

The Early Days of PEM Friends

I was diagnosed with PV in August 1999 and, by early 2000, decided to start a support group. As they say, the rest is history.
Pemphigus Vulgaris and related diseases are brutal autoimmune conditions. While I had a supportive family, I soon realized many patients faced this struggle alone. PEM Friends became a vital lifeline—offering non-medical advice, companionship, and eventually, deep friendships forged at our social events.

Though dates escape me, I began organizing annual lunches:

- One in the Midlands
- One at Peter Jones' top-floor restaurant in London

These gatherings helped patients (and their carers) feel less isolated. Over time, we even built relationships with leading medical professionals, some of whom joined us.

Expanding the Community

At the time, I ran three Airbnbs, including The Stables, which housed groups for "away weekends." Our community grew beyond the UK:

- A support group leader from Holland joined us one year.
- A commercial pilot from the U.S. visited, followed by another American patient.

I hope everyone who attended left feeling less alone—they'd found friends who truly understood.

Passing the Torch

Between running businesses and local commitments, I needed to step back. Isobel Davies, a regular at our London lunches, took over after some initial hiccups with others. **BLESS HER**—she

PEM Friends Lunch at Peter Jones – November 2014 (Isobel in blue, Prof. Jane Setterfield, Carolyn seated at far right)

PEM Friends AGM – June 2022 (L to R: Ingrid, Carolyn, Isobel, Trina, Andy) transformed PEM Friends into a far more efficient and impactful organisation.

Trina later joined Isobel, and when Isobel retired, "Saint Trina" (as I call her!) took the reins. Under their leadership, PEM Friends has flourished—the magazine alone is a testament to their dedication.

Beyond What I Imagined

I never dreamed PEM Friends would grow this much. Today, we:

- Participate in drug trials and research
- Collaborate with global patient organisations

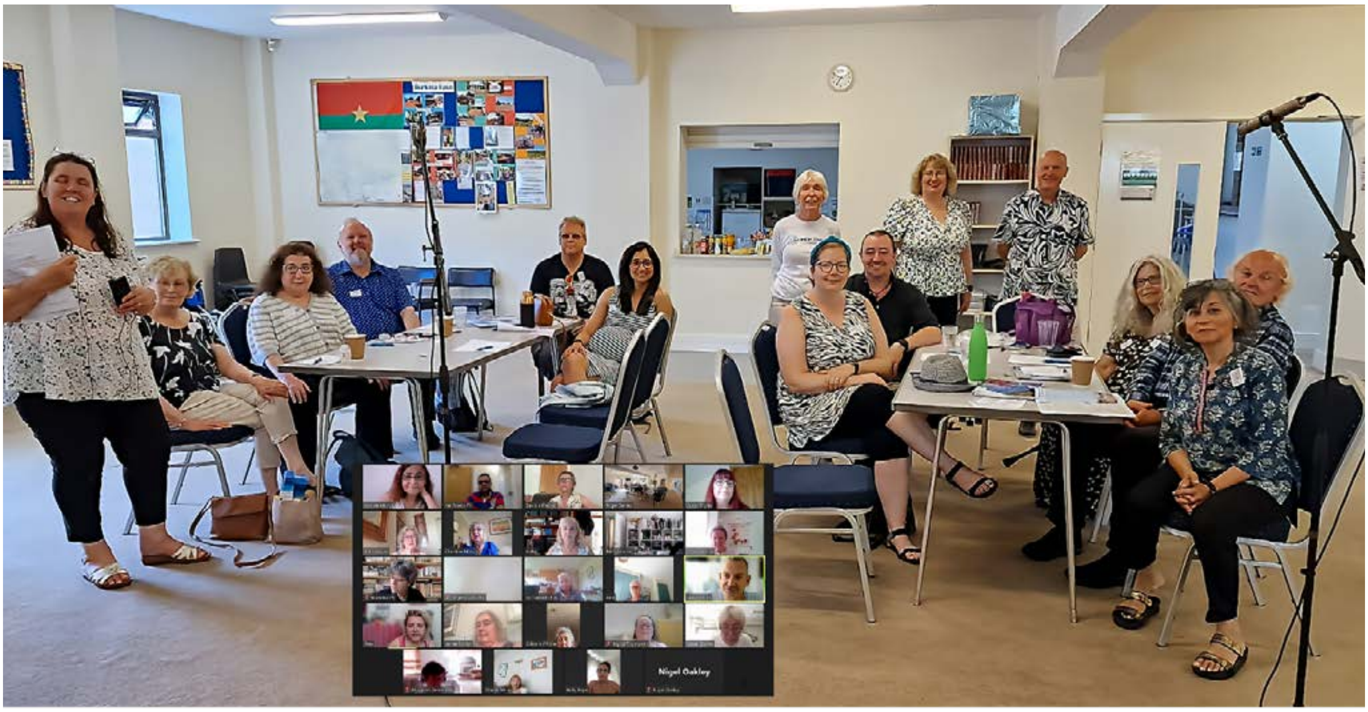
A small request: If you know of a well-known figure affected by these diseases, would you ask them to consider becoming our Patron? (Harold Pinter, our first Patron, agreed after a carefully drafted email—sadly, he's since passed.)

Final Thoughts

Donate if you can, this cause is so worthwhile.

With Love and Hope
Good health and love to you all,

Carolyn
Carolyn



From a Whisper to a Movement:
25 Years of PEM Friends – A Patient-Led Legacy

The Humble Beginnings:
A Vision Takes Shape

In 2000, Carolyn Blain laid the foundation for what would become PEM Friends, a patient-led support group born from the shared struggles and resilience of those living with a rare disease. What started as a small gathering of voices soon grew into a thriving community, united by a common mission: No one should face this journey alone.

When Carolyn retired in 2013, Isobel Davies stepped forward to lead, bringing her own lived experience and unwavering dedication. Under her guidance, the group expanded, welcoming new volunteers like me in 2015 and Ingrid Thompson, who later crafted our first official website. Together, we formed the PEM Council, a team of patient advocates determined to make a difference.

Strength in Virtual Connection:
The Pandemic Pivot

When COVID-19 forced the world into isolation, our immuno-compromised members faced heightened risks—and loneliness. But PEM Friends adapted swiftly. Our **Thursday Zoom sessions** became a lifeline, transforming screens into spaces of laughter, solidarity, and even celebration. We marked **Rare Disease Day** in stripey socks, toasted birthdays virtually, and donned festive hats (and Ingrid's unforgettable **Brussel sprout earrings!**) for Christmas. The pandemic didn't weaken our bonds—it reinforced them.

Amplifying Our Voice:
The Birth of PEM Lives Magazine

In April 2020, we launched **PEM Lives Magazine**, a testament to the power of storytelling. Spearheaded by the indomitable **Trina Harris**, this publication became a beacon of knowledge and connection. With contributions from patients and clinicians alike, it reached not just our online community including medical professionals and stakeholders, but also those offline, who are our most vulnerable PEM Friends.

Breaking Barriers:
Advocacy, Trials, and Charity Status

As the world reopened, PEM Friends took bold steps forward. Members participated in groundbreaking drug trials proving that patient voices could shape medical research. The medical and pharmaceutical communities began to take notice; it was time to formalize our impact.

After months of deliberation, Isobel led the charge in securing charity status (February 2024), a milestone that cemented our credibility. Meanwhile, **Andy Heath** transformed our digital presence with a sleek new website, complete with a photo library and diagnostic tool—essential resources for medics and patients alike.

Passing the Torch:
A New Chapter Begins

In 2024, after over a decade of tireless service, Isobel Davies stepped down, leaving an extraordinary legacy. Stepping into her shoes, **Trina Harris** now chairs PEM Friends, ensuring the group continues to evolve

The Next 25 Years:
A Promise of Solidarity

From a handful of patients to a registered charity, PEM Friends has always been about **community, courage, and hope**. As we celebrate 25 years, our message remains unchanged:
"You are not alone."

Here's to the next chapter and to every voice that makes this movement stronger.

Julie Martin

Julie Martin
PEM Council Member
Julie@pemfriends.org.uk

News From Abroad

By Laurence Gallu

The IPPF conference took place on October 26th & 27th 2024

2024 is quite special for the IPPF as it marks its 30th anniversary and this conference was its first in-person event since the pandemic (it was held in Newport Beach, CA)

Diverse topics were addressed ranging:

- From "creating Meaningful Discussions with Your Doctors" to "Mental Health and Finding Support"
- From discussions with the Peer Coaches, to "Emerging and Current Therapies in Pemphigus and Pemphigoid," from "Oral disease and care" to "skin and wound care"
- From "health journaling" to tips on how to "stand stronger Together: Patients as True Partners" (with doctors and pharmaceutical companies like Sanofi Regeneron and Cabaletta – both of which are involved in our disease treatment research: Sanofi Regeneron with Dupixent for BP and Cabaletta with the CaarT-cell therapy for PV)
- There was also a talk on clinical trials and why some of them are unsuccessful and what the medical community can learn from these failures.
- Day-to-day life tips were discussed along with on-going medical research.

These conferences are useful and are held now both in person and virtually. There is a fee attached to these of course; but the virtual fee is much less than a plane ticket to the US –free tickets are available if you ask for them.

The next IPPF conference will be held in Atlanta (both in person and virtually) – November 7th to 9th.

The IPPF has also put a Health Tracker on its website:

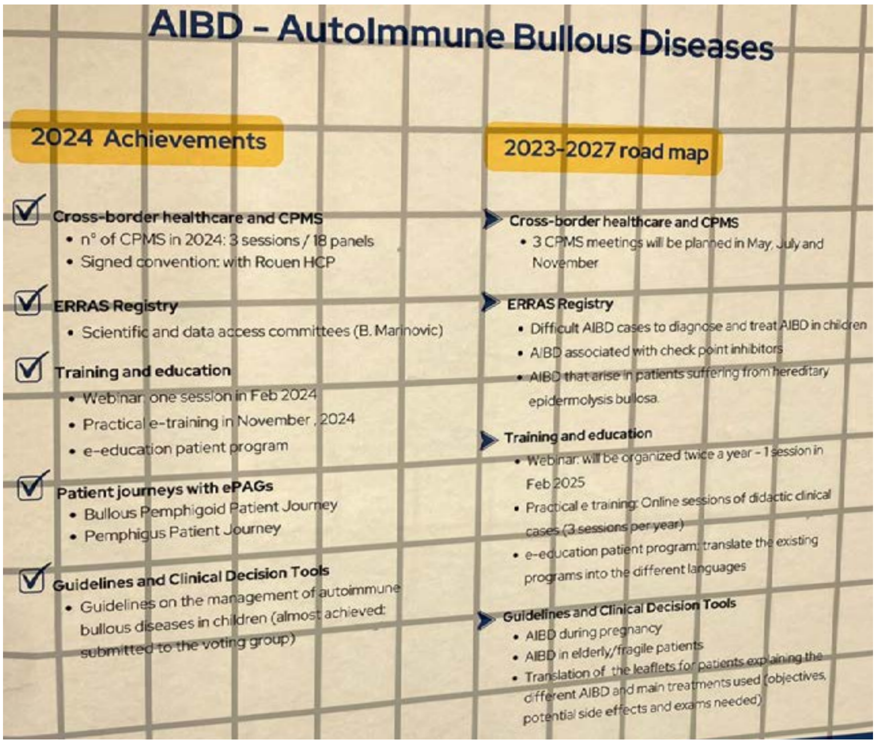
https://www.pemphigus.org/patient-resources/

- It is a tool to help patients monitor their symptoms, treatments, and overall daily life well-being.
- It consists of downloadable pages to help us track our overall health.

And don't forget to check the IPPF patient education webinars: https://www.pemphigus.org/patient-education-webinars

For 2025, you will find an overview of P/P and their current treatments; help and hope for patients living with P/P; and a webinar on the CAR T potential in PV presented by Cabaletta, the pharma sponsoring it.

ERN SKIN AIBD annual Board meeting (AGM): October 24th & 25th (Paris, Laurence went in person)



AIBD - AutoImmune Bullous Diseases

2024 Achievements

☑ Cross-border healthcare and CPMS
- n° of CPMS in 2024: 3 sessions / 18 panels
- Signed convention: with Rouen HCP

☑ ERRAS Registry
- Scientific and data access committees (B. Marinovic)

☑ Training and education
- Webinar: one session in Feb 2024
- Practical e-training in November , 2024
- e-education patient program

☑ Patient journeys with ePAGs
- Bullous Pemphigoid Patient Journey
- Pemphigus Patient Journey

☑ Guidelines and Clinical Decision Tools
- Guidelines on the management of autoimmune bullous diseases in children (almost achieved: submitted to the voting group)

2023-2027 road map

➤ Cross-border healthcare and CPMS
- 3 CPMS meetings will be planned in May, July and November

➤ ERRAS Registry
- Difficult AIBD cases to diagnose and treat AIBD in children
- AIBD associated with check point inhibitors
- AIBD that arise in patients suffering from hereditary epidermolysis bullosa.

➤ Training and education
- Webinar: will be organized twice a year – 1 session in Feb 2025
- Practical e training: Online sessions of didactic clinical cases (3 sessions per year)
- e-education patient program: translate the existing programs into the different languages

➤ Guidelines and Clinical Decision Tools
- AIBD during pregnancy
- AIBD in elderly/fragile patients
- Translation of the leaflets for patients explaining the different AIBD and main treatments used (objectives, potential side effects and exams needed)

The ERN SKIN includes 8 rare skin disease subgroups, one of which is our autoimmune blistering diseases (AIBD). The coordinators of each group present and discuss what has been achieved and what has failed in terms of research in the past year, as well presenting a recap of what is on-going.

- We were warmly thanked for our work on the BP patient journey.
- What stood out also were the **e-education patient training sessions:**
  - these are virtual scheduled sessions with patients and ERN center physicians, nurses, psychologists to “train” patients about disease, treatment, understanding of blood work results – they are homogenous groups (same AIBD or oral lesions, ocular lesions)
  - The nurse calls the patient to explain how the session will proceed & check all the tech details to make sure all will work out.
  - These are especially helpful to patients with mobility issues.
  - The sessions themselves include the following activities: a PowerPoint presentation followed by a brainstorming of the disease, treatments, blood test results; then object & art language images are proposed to illustrate different aspects of treatment constraints & benefits – and explain why; images are used also to express either well-being and difficulties
  - A complementary workshop on fatigue is also part of this training.
  - **So far, the feedback has been quite positive:** patients appreciate it a lot; it is time consuming for doctors and there are limitations due to the use of computers – need to realize technical test before the e-session (unstable connections, inadequate material, ability to navigate different screens
- Comment: need to advocate to doctors so that this becomes more widespread
- **Clinical practice guidelines:**
  - **Most have already been published by the EADV taskforce:** BP, MMP, PV, DH, LABD, PNP & AIBD in children.
  - **Some have even been revised:** BP & PV
  - Proposal to prepare guidelines on: AIBD during pregnancy & AIBD in the elderly & fragile patients.
  - Next Board meeting will be held November 13th & 14th (Paris)

ERN SKIN ePAG Road map: 2025 projects

European Patient Advocacy Group

- Map of expertise
- Brochures about mental health on living loss
- Translation of a card game on palliative which opens discussion about palliative care.
- Work on the patient journey update

Innovation in Eye Drops: A New Era for Ocular Surface Disease Treatment

Scientists and clinicians at the University of Birmingham have developed a breakthrough eye drop technology aimed at improving treatment for conditions such as Ocular Mucous Membrane Pemphigoid (OcMMP). This work, now advanced through the university spin-out Healome Therapeutics, addresses longstanding challenges in treating dry eye and ocular surface disorders.

The Problem

Standard eye drops often provide only short-term relief because they are quickly cleared from the eye. Many patients need frequent applications, sometimes using multiple products hourly. Thicker drops may last longer but can blur vision and cause discomfort. For those with OcMMP, a condition that may scar the eye and threaten vision, treatment can be burdensome and impact daily life.

A New Solution

The team developed a novel eye drop that forms a thin, soft, clear layer over the eye. It acts like both a lubricant and a protective bandage, cycling between liquid and gel states with each blink. This technology has shown promise in pre-clinical studies to promote healing and reduce scarring, even without drugs. Therapeutic agents can be added to further boost treatment effects. (Figure 1.)

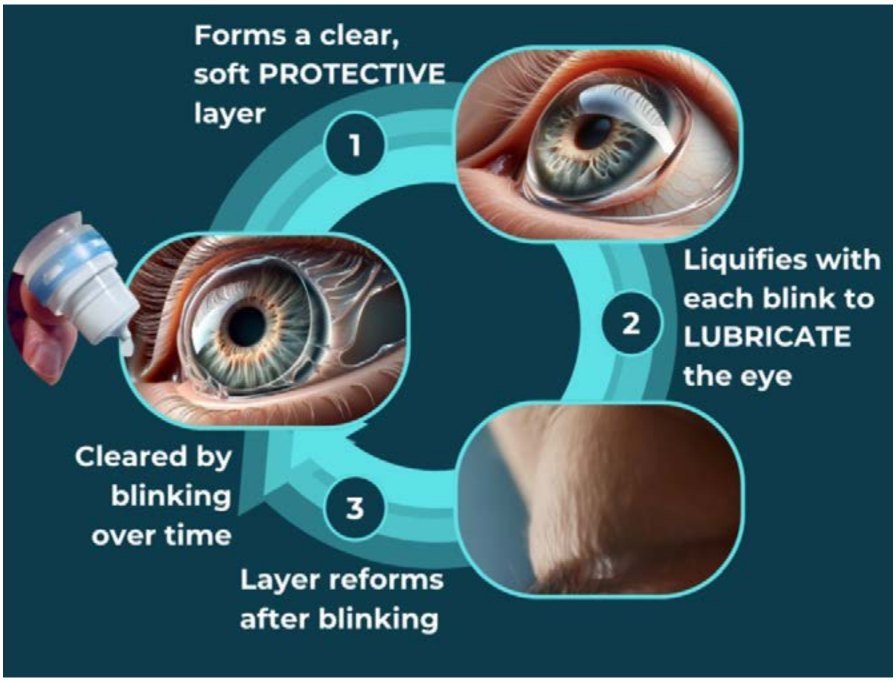


Figure 1: diagram showing how the eye drop technology works and could offer enhanced ocular surface protection without compromising on comfort. Pre-clinical studies show it can reduce fibrosis and promote healing—even without drugs. The preservative-free formulations come in multi-dose bottles.

[1] *Identifying patient-valued outcomes for use in early phase trials of ocular surface disease interventions; The Ocular Surface, Volume 29, July 2023, Pages 550-556; https://doi.org/10.1016/j.jtos.2023.07.005*

[1] *A systematic review assessing the quality of patient reported outcomes measures in dry eye diseases. PLoS ONE 16(8): e0253857. https://doi.org/10.1371/journal.pone.0253857*

[2] *Achieving net-zero in the dry eye disease care pathway; Eye (2024) 38:829–840; https://doi.org/10.1038/s41433-023-02814-3*

[2] *Patients' perspective on the environmental impact of the severe dry eye disease healthcare pathway; Eye (2025) ; https://doi.org/10.1038/s41433-025-03747-9*

Regulatory Milestones and Manufacturing

The MHRA has approved this technology for use in a Phase 1 clinical trial, validating its safety and design. To support early-stage manufacturing, the team built a clean room at the university (Figure 2). While scaling up remains a UK-wide challenge, Healome is developing flexible regulatory systems to support future development and global partnerships.

Figure 2: Photo of the serum eye drop bottle filling process during a validation run to support our regulatory application. At this small batch scale, filling is done manually - leading to some long days in a hot cleanroom suit for our team members, Richard Moakes and Rachel Vincent!

Patient-Driven Innovation[1]

Patient input has shaped every step of this journey. In a project with PEM Friends, group concept mapping helped ensure that clinical outcomes align with real patient priorities. This work led to updates in our Patient Reported Outcome Measures (PROMs), which are now part of our approved trial design. To make the trial more practical, hospital visits were reduced from nine to three, and information materials were redesigned for clarity and accessibility. These efforts not only helped patient participation but also challenged regulatory norms for patient communication.

Sustainability and NHS Net Zero[2]

Patients also raised important points about sustainability. Our work has helped the NHS explore how to reduce travel and improve packaging, supporting broader environmental goals. While packaging changes are complex, insights from patients have guided more feasible innovations.

Looking Ahead

Healome Therapeutics is now raising investment to take the next step: bringing this technology to patients. With experienced industry professionals on board, we aim to form strong partnerships and deliver meaningful impact. Patient organisations like PEM Friends remain vital to this mission, from shaping solutions to accelerating innovation into clinical practice. We are committed to developing safer, more effective, and user-friendly treatments that help people maintain good vision and quality of life.

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Views are those of the authors and not necessarily of the NIHR or Department of Health and Social Care.
Birmingham & Midland Eye Centre is part of Sandwell and West Birmingham NHS Trust.

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Update on Research at the Centre of Evidence Based Dermatology, University of Nottingham

Researchers led by Dr Sonia Gran have been working hard finishing off two important projects on autoimmune blistering diseases (AIBDs). Firstly, Dr Lydia Tutt (Research Fellow) has conducted interviews with 20 GPs around the UK to determine the challenges of recognising AIBDs and to find out what support GPs would like. Findings highlight a lack of experience with AIBDs and little understanding of the pre-bullous phase. Complex presentations and resemblance to other skin conditions were key challenges affecting recognition. Referral options and waiting times varied greatly across the UK.

To improve the care pathway to diagnosis for people with AIBDs, GPs say they require support including brief tailored training, more joined up care and collaboration opportunities with other healthcare professionals. Tools to support GPs with early identification and referral could help address knowledge gaps and support better integration between primary and secondary care. Secondly, Mikolaj Swiderski (Research Associate) has used routinely collected electronic healthcare primary care records to determine if there is an association between the Covid-19 vaccine and bullous pemphigoid. Preliminary results show that there probably is no association, but further research is currently underway, by the team, to confirm these results by conducting another project. We hope to let you know the results by the end of the year.

Both projects will be presented at national conferences in July: Lydia will present at the Society for Academic Primary Care conference in Cardiff and Mikolaj will present at the British Association of Dermatology conference in Glasgow. If you are interested in finding out more about our research, please take a look at our webpage: https://www.nottingham.ac.uk/research/groups/cebd/projects/blistering-diseases/blistering-diseases.aspx
We would like to thank our patient members involved in both projects for inspiring us to conduct the research and helping us with study planning, interpretation and dissemination of results. We would also like to thank the National Institute of Health Research School of Primary Care Research for funding our projects.

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About Dr. Sonia Gran: Dr Sonia Gran is one of The PEM Advisory Group clinicians. PEM Friends works with a group of specialists who have offered to provide expert advice and guidance. There are occasions when we do not know what to suggest for a specific troublesome case or when we have seen a pattern emerging that would benefit from knowledgeable input. Likewise, we develop our plans based on our best understanding of our PEM Friends' needs in the context of clinical and research guidelines. We hope that the overview of people with a medical or research perspective, some with specific expertise in pemphigus or pemphigoid, will add a much better challenge and support to our objective setting. Health care professionals and medical researchers are increasingly required to consult with patient groups and PEM Friends are the main, possibly only, patient support group in the UK that focusses on autoimmune blistering diseases.

When Remission Took a Detour: My Journey with Bullous Pemphigoid

Living with Bullous Pemphigoid teaches you resilience. Just when you think remission is within reach, the condition reminds you who's in charge. That's exactly what happened to me in March 2025.

A Hopeful Pause

On 7 March, my dermatology team stopped my daily steroid treatment—my skin had finally stabilized! For two glorious weeks, I felt free. No blisters, no itching, just peace. I let myself dream of a future beyond medication.

The Unwelcome Surprise

Then, on 23 March, after a fun weekend with friends, new blisters appeared. My heart sank—remission had slipped away. My symptoms worsened, but initial appointment dates were too far off. I had to take matters into my own hands. A direct email to the clinic secretary secured me an urgent consultation on 4 April. **Advocating for yourself matters.**

Beyond the Surface

At my appointment, my flare-up was worse than expected. But beyond that, my breathing had become difficult. I was admitted to the hospital, placed on a nebuliser, and reminded that Bullous Pemphigoid isn't just a skin condition—it can affect so much more.

Finding Joy in the Chaos

Even in tough moments, laughter finds a way. I ended up in a children's ward gown (it fit perfectly!) and sipped tea by the window, soaking in the sunlight. Sometimes, **small joys make all the difference.**

Reflections on My Journey

I'm back on treatment now, slowly regaining strength. This experience reinforced what I already knew: **listen to your body, speak up, and fight for the care you deserve.**

To the PEM community—**you are not alone**. Flare-ups don't erase progress, and healing isn't a straight path. You are strong. You are resilient. And we will get through this **together**.

With love and solidarity,

Hamza Shaikh

Hamza Shaikh
Deaf Advocate | *Language Support Professional* | *PEM Warrior*

From Despair to Hope: My Battle with Pemphigus Vulgaris – A Journey of Resilience

The First Signs of Trouble

In early 2023, I noticed a persistent sore throat and hoarseness. At first, I dismissed it as strain from a noisy social event. But when the symptoms lingered, I grew concerned. My GP initially brushed it off as minor, advising me to return if things worsened. They did—dramatically.

A Terrifying Turn: “I Coughed Up Flesh”

One lunchtime, after eating, I coughed up what felt like part of my throat lining. Shocked, I rushed back to my GP, only to be told it was “just mucus.” But I knew better—it was tissue. Over the weekend, the situation deteriorated, with more flesh coming up. Desperate, I returned on Monday and finally saw a doctor who took me seriously.

The Diagnostic Maze: From Sleep Apnea to Cancer Scares

Referred to ENT specialists, I underwent tests and a sleep study, which diagnosed severe sleep apnea—but not my throat condition. Escalated to UCLH’s Macmillan Cancer Centre, I faced the terrifying prospect of cancer. Thankfully, it was ruled out, but my tonsils were severely inflamed. By June, ulcerations spread in my mouth, making eating agonizing.

Breaking Point: Blisters, Pain, and Emotional Turmoil

Referred to Eastman Dental Hospital, I underwent MRIs and received interim relief with a nasal rinse. But by July, lesions spread to my nose, scalp, and neck. A planned holiday became an ordeal—I survived on soft foods, losing weight rapidly, my body covered in blisters. Emotionally, I was shattered.

Finally, a Diagnosis: Pemphigus Vulgaris

Late July brought answers: Pemphigus Vulgaris (PV). But relief was short-lived—dormant tuberculosis in my system delayed treatment. A three-month antibiotic course followed, then a liver recovery period. By then, my torso and genitals were covered in blisters, and constant nosebleeds left me looking “like I’d been in a car accident.”

Gratitude and Resilience

Finally, in November 2023, I began Mycophenolate and Prednisolone. Progress was slow, but by March 2024, most lesions had healed. Steroids restored my appetite, and I regained weight. Though I’ve had minor flare-ups since, they’re just bumps in the road

Looking Ahead: Gratitude and Resilience

Today, I’m nearly steroid-free and reclaiming my life. This journey taught me the power of persistence, the importance of advocacy, and the value of compassionate care. To others battling PV:

Hold on. Better days will come.

Dan Barker

Dan Barker

PEM Friends & PV Advocate

Meet the PEM Council Member: Julie Martin

A Diagnosis That Changed Everything

On my **50th birthday in 2011**, I didn't just celebrate reaching half a century—I also entered the world of **Pemphigus vulgaris**. Before my diagnosis, I was full of energy and rarely ill. So, to suddenly find myself battling a severe autoimmune disease was both shocking and overwhelming.

Thankfully, I found support through the IPPF (before it officially adopted that name). A dedicated mentor helped me through those early months, guiding me through the uncertainty and challenges of my condition.

Finding Strength in Community

At some point, though I can't remember exactly when, I stumbled upon **PEM Friends** on Facebook. It was a lifeline. Attending a **lunchtime meet-up in London** gave me the chance to connect with others who truly understood my journey. I realised then that, despite my struggles, my **PV was relatively manageable** compared to what others faced. That perspective helped me move forward.

Becoming a Voice for PEM Friends

Isobel Davies, who ran PEM Friends at the time, must have seen something in me. **By March 2015**, I was helping manage the private Facebook group—admitting new members, offering support, and keeping an eye on potential scammers. It became more than just a role—**it was my way of giving back.**

Naturally, this led to me joining the **PEM Council** and, eventually, becoming one of its **Trustees** when we officially became a charity.

A Milestone Moment—Remission

Fast forward to my **60th birthday in 2021**, and I was celebrating something extraordinary: **my last dose of Azathioprine.** After a decade of navigating treatment, I had finally reached **drug-free remission**—a milestone I never imagined possible.

Leaving a Lasting Impact

If there's one contribution I hope to be remembered for, it's my passion for **PEM journaling**. I've always believed in the power of documenting our journey—both for personal reflection and for medical reference.

That belief turned into action when, thanks to a grant from the **British Association for Dermatologists (BAD)**, we produced **PEM Friends logoed journals** for our members. These journals are available for a donation, ensuring we can continue making them accessible to those who need them.

The Power of Shared Experience

PEM Friends has been more than just an organization, it's a community that reminds us that we are not alone. No matter where we are in our journey, we can lean on each other, share our stories, and empower one another.

I'm grateful for every step of this path—both the hardships and the victories. And if sharing my experience helps even one person feel seen, supported, or hopeful, then it's all been worth it.

Isobel Davies, me holding a PEM Friend's journal and my Beacon for Rare Disease's mentor Ankita Batla.

A Journey of Strength: My 20-Year Battle with Pemphigus Vulgaris

By Divya Patel

The Unexpected Diagnosis

Twenty years ago, my life took a sudden and drastic turn. I was the fittest person I knew—or at least, I thought I was. Then, out of nowhere, painful sores appeared in my mouth and gums. My skin inside would peel away when rubbed, leaving me terrified that I had cancer.

The dentist suspected gum disease and prescribed strong antibiotics, but nothing worked. A year later, I was referred to Liverpool Dental Hospital, where doctors initially believed I had lichen planus, a condition similar to Pemphigus Vulgaris (PV). But after a biopsy, the truth became clear—it was PV.

Struggles & Survival

The early days were brutal. I was so ill for so long, trying to push through by keeping busy with work. I thought ignoring the disease would somehow make it disappear, but my reality was far from that. I couldn't eat or drink—even water felt impossible to swallow. I lost a tremendous amount of weight and barely functioned. At times, I thought I was facing something that could end my life. I was exhausted beyond belief, even falling asleep sitting upright at work, waking suddenly as my head dropped forward. Life felt impossibly hard.

Finding the Right Treatment

Liverpool Dental Hospital finally performed a biopsy and diagnosed me properly. I was put on Cellcept, with the dosage gradually increasing to 3,000 mg daily. Slowly, my body responded, and remission came—but it wasn't permanent. When the disease returned, I was referred to Broadgreen Hospital, where Dr. Parslew became my lifeline. He monitored my condition and eventually prescribed Rituximab infusions, which were incredibly rare for treating PV at the time.

The Road to Remission

The Rituximab infusions were intense—eight-hour sessions every two weeks, later stretched to monthly and then every two months. Fatigue was the only major side effect, but the results were worth it.

I stayed on the treatment for a long time, but eventually, I reached remission. During that period, my Cellcept dosage was gradually reduced.

Today, I still see Dr. Parslew every four months and take just 500 mg of Cellcept (250 mg twice a day). He hesitates to stop my medication completely because occasional spicy foods still trigger a small blister—but unlike before, it heals quickly and disappears.

Ongoing Challenges & Strength

The last two decades have been a whirlwind—not just because of PV but also due to the side effects of my treatment. With an extremely weak immune system, I catch every infection going around, and even a common cold takes weeks to recover from.

But despite all of this, I am here. Still standing. Still fighting.

Final Thoughts

This journey has tested me in ways I never imagined. PV is relentless, unpredictable, and exhausting, but it has also taught me resilience, patience, and the importance of great doctors like Dr. Parslew.

To anyone going through something similar—you are not alone. It may take time, but there is hope, and there are treatments that can help. **Keep pushing forward.**

Keep believing.

Divya Patel

Divya Patel

As a patient leader, what does it mean to you to be a CHAMPION?

Creative expressions award: Members of GlobalSkin were encouraged to contribute an entry for the Creative Expression Award, prompted by the question: 'As a patient leader, what does being a CHAMPION signify to you?' This is the submission authored by Trina. Five submissions were shortlisted for all delegates to evaluate and cast their votes before the GlobalSkin Conference 2025. Unfortunately, Trina's submission did not make the shortlist, so we are sharing it with everyone.

Poem – A Patient Leader, A True Champion

By Trina Harris – PEM Friends Chair

The skin, a canvas, blistered and frail, a mirrored pain, a
whispered tale.

Pemphigus & Pemphigoid's blight, stealing comfort,
hiding the light.

But hope remains, a friendly hand, a PEM Friends
Leader, taking stand.

Not an expert, but shared they've known, the lonely
path, the weary groan.

A PEM Friends champion, as a Patient Leader true,
means more than titles, or successes accrued.

It means to hear the members' whispers, soft and low,
the doubts and fears that silently grow.

Each blistered journey, a story shared, with empathy,
with concerns bared.

To see the burdens, heavy on hearts and help from the
diagnosis start.

In the heart of PEM Friends, where voices unite, A
patient leader champion stands, shining bright.

With open ears waiting, they listen with grace, the
journeys of many, their hopes to embrace.

Speaking with Advisory Doctors, concerns take flight,
sharing experiences, gaining insight,

With purpose and passion, they softly steer,
championing the needs, they hold all dear.

At the GlobalSkin conference, hear a buzzing sound, of
shared experience, but hopeful ground.

A champion shares, patient and wise, with listening ear
and gleaning eyes.

Networking gently, gathering every clue, whispers of
treatments fresh and new.

Drug trials appearing, treatments yet unknown,
a seed of hope for PEM Friends who feel alone.

A Patient Leader, the champion, patient and wise,
beneath ever-changing skies.

Hearing stories of members, they focus and strive, for
every member, their determination thrives.

A champion's role, confidence is a must,
to serve the PEM Friends, to gain their trust.

A hand outstretched, a bridge we build, to reach the
hearts, the needs fulfilled.

A champion's heart, our guiding star, to research and
campaign, near and far,

From diagnosis and fear's cold grip, to treatment's
journey, steep and slip,

For quicker diagnosis, treatments anew, drug trial
opportunities, to see us through.

A champion's heart, with patience deep, for the sufferer,
a promise to keep. Not swift to judge, but slow to speak,
to hear the needs, their journeys seek.

In PEM Friends, the champion Leader, a beacon bright,

Ensures patient voices are heard and transforms
darkest nights.

A testament to strength, resilience, grace,
Creating hope, etched on every heart space

Letter From Our Star – Felicity

Dear Pem friends, hope you
enjoy yor summer, Guess
what im getting a... !DOG!
next week!!!! Im so excited.
were calling him neep. I. am
looking forward to playing
with him. Hope your all well. love felicity
xxx

In Memoriam

We were saddened to hear about the passing of Deirdre in March 2025. Her children Dominic and Rebecca contacted us to say that Deirdre died in hospital suddenly and unexpectedly after a fall at home led to a pulmonary embolism. Deirdre was a much-loved mother and grandmother whose greatest passion was classical music, and in particular Lieder. Her later years were impacted by Pemphigoid, however she drew great strength from her involvement with Pem Friends and the friends she made there.

Our sincere condolences to the family!

"I was very sad to hear about the passing of my friend, Deirdre. She and I hadn't spoken for some time, but I will still miss her. She was a huge support to me when I first took over PEM Friends from Carolyn Blain. Her intelligence, (occasionally acerbic) humour and warm friendship were indispensable during those challenging years while I was developing PEM Friends and doing a full time job. She and I spoke regularly and I am sorry that I hadn't stayed in touch in more recent years. I know she was watching the progress PEM Friends was making. I wish her family all the best – I feel I know them a little, as she spoke about them often."

Isobel Davies

Isobel Davies

How Advocacy Shaped Policy: From Past Wins to Future Breakthroughs in PEM Care

Celebrating Our Progress, Amplifying Our Voice, and Setting Bold Goals for Pemphigus and Pemphigoid Advocacy

Advocacy as a Force for Change

Advocacy has long been the driving force behind policy shifts, influencing treatment accessibility, research funding, and pharmaceutical investment. For the pemphigus and pemphigoid community, these efforts have transformed public awareness and accelerated scientific advancements. Now, as we reflect on past victories, we must sharpen our focus on what's next - uniting voices to propel new priorities forward.

Current Challenges: Where Advocacy Must Push Harder
Despite progress, gaps remain:

- Many patients in our community still face delayed diagnoses and limited treatment options.
- Research lags behind more common diseases, leaving unmet needs in pain management and remission.
- Delays in approvals of targeted therapies as first line to reduce reliance on harsh immunosuppressants

Our mission?

Turn these challenges into opportunities—by making the patient's voice louder, clearer, and impossible to ignore.
Current Goals: Where We Go from Here

1. **Driving Research & Industry Engagement**

- We're partnering with research organizations to advance studies in pemphigus and pemphigoid, aiming to speed up the development of better treatments.
- Work with pharmaceutical companies to invest in affordable, innovative treatment options.

2. **Empowering Patient Voices to Influence Policy**

- Strengthen public awareness campaigns to push for better governmental support.
- We're working to strengthen our patient stories so they're heard more consistently through PEM Lives Magazine. We encourage you to share your story here.

3. **Expanding Professional & Community Networks**

- Forge collaborations with healthcare professionals, ensuring pemphigus and pemphigoid are prioritized in medical education.
- Build partnerships to unify advocacy efforts.

Simple but Powerful Ways to Advocate Right Now

Advocacy isn't just for experts, it is for every patient, caregiver, doctor, researcher, and supporter who cares about changing lives.
Here's how you can make an impact:

- **Share Your Story –** Policymakers and researchers respond to real experiences. Submit yours to PEM Friends' Story Bank.
- **Support Research –** Participate in studies or engage with scientists on meaningful research topics.

Audacious Goals: What If We Aimed Higher?

Our advocacy won't stop with incremental changes; we aim to reshape the future of pemphigus and pemphigoid treatment through bold initiatives:
Why settle for incremental change? Let's chase transformative wins:

- Contribute to Efforts to Improve Care – Push for increase in committed research funding and Push for Improved Care -Oriented Research
- Zero Diagnostic Delays – Support awareness of more healthcare professionals via PEM Friends' medical education program and outreach programs.
- Improve Access to Care and Support for our community

Your Voice = Our Future

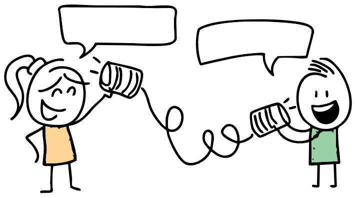
Progress starts with you. Whether you're a patient, caregiver, clinician, or ally - we need you in this fight.

Advocacy is powerful, it moves policy, shapes funding, and defines the trajectory of medical research. By building on our wins and pushing forward with fresh determination, we will ensure the pemphigus and pemphigoid community is heard, valued, and prioritized. Let's make 2025 the year our collective voices to transform the future.

The time is now. Let's amplify our voices. Let's create change. "Advocacy is the bridge between despair and hope. Cross it with us." With Love and Care,

Wale Akinbowale
Wale Akinbowale
PEM Friends Council Member

The Future of PEM Friends:
Safeguarding Our Legacy



Join Us in Strengthening Our Community

For 25 years, PEM Friends has been a lifeline for those affected by Pemphigus and Pemphigoid. With over 850 UK friends, including patients and their loved ones, we've worked tirelessly to:

- Connect people and foster meaningful support networks
- Share experiences, advice, and emotional encouragement
- Raise awareness among healthcare specialists to speed up diagnoses and ensure access to cutting-edge treatments

But here's the reality—our dedicated volunteer team is small, and our ambitions are big. To continue making an impact, we need YOU.

We Need Your Help

Whether it's your time, skills, or simply spreading the word, every contribution helps sustain our mission. Do you have expertise in business, finance, marketing, technology, or community-building? Maybe you know a friend or family member looking to make a meaningful difference?

Pass this message on - someone in your network might be the perfect fit!

Volunteer Opportunities

We are actively seeking **new volunteers** to help us expand and evolve in key areas:

PEM Council Members & Trustees

Be part of our core team, helping shape the future of PEM Friends. There are two primary ways to contribute:

1. Join discussions on how we work and develop new ideas
2. Lead or support key projects and initiatives

We meet once a month for one-hour virtual sessions, with occasional longer planning meetings (such as strategy workshops and the AGM). The experience is rewarding, collaborative, and deeply impactful.

Editorial Team: Magazine & Website

Help us gather stories and curate engaging content for the PEM Friends magazine and website. If you have a knack for writing, editing, or storytelling, we need your skills!

Setting Up a Regional Network

We envision a local support structure, where members can share resources and hospital recommendations, and perhaps even arrange occasional meet-ups. This initiative is still in its early planning stages, and we need a team to brainstorm and shape its future.

Joining this working group doesn't mean becoming a regional representative—but if you're interested in being a local 'pilot,' we'd love to hear from you!

Get Involved Today!

If any of these opportunities resonate with you, we would love to hear from you! Drop us an email at mail@pemfriends.org.uk to learn more.

Together, we can preserve our legacy, empower our community, and continue the vital work of PEM Friends for years to come.

Join us—because support, awareness, and connection matter.

Trina Harris
Chair, PEM Friends Council

Financial Update – Start of 2025

By John Kendrick, Treasurer

Introduction

It has been an interesting start of the year for me having taken over from Kal as Treasurer. Being a charity has a number of reporting requirements that were not needed as a volunteer organisation. We will be preparing a formal set of report and accounts for filing with the Charity Commission during the next couple of months and, once filed, these will be available to see via their website.

Current Financial Position

As of April 2025, our financial standing is sound:

- End of 2024 Balance: £10,600
- Current Balance (April 2025): £17,900
- This growth reflects the incredible support from our donors, fundraisers, and grant providers.

Key Income Highlights

1. Charity Dinner Fundraiser

- Amount Raised: £5,400
- Organized by: Hazel Marsden (Scotland)
- Cause: In support of her son.
- Our Thanks: A heartfelt thank you to Hazel for this outstanding contribution.

2. Memorial Donations

- Sprake Family: Donated in memory of their mother.
- Des Walsh: Contributed in memory of his mother.
- Total Received: £429
- Our Thanks: We deeply appreciate their kindness during such a difficult time.

3. Grant from British Association of Dermatologists (BAD)

- Amount Awarded: £938
- Purpose: A new laptop for our chair, Trina. This laptop, fully funded by BAD's grant, is significantly enhancing the operations of PEM Friends. The laptop is already greatly improving Trina's communication capabilities.

4. AFPA Trust Sponsorship

- Amount Donated: £600
- Rob Frankow, Day 6 winner of the AFPA Trust: www.afpatrust.com – Raising money for good causes for Christmas Giveaway sponsored by LTi Technology Solution: www.ltisolutions.com donated their £600 win to PEM Friends, their chosen charity. Thank you, Rob Franklow.

5. Regular Monthly Donors

- Our loyal monthly donors remain the backbone of our finances.
- Call to Action: If you're reading this, please consider setting up a monthly standing order, no amount is too small!

Summary of Income Highlights

- Overall, our income for the 4 months to the end of April was around £8k.

Expenditure Overview

- Early year spending is typically low, but we maintain essential costs such as:
  - Website & Mailchimp maintenance
  - Insurance
  - Zoom subscriptions
- Major Upcoming Expenses (Mid-2025):
  - Conference attendance
  - Magazine printing & distribution

How You Can Help

Your support enables us to continue providing vital assistance to those in need. Donations can be made via:

1. Bank Transfer:
   - Account Name: PEM Friends
   - Sort Code: 55-70-06
   - Account Number: 76292266
2. Website Donation Button
3. Give As You Live platform

Thank you for your unwavering support! Together, we make a difference.

John Kendrick

John Kendrick
Treasurer I PEM Friends Council Member

Digital Innovation:
Transforming PEM Care & Connection

By Manny, PEM Friends Council

A New Way to Support PEM Patients

At PEM Friends, we're working to make life easier for people with pemphigus and pemphigoid (PEM). Our goal is simple: to provide support, improve care access, and strengthen community connections.

Helping You Navigate Healthcare

Managing PEM can be overwhelming, but our upcoming Patient

Navigation Services Platform will help:

- Find trusted healthcare resources quickly.
- Connect with others who understand your journey.
- This user-friendly tool is designed to make everything simpler, giving you confidence at every step.

We're just getting started, and there's so much to look forward to! Keep an eye out for more updates as the project unfolds.

Making Information Easy to Find
We're improving our website so you can get what you need **fast**:

- A smoother, quicker site that works well on any device.
- Better search features so you can find reliable information effortlessly.

Connecting on Social Media

We're making it easier to stay informed and engaged. Expect:

- Simple updates on treatments and research.
- Live Q&A sessions with medical experts.
- Stories from the community to help inspire and support each other.

Working Smarter Behind the Scenes

We're improving our internal systems to save time and focus on helping you. That means:

- Less paperwork, more support.
- Secure ways for our team to communicate and share knowledge.

Security You Can Trust

Your safety is our priority. We use strong security measures to protect your information, so you never have to worry.

Looking Ahead

Our focus isn't just on technology, it's on people. By thoughtfully using smarter tools, we're making sure that:

- PEM patients have easy access to helpful resources.
- The community stays connected and supported.
- Research and care keep moving forward efficiently.

Together, we're creating a future where support is **simple, effective, and within reach**.

Explore More:

Visit our website

Follow us on social media:

Instagram

Facebook

Share your Feedback

Innovation driven by you, for you

Stay Informed:

How We Keep You Updated

At PEM Friends, we take your privacy seriously and handle your personal details with care. To ensure you never miss important developments in pemphigus and pemphigoid research, treatments, and community news.

Subscribe or share your details here

You can choose to receive updates:

- **By email:** News alerts and digital updates
- **By post:** Printed copies of our PEM Lives magazine (if you've shared your address and given permission)

We keep postal mailings minimal due to costs, just essential updates and our magazine. You can subscribe for free or adjust your preferences anytime via our mailing list form.

Your trust matters.
Unsubscribe or update your information whenever you wish

Manny Olawale,
Manny Olawale
PEM Friends Council Member.

Thank You BAD – Grant for a laptop

PEM Friends would like to say:

BRITISH ASSOCIATION OF DERMATOLOGISTS
HEALTHY SKIN FOR ALL

A big THANK YOU to The British Association of Dermatologists (BAD)

who supported a grant we submitted for a new laptop for our new chair Trina. The laptop was fully funded by BAD and will assist with the running of PEM Friends. This new laptop will make it so much easier for Trina to communicate with everyone (she was using her phone). The ability to share documents, communicate via video calls and virtual conferences, and to be able to collaborate with projects, emphasises the importance of this new laptop! Thanks again BAD, this will really make a difference in the smooth running of PEM Friends.

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ANNIVERSARY

PEMPHIGUS AND PEMPHIGOID

PEM Friends

You are not alone

To get in touch with PEM Friends: please contact us:
Email: mail@pemfriends.org.uk
Website: https://www.pemfriends.org.uk/
QR Code: