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SUMMER EDITION

This magazine by PEM Friends is for people in the UK living with pemphigus or pemphigoid, and for those who care for and support them.

PEM LIVES
MAGAZINE

PEMPHIGUS AND PEMPHIGOID
PEM Friends
You are not alone

From Wounds to Wellness: Practical Wound Care in Pemphigus and Pemphigoid

Table of Contents

Chair's Message

1. Chair's Editorial
2. Key Announcements and Updates from the Chair of PEM Friends

Science and Innovation: Understanding and Improving Wound Care

3. Understanding Wound Healing in Autoimmune Blistering Diseases - Dr Thomas Tull
4. Practical Wound Care: A Specialist Nursing Perspective - Julie Van Onselen
5. Research and Innovation Spotlight -Mikolaj Swiderski, CEBD

Voices from the PEM Community

Real-life experiences of wound care, pain management, infection, dressing challenges, scarring and emotional wellbeing.

8. Living with Fragile Skin: The Daily Impact of Treatment and Blisters - Jean Fitter
9. Healing Takes More Than Time: The Emotional Impact of PEM Wounds - Michael Reilly
10. PEM Friends at Guy's Hospital - Gillain
11. When Skin Won't Heal: Finding the Right Dressings and Overcoming Setbacks - Annemarie Xavier
12. A Blister That Wouldn't Heal: My Journey to a Bullous Pemphigoid Diagnosis - Alison Jane
13. Meet a PEM Council Member - Hazel
14. Letter from Our Star - Felicity

Advocacy and Community Impact

15. Financial Update - John
16. Fundraising Update - Mark
17. Thank You, Community Recognition and Summer Message

Chair's Editorial

From Wounds to Wellness: Practical Wound Care in Pemphigus and Pemphigoid

Trina Harris, Chair, PEM Friends

Over the past year, we've had so many conversations with our members, some planned, some unexpected, and some that happened simply because someone needed a moment to talk. And in those moments, one topic comes up again and again: wound care. Not in a clinical sense, but in the very real, very human sense of "*How do I get through today without hurting,*" *or "Why does this feel so hard*."

I'm not medically trained, and I never pretend to be. But I am here to listen. And what I hear tells me that wound care is one of the most emotionally and physically draining parts of living with pemphigus and pemphigoid.

People tell us about the slow, careful way they get out of bed, the hesitation before stepping into the shower, the dread of catching a bit of skin on clothing, the frustration of trying a dressing that doesn't quite work, the relief when they finally find something that does. Some have brilliant support from their clinical teams. Others feel they're left to figure things out on their own. Most are somewhere in the middle, grateful for the help they get, but still unsure, still overwhelmed, still wishing things were clearer.

These aren't complaints. They're simply the truth of what people are living with.

A moment to talk about this issue

I'm really excited about this issue because it brings together so many of the things our PEM Friends community has been talking about for ages. Wound care isn't just a medical topic for most people, it's something that affects how you move, how you sleep, how you feel about yourself, and how you get through the day. That's why we wanted this issue to look at it from every angle that actually matters. We've included pieces from people who really understand the clinical side, as well as updates on new research and therapies that might offer hope for

the future. But just as importantly, we're sharing the real-life challenges so many of you have told me about: the pain, the infection worries, the dressing struggles, the scarring, and the emotional weight that often gets overlooked. And yes, we're also talking honestly about the gaps in care that make things harder than they should be. My hope is that by putting all of this in one place, you'll feel understood, supported, and maybe even a little less alone.

Why wound care feels so big

When members talk about wound care, they're rarely talking about products or techniques. They're talking about the things that shape their everyday life:

- **Dignity**, being able to wash, dress, and move without fear
- **Pain**, the kind that wears you down even on a "good" day
- **Quality of life**, because wounds affect everything from sleep to social life to confidence
- **Independence**, the ability to manage daily routines without feeling helpless

One member told PEM Friends, "*It's not the diagnosis that gets me — it's the wounds*." Another said, *"I can handle medication. I can handle appointments. But I can't handle not knowing how to look after my skin."* Those words stay with us.

The emotional side we don't talk about enough

Wound care isn't just physical. It's emotional. It's tiring. It can be lonely. It can make people feel vulnerable in ways they never expected. I've heard from people who avoid going out because they're worried about their skin tearing, people who dread bedtime because lying down hurts, people who feel embarrassed asking for help, people who feel guilty for struggling.

And yet, despite all of this, our community shows incredible resilience. Members share tips with each other, they support one another, they celebrate the small wins, they keep going.

But they shouldn't have to do it alone.

What people say would help

Across all these conversations, a few hopes come up again and again:

- **More joined-up care**, where dermatologists, wound-care nurses, and GPs talk to each other
- **Clearer guidance,** so people aren't left comparing conflicting advice
- **Better access to dressings**, without the stress of chasing supplies
- **Practical education**, simple, accessible information that helps people feel more confident
- **Recognition of the emotional impact**, because wound care affects mental wellbeing too

These aren't demands. They're heartfelt wishes from people trying to live their lives with as much comfort and dignity as possible.

Where PEM Friends fits in

As a patient organisation, our role isn't to give medical advice. It's to listen, to amplify, and to advocate. It's to make sure the voices of people living with pemphigus and pemphigoid are heard in the places where decisions are made.

We're here to bring together patient experience and clinical expertise, not to replace one with the other, but to help them work side by side.

From wounds to wellness

"From wounds to wellness" isn't just a theme. It's a journey. And it's one our community shouldn't have to walk alone. If we can help make wound care feel less frightening, less confusing, and less isolating, then we're moving in the right direction.

If we can help people feel more supported, more understood, and more confident, then we're doing what we're here to do.

Take care,

Trina

Key Announcements and Updates

From the Chair of PEM Friends

New Patient Information Leaflets

I am pleased to announce that our updated patient information leaflets are now available to download and share from our website: www.pemfriends.org.uk/raising-awareness. These redesigned resources aim to support newly diagnosed patients and their families with clearer, more accessible guidance. Work is also underway on a new Pemphigus Foliaceus leaflet, which is currently in draft form and will be reviewed shortly.

We are delighted that Julie Van Onselen, has also agreed to help us create a dedicated Wound Care leaflet, an area where patients consistently tell us they need clearer, practical advice. Julie is a Primary Care Dermatology Society (PCDS) committee member and works on national projects. Julie is passionate about improving care for people with skin conditions through developing educational initiatives for both healthcare professionals and patients. Watch this space…

Southampton BP Research Collaboration

A new and promising collaboration has begun with Dr Anuj Dwivedi in Southampton, focusing on how FcRn regulators may be targeted to create safer, steroid-sparing treatments for Bullous Pemphigoid. This research group includes four BP patients and myself as Chair, ensuring that patient experience and priorities are embedded from the outset. We look forward to sharing developments as this important work progresses.

PEM Friends at Guy's Hospital

I have supplied a range of PEM Friends materials to Gillian, CNS at Guy's Hospital, for her immunobullous disease stand. Her article in this edition highlights the importance of accessible patient information and the impact of collaborative awareness-raising.

UK DCTN / Centre of Evidence Based Dermatology Meeting – 21st May 2026

I attended the UK Dermatology Clinical Trials Network (UK DCTN) / Centre of Evidence Based Dermatology online meeting on 21st May 2026, which was attended by approximately 100 dermatologists and healthcare professionals with an interest in autoimmune blistering diseases.

As the patient representative from PEM Friends, I shared my personal pemphigus journey and delivered a 10-minute presentation on the lived experience of pemphigus and pemphigoid. Following the presentations, I also participated in a one-hour interactive Question and Answer panel, responding to questions submitted by attendees and providing the patient perspective on diagnosis, treatment, support needs and living with these rare conditions.

The meeting covered a wide range of important topics, including:

- Dupilumab clinical trials in Bullous Pemphigoid
- Use of rituximab in Pemphigus Vulgaris
- Current diagnostics in autoimmune bullous disorders
- The association between prescribed drugs, vaccines and Bullous Pemphigoid
- Linear IgA Bullous Disease and Epidermolysis Bullosa Acquisita
- Treatments for Mucous Membrane Pemphigoid
- Time to Disease Control with Dupilumab for Bullous Pemphigoid: A Systematic Review

It was a privilege to represent PEM Friends and ensure the patient voice was included throughout the meeting. The discussions highlighted the exciting research currently underway in autoimmune blistering diseases and reinforced the importance of involving patients in shaping future research, treatment pathways and care.

BAD Annual Conference – 30 June to July 2026

PEM Friends will be strongly represented at the **British Association of Dermatologists Annual Conference**, taking place from **30 June to 2 July 2026**. Attending on behalf of PEM Friends will be:

- Myself (accompanied by my wonderfully supportive husband, Simon)
- Heather Hughes
- Sean McInnes
- John Kendrick

I am currently preparing updated materials, leaflets, and display resources to ensure our presence is informative, visible, and impactful.

IPPF Scientific Symposium – Lübeck, Germany (28–29 September 2026)

We are delighted that Hugh Gardner will represent PEM Friends at the IPPF Scientific Symposium on Pemphigus and Pemphigoid in Lübeck, Germany. This prestigious event will bring together around 200 global experts in autoimmune blistering diseases. Hugh has been invited to share his Pemphigus Foliaceus journey, offering a powerful patient perspective alongside leading clinicians and researchers.

Supporting Patients in Crisis

In recent weeks, I have taken several calls from individuals struggling to obtain a diagnosis or feeling overwhelmed by symptoms. These conversations highlight the significant burden of pemphigoid/pemphigus diseases and the essential role PEM Friends plays in offering guidance, reassurance, and connection. By directing people to our website and helping them join our private Facebook group, we continue to make a meaningful difference to those who often feel isolated and unheard.

Fundraising

We continue to explore opportunities to strengthen our fundraising efforts to support our expanding activities. You will find further details in our fundraising reports and finance update within this edition.

PEM Council and Advisory Group **Meeting: 2nd March 2026**

The PEM Council met online with some of the PEM Advisory Group on 2 March 2026. The Meeting Highlights

- **Research Updates**: Dr Tom Tull shared progress on several ongoing research projects
- **Birmingham Research**: Mike provided an update on the tablet trial and ocular MMP anti-scarring research
- **Guideline Development Group**: Continued focus on securing rituximab as first-line treatment for pemphigus in England.
  The first meeting took place in January, attended by Dr Tull, Prof Jane Setterfield, and Trina and Sharon representing PEM Friends
- **PCDS Conference**: PEM Friends materials will be provided for the conference table.

The PEM Council works tirelessly, meeting every other month to review progress, discuss challenges, and ensure that all aspects of PEM Friends' work continue to move forward with purpose and momentum.

As always, my heartfelt thanks to everyone who continues to support, volunteer, and champion PEM Friends. Together, we are making a real and lasting difference for those living with pemphigus and pemphigoid. I look forward to sharing more progress with you in the months ahead.

Trina

Connections and Community:

Our London Lunch in March 2026

Hugh Gardner

Meeting friends in person and sharing stories over lunch can brighten any day. In early March, eight members of our **PEM Friends** community gathered in a private space, kindly made available by John Lewis on the top floor of Peter Jones in Sloane Square, for a low-key lunchtime get-together. Over a spread of sandwiches, soft drinks and plentiful tea and coffee, we listened to each other and exchanged ideas, warmth and support in a way that is just not possible digitally.

Although we may have come together as individuals living with different conditions such as PV, PF, MMP and BP, we are united by shared experiences and challenges. There is a unique relief in speaking with others who have a genuine inkling of what each has been going through and, even better, to impart personal experience and knowledge for the benefit and comfort of fellow sufferers.

Perhaps inevitably, part of the discussion centred on how to best navigate our healthcare system. Our Chairperson, Trina, emphasised how we should each:

1. **Educate Ourselves**: Use the PEM Friends website and this magazine—both are written and edited by people who live with the condition—to understand better our respective diagnoses and treatments.
2. **Be Our Own Advocate**: Don't feel we must blindly accept every diagnosis or remedy. Do not be afraid to challenge our own doctor; remember, we have the right to request a second opinion if a treatment isn't working.
3. **Document our Journeys**: No two journeys are the same. Keep detailed records and photos of our skin's progress to provide clear evidence of our own journey for the benefit not only our ourselves and our clinicians but, by sharing it, also for others who will follow in our footsteps.
4. **Reach Out**: Never hesitate to contact another PEM Friend if any of us is in doubt about anything. None of us should feel alone.

Although this was the first gathering in London for some time, we left looking forward to the next one which is likely to be in September (and hopefully on a Saturday) this year. Further details to follow by email
A huge thank you to everyone who made the trip!

Hugh Gardner

Understanding Wound Healing in Autoimmune Blistering Diseases

Dr Thomas Tull

GUY'S AND ST THOMAS' NHS FOUNDATION TRUST

Introduction

Wound formation is common following the rupture of skin blisters that arise from immunobullous conditions. The management of wounds are important as they cause significant pain as well as increasing the risk of infection. This article will describe how wounds arise from blisters and the processes necessary to enable them to heal.

What is a wound?

A wound is defined as a break in the skin where the epidermis (the top layer of the skin) is damaged. Wounds can arise from a number of mechanisms including trauma and inflammation.

How are wounds formed in immunobullous conditions?

Immunobullous diseases are characterised by antibodies that bind various proteins within the skin and cause tissue damage and inflammation. This can form a split in the skin either within the epidermis (the upper most layer of the skin) or where the epidermis meets the dermis (the basement membrane zone).
If the split occurs in the epidermis, which occurs in conditions such as pemphigus, the resulting blisters tend to be very fragile and rupture easily to leave a relatively shallow wound.
If the split occurs in the basement membrane zone, such as in bullous pemphigoid, then the resulting blister tends to be more tense and difficult to rupture and the resulting wounds can be deeper.

How does the skin repair wounds?

Wound repair is integral to human health to enable restoration of the skin's barrier function. The human body has therefore developed advanced mechanisms to enable rapid healing of wounds. There are four main stages of wound healing, these being; 1. Haemostasis or the control of bleeding; 2) inflammation; 3) proliferation and 4) remodelling. Haemostasis occurs by constriction of blood vessels and the formation of platelet plugs to block vessels to prevent blood flow. Inflammation then occurs where the white blood cells of the immune system accumulate and clear any debris and infection. The proliferation stage is characterised by activation of a type of cell called fibroblasts which produce an important structural protein known as collagen. Collagen forms a scaffold containing cells such as fibroblasts and facilitates the migration of new skin cells that grow from the edge of the wound towards the centre. These cells then reform the epidermis to restore the skin barrier function. In this process excess production of collagen can result in scar formation.

What do some wounds cause more scarring than others?

Immunobullous diseases vary significantly in the degree of scarring that occurs when wounds heal. Diseases such as mucous membrane pemphigoid and epidermolysis bullosa acquisita tend to scar much more than bullous pemphigoid or pemphigus. This observation may in part be due to the deeper wounds that occur in MMP or EBA, but it might also be due to the type of inflammation that occurs downstream of antibody binding and this requires more research to understand better.

Why do some wounds take longer to heal?

People who suffer from immunobullous conditions tend to report that their wounds take much longer to heal than normal. The reasons that underly this are not completely understood. It is known that with prolonged disease activity the skin is depleted of important structural proteins that make it much more fragile and may delay wound healing. Recurrent infection can also prevent healing. Ongoing inflammation and tissue damage will also prevent new keratinocytes from migrating across the wound surface. Due to ongoing skin fragility the use of non-adhesive dressings can therefore aid healing and prevent pain from open areas rubbing on clothing or bedding.

Summary

Wounds are commonly encountered in immunobullous diseases but vary in depth and the degree of associated scarring between different conditions. Further research is needed to understand the mechanisms that result in more scarring in conditions such as MMP and the reasons underlying delayed wound healing in immunobullous disorders.

Dr. Thomas Tull

Practical Wound Care: A Specialist Nursing Perspective

Julie Van Onselen,
DERMATOLOGY LECTURER PRACTITIONER, OXFORD

Introduction

Wound care for anyone with a blistering condition is incredibly important. Systemic (drugs) and other advanced treatments (biologic therapies) will treat and control the underlying blistering condition and symptoms. However, when blisters and erosions are present, effective skin and wound care is key to support fragile skin, prevent itch and pain, reduce skin infection risk and improve quality of life.

How is skin is affected?

In bullous pemphigoid (BP) and pemphigus vulgaris (PV) the skin is affected differently and requires different practical wound care approaches. In bullous pemphigoid, the starting point is a very itchy rash (like eczema or sometimes like hives) which can last up to three weeks before blisters appear, blisters can then form anywhere on the body, generally the trunk, limbs, and skin folds. Occasionally the mouth and genital areas are affected. The blisters are sub epidermal (middle skin layer), so form as large, tense and fluid filled blisters, which can become widespread in days. In pemphigus vulgaris, blistering is both mucosal (in mouth and genitals) and the trunk, scalp, face, axillae, groins and pressure points. Blisters are flaccid, fragile and filled with clear fluid that arises on healthy skin or on an erythematous (red or darker areas for people with skin of colour) base. Blisters often rupture, producing painful erosions and then the areas affected generally heal slowly without scarring. The blistering is epidermal (top skin layer) and usually starts in the mouth before the skin.

Practical wound care

Here are ten practical tips to help you manage wound care for blisters and erosions, prevent infection and reduce pain/discomfort.

1. Keep the blister roof in place

Wound care will be required as soon as blisters and erosions form. In BP blisters should be left intact, as the blister roof acts as a 'natural protective' dressing. Never allow blisters to be de-roofed, as this will cause intense pain and makes you more susceptible to infection. If the blisters are large and fluid filled, or somewhere on the body where they interfere with moving (for example the sole of the foot), then they can be pierced with a large sterile needle. Firstly, use some gauze and apply gentle pressure to one half of the blister, pierce the blister, remove the needle, apply more gentle pressure and allow the blister fluid to expel and 'drip out' of the blister. Do not use a syringe and aspirate fluid as this is likely to result in total collapse of the fragile blister wall or rupture. When the blister fluid has been depressed and expelled, the roof of the blister will rest on the fragile skin and help the blister to heal. The blister should then be dressed.

2. Reduce weepy areas

In PV the areas of blistering are erosions which become open, raw and sore, so there is no blister roof to preserve. The sore wet weepy areas can be reduced and soothed by bathing with antiseptic lotion, which is best added to the water (e.g. Dermol® lotion or Octenisan® wash lotion); bath oils can also be used but prescribing is often restricted(e.g. Dermol 600® or Oilatum Plus®). If some areas of skin are very weepy, two-three days using potassium permanganate in the bath can be helpful. This is an antiseptic solution which helps to 'dry up' weepy areas, long term use is not encouraged, and it can stain the bath – so wash the bath with bleach immediately after use.

3. Apply topical corticosteroid preparations by spreading on dressings

Topical corticosteroid preparations (creams and ointments) will need to be applied to the blisters/erosions. If the skin is dry an ointment may be preferable, but if the skin is weepy, cream is a better option. The best method of application is to spread the topical corticosteroid preparation onto the dressing and never directly to the skin, even the gentle application with fingers can tear fragile skin or deroof blisters and could be an additional infection risk. Use enough topical corticosteroid on the dressing, aim for a fingertip unit (measure from the tip of your index finger down to the first crease) on each 10 x 10 cm dressing. All blistered, eroded and raw area need to be covered with a non-adherent dressing and then secured with elasticated viscose stockinette (e.g. Comfifast® or , Tubifast®), and then secure with micropore tape on the stockinette, never apply adhesive tapes of dressing directly to the skin.

4. Chose the right dressing for you

Dressings are chosen according to the type of wound and the amount of fluid

being produced. Some dressings help absorb excess fluid, while others keep dry wounds moist to support healing. Finding the right dressing is essential to improve comfort and comfort and quality of life. Soft silicone-based mesh dressings are commonly used on blisters because they have a transparent mesh which allows fluid to escape and be absorbed onto a secondary gauze dressing, or even if blister roof is intact this secondary dressing provides a protective cushion. For people with BP, Mepitel® or Autraman® are generally recommended, and there is other silicone-based dressings available. For people with PV the eroded areas can be weepy, so an absorbent dressing is often required, an ideal dressing is a cushioned silicone dressing (e.g. Allewyn® gentle border or Cutiderm®), these dressings do not require a secondary dressing. Never use jelonet or basic non adherent dressing as they are likely to stick and cause trauma, these must be avoided.

5. Always soak off your dressings
Ongoing blistering and inflammation can be made worst and be very painful with trauma dressing changes. This can be avoided by soaking off dressings in the bath (or shower but ensure power shower mode is not engaged). If a bath or shower is not possible, squeeze water onto the dressing with a sponge and gently remove. Never remove dressings dry and if pain is anticipated, take analgesics (pain killers) before dressing removal.

6. Keep a good supply of dressings
As flares can be unpredictable, always keep a good supply of your preferred dressings and viscose stockinette. Ensure your dressings are on a repeat prescription. If you are asked to swop dressing for ones that are similar, be warned they are often not the same and have been offered to you because they are a cheaper option for the NHS. Be firm and insist that your individual dressing works for your skin, you are the expert and often will be self-managing your wound care.

7. Don't forget daily skin care
Keep up a good skin care routine, using emollients for washing and moisturising. Avoid soap and detergents, as they increase the ph of skin and cause barrier damage. Unfragranced medical moisturisers will help repair the skin barrier and reduce skin ph to a healthy acidic level (ph 5.5) and they should be used daily. Continue moisturising around your blistered and eroded area when you have a flare. Keep your skin protected from the sun, wear 50SPF, sun protective clothing and a wide brimmed hat, following sun safety advice.

8. Prevent infection
Wash hands before applying moisturisers and dressings – remember to spread topical treatments on dressings. Use antimicrobial baths/showers when you have a flare. Change dressings regularly. Keep checking your skin, if you have increased pain, redness (or darker areas), weeping, swelling, yellow/orange crusting or malodour; and/or if you feel unwell (flu-like symptoms) and have a temperature, please seek immediate medical help.

9. Nutrition is important for wound healing
Ensure you have a healthy balanced diet including all five food groups (protein foods, dairy, vegetables, fruits). Protein is vital for cell growth, tissue repair and building collagen, which is essential for wound healing, so increase protein intake. Certain micronutrients are essential for wound healing, iron, zinc and vitamin C, dietary supplements are not always necessary (unless advised by a dietcian) as these micronutrients can be obtained from a healthy diet. Make sure you have a adequate calorie input and keep hydrated (aiming to drink 2 litres of water, milk or clear soups daily).

10. You may need help from more than one health care professional
It is important to be assessed and supported in wound care management. Identify a named health care professional (HCP) to support you, especially if you are self-managing. This HCP maybe a practice nurse, nurse practitioner (from your health centre) or a dermatology nurse specialist. If you have complex dressing needs, a multi-disciplinary (MDT) approach is essential including, dermatology, tissue viability, podiatry, dietetics, pain teams and psychological support.

Conclusion

While treatments with drugs and biologic therapies improve outcomes in blistering skin disease, expert wound care remains fundamental. Small adjustments in dressing choice, skin handling and symptom management can significantly reduce pain, minimise trauma and improve quality of life for people living with blistering conditions.

Useful resources
PEM Friends website: Page on wound dressings
www.pemfriends.org.uk/dressings
Includes a link to The French Pemphigus support group and a useful document written in English:

www.pemfriends.org.uk/_files/ugd/721867_bcf971fedef-14541900b931649e05006.pdf

Research/ Innovation Spotlight
Identifying Characteristics of People with Bullous Pemphigoid Prior to Diagnosis:

Insights from a UK Population-Based Case-Control Study

Mikolaj Swiderski

Hello Everyone,

I am pleased to share an update from our project where we looked at the associations between drugs and bullous pemphigoid.

Our paper on identifying the characteristics of people with bullous pemphigoid was recently accepted. The work used clustering analysis, a machine learning technique. We used this technique to find groups of people with BP who are prescribed similar drugs and/or have the same conditions.

The results were published in the Clinical and Experimental Dermatology journal in the open access stream: academic.oup.com/ced/advance-article/doi/10.1093/ced/llag144/8571339?

All results and findings from this publication can be shared without any restrictions.

Best Regards,

Mikolaj Swiderski

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Voices from the PEM Community - Real-world patient challenges (pain, infection, dressing, scarring, mental health)

Personal Story:

Living with Fragile Skin: The Daily Impact of Treatment and Blisters

Jean Fitter

I was diagnosed with Bullous Pemphigoid in January 2024 after three or four visits to the GP and getting nowhere. We decided to go private as a referral to dermatology was months away.

Day to day, it's the small things that show just how much this condition affects my life.

My skin has become very thin due to using Dermovate cream, and it can get quite sore, even when I'm just drying myself after a shower. Something as simple as that can be uncomfortable.

I do use a moisturiser, but I've been told I need to leave a gap between applying it and the steroid cream. In practice, that isn't ideal and makes things more difficult to manage.

The blisters are another problem. It was annoying when my hip replacement operation had to be postponed. I'd had the pre-op and I have an ileostomy which is on the same side as the hip that needed replacing and I had blisters around the stoma so could have caused infection to the wound after the operation.

The operation I'm waiting for is a hernia behind my stoma. Although I don't have blisters at the moment, the skin around the stoma is still healing. It takes time to heal, probably because of having to take the bag off to put a clean one on, so the adhesive doesn't help.

Steroids bring their own concerns. I don't like having to take steroids but unfortunately sometimes they're

needed. I know they affect a lot of things in the body, they affected my cholesterol, my thyroid and osteoporosis.

I find the constant itchiness and pain when blisters appear makes you feel very weary. I don't think healthcare professionals realise the impact this disease has on us and how tired it makes you feel.
One thing I do feel would really help is if there was a dedicated nurse specialist that could be contacted if there's a problem as my consultant appointments are every four months.

I hope this gives some idea of what it's like living with fragile skin and blisters, and living with this condition.

Jean Fitter

Personal Story:

Healing Takes More Than Time: The Emotional Impact of PEM Wounds

Michael Reilly
TECHNICAL DIRECTOR - FOOD, HEALTH AND SAFETY, WSH

It was the beginning of June 2023. My right thumb pad had been numb for over a week. Trauma hadn't caused it, and a Google search gave me a list of conditions that made me think I needed to order my coffin urgently.

I went to my GP, who said the numbness was likely mechanical, but they took blood tests anyway. The tests showed very low potassium, and they prescribed me vitamin D. I can still recall being irritated that I was paying the thick end of ten pounds for something I could buy in Boots for half the price.

I took one capsule and felt an immediate flushing which soon dissipated. I thought nothing more of it, but within a few hours I noticed a couple of blisters on my nose and a mouth ulcer. I mistook the nose blisters for spots, and the following week I took the second dose of vitamin D.

By this time, the mouth ulcers had increased, and the blisters on my nose were appearing on my scalp. I had no flushing on the second dose, but my gut told me to check the instructions on the prescribed vitamin D. The dose was 42 thousand milligrams (known as a loading dose), which raised my eyebrow, and I concluded I must have been having an allergic reaction.

I phoned my GP, who concurred and told me to stop taking the vitamin D.

Over the following three days, the blisters worsened, moving down to my chest. I went back to the GP, who diagnosed impetigo and prescribed me antibiotics.

Two days later, my instinct told me to seek a second opinion. I attended a walk-in centre. The doctor took one look at me and gave a preliminary diagnosis of Stevens-Johnson Syndrome. He referred me to The Royal Berkshire Hospital (RBH) in Reading.

After a five-hour wait at RBH, I was seen and referred to dermatology.
I lost count of the number of blood tests they took to rule out the plethora of conditions my symptoms could be—HIV, monkeypox, and cancer, to name but a few—before they took an x-ray and carried out a chest biopsy.

They immediately put me on prednisolone and mycophenolate (later changed to Azathioprine after a year) and told me they suspected Pemphigus Vulgaris. A few days later, the biopsy confirmed PV.

I had never heard of this and, given I had never used the NHS in all my then 55 years and was otherwise fit and healthy, I was left asking the proverbial "why me?"

What followed was frankly a nightmare of pain and disability.

The condition worsened, causing large blisters across my scalp, hair loss, blisters on my back and chest, and all over my face. I could barely

walk, sleep, or even lift a carton of milk. I didn't eat for five days due to the mouth ulcers. Anything acidic, including ketchup, was unconsumable.

I ended up surviving on custard and rice pots and was given Betamethasone mouthwash and Fluconazole. Showering was agony. The water hitting my skin felt like razor blades. I walked out into the garden one day and it felt like someone had fired a flamethrower over my scalp due to the sun exposure on my blistered scalp.

I started to wear hats and was given Etrivex shampoo.

The prednisolone dose was systematically increased over the next 12 months, topping out at 80mg. I spent two of those months off work as I was unable to wear a shirt due to the blisters, which were constantly bleeding through my shirt. My pillowcase and sheets had to be washed daily at one point, and I was surviving on four hours' sleep a night.

The blisters eventually started to reduce with liberal applications of Betnovate combined with the 80mg dose of prednisolone.

However, I noticed my eyesight had begun to deteriorate around August 2024. I had only been to the opticians four months earlier and had purchased a new pair of glasses. I went back to the opticians, and they diagnosed steroid-induced cataracts.

I had both eyes operated on to replace my cataracts.

At roughly the same time, my back became sore. I ignored it and blamed it on my limited attempt to do some gardening. Another mistake in not trusting my instincts, but maybe forgivable given everything else that was going on.

The pain worsened to the extent that getting out of bed became very painful. The crunch (no pun intended) came when I could not get out of bed. I needed to wee desperately but could not move. I considered calling an ambulance as the pain was so severe. I ended up weeing in a bottle, a particular low point of this condition.

It took me just over an hour to get out of bed. Once I was standing, the pain was less severe but nevertheless still painful. I went back to my GP, who sent me for an x-ray. Nearly 10 days later, the receptionist telephoned me and said I had fractured one of my vertebrae.

I took the opportunity to go private (Bupa) and was sent for an MRI.

They confirmed multiple fractures to T8, T9, T10, T12, L1, and L2. I had steroid-induced osteoporosis and was advised to have an infusion of Zoledronate.

BUPA wouldn't fund this, despite their own consultant recommending it. It is available on the NHS, but that involved waiting longer than I was prepared to. I took the £800 hit and had it within two days. I have since had one further Zoledronate infusion via the NHS and will need at least another three treatments over the next three years.

Around August 2025, I had managed to reduce my prednisolone down to 6mg before it flared up. I was increased to 35mg, but on the positive side, this event provided enough evidence to have the Rituximab infusion.

I had long known about Rituximab and the disappointing fact that it remained a secondary treatment in England. This is likely because of cost (circa £11,000 according to NICE), but clearly a false economy given the cost of multiple x-rays, multiple hospital visits with multiple consultants, MRI scans, tens of thousands of tablets, numerous blood tests, and cataract treatment—not to mention time off work.

Today, a few weeks from first symptoms and circa I month from my diagnosis at the end of June 2023, I am down to 1mg of prednisolone. I am still on 250mg of Azathioprine, 30mg of Lansoprazole, co-trimoxazole, calcium, and vitamin D.

I am asymptomatic and remain hopeful and optimistic for the future. I also remain puzzled as to what the trigger was for my PV. I am minded of the adage that association does not necessarily mean causation, although it is a known fact that people with PV have low vitamin D levels.

Personally, I remain convinced that my body reacted to the high loading dose of vitamin D I was given, and so began this unwanted and painful journey.

Michael Reilly

PEM Friends at Guy's Hospital

Gillain Natividad

GUY'S AND ST THOMAS' NHS FOUNDATION TRUST

As a Clinical Nurse Specialist in a tertiary immunobullous clinic within a busy London hospital, my background has primarily been in paediatrics, where I only occasionally encountered immunobullous conditions, most notably linear IgA disease. Joining the immunobullous team provided me with valuable insight into the wide spectrum and complexity of these rare conditions, as well as the profound impact they can have on patients' lives.

Although there is significant awareness surrounding more common inflammatory skin conditions such as eczema and psoriasis, we felt it was equally important to highlight immunobullous diseases, particularly as some can become life-threatening if left untreated. Through my role within the clinic, I have followed patients through severe flare-ups, complex treatment pathways, and, in some cases, remission. It has been incredibly rewarding to witness the positive difference that timely treatment, specialist care, and ongoing support can make to a patient's comfort and quality of life.

This experience motivated our team to develop an awareness stand within the hospital. Our aim was not only to educate the public, but also to increase awareness amongst healthcare professionals to encourage earlier recognition and improve care for people living with immunobullous disease. We also wanted to reassure patients and families that they are not alone, and to highlight the support available through specialist healthcare teams and charities such as PEM Friends.

We positioned the stand at the main entrance of the hospital so it would be visible to all staff, patients, and visitors entering the building. The display included images of real patients kindly supplied by PEM Friends, alongside examples of topical treatments and dressings commonly used in management. Reactions from passers-by ranged from curiosity to visible discomfort, reflecting the painful and distressing nature of these conditions when left untreated. While some of the images were difficult to look at, they represented the reality experienced daily by many individuals living with immunobullous disease and reinforced the importance of improving awareness and understanding.

The response to the stand was overwhelmingly positive. Members of the public asked thoughtful questions regarding the causes of immunobullous disease, available treatments, and the practical use of topical therapies and dressings. We also had valuable discussions with healthcare professionals who shared their experiences of managing patients with immunobullous disease in surgical settings. In addition, several dental students enthusiastically engaged with us about pemphigus vulgaris and mucous membrane pemphigoid, as these conditions formed part of their upcoming examinations.

Overall, the event was an extremely rewarding experience, particularly as it was the first time our team had organised an awareness initiative for immunobullous disease. Due to the positive engagement and feedback received, we hope to continue this annually, ideally coinciding with Rare Disease Day. Reflecting on this experience, we would also like to make future stands more interactive to encourage further discussion, promote earlier recognition, and improve understanding of these rare but potentially life-changing conditions.

Gillain Natividad

Personal Story:

When Skin Won't Heal: Finding the Right Dressings and Overcoming Setbacks

Annemarie Xavier

I came down with a range of strange symptoms in late 2024. I was exhausted, my legs swelled, and I had blisters on my body and in my mouth. I was not yet diagnosed but was seen at the wound clinic while on the dermatology waiting list.

Finding the right dressings took months. The wrong dressings caused some awful damage. I was admitted as an inpatient in various wards, none with much Pemphigus/Pemphigoid experience.

Plastic-backed adhesive dressings like Allevyn – AWFUL
The wound clinic used them, and they were a frustratingly popular choice on wards. They made the skin hotter and pulled wounds open even more. A small 50p-sized wound would quickly become a 15 cm one. You can see the photo of my knee with the stupid dressing making things worse!

Gauze and tape – Terrible damage
I got an infection and had to be admitted to AMU. The burns nurses placed gauze on the wounds and held it in place with medical tape. When they later peeled the tape off, it pulled a line of skin off and hurt like hell. I then had strips of skin missing around the wounds.

Jelonet covered with thick cotton burns dressings to absorb fluid and bandages – OK if kept moist and removed with care
The dermatology and burns nurses recommended these. I was bandaged from head to toe by this time! When smothered in emollient six times a day, it worked. If they dried out, they needed to be re-soaked in emollient, otherwise they would pull skin off when removed. So a dressing change took a team of nurses and several hours. The cotton and the bed would quickly become soaked in between changes, and I would get very cold.

Paper towels soaked in emollient - surprisingly effective
Not recommended as they are not sterile, but once there was no Jelonet or appropriate dressings on that ward, so we soaked some paper towels in emollient and placed them on the wounds under the bandages. These worked surprisingly well and kept the wounds protected and moisturised between dressing changes.

Mepitel – Brilliant
The DEBRA EB charity recommended using these dressings, and it was a real turning point. They are non-adhesive but slightly tacky, so they stay in place. They need a secondary dressing. At first, I wore body bandages and then smaller bandages as I healed. Around my bottom, where it was worst, they never stayed in place for long but were easily repositioned.

Even months after admission, I continued to have new ward staff who used Allevyn and taped gauze, despite my notes saying these should not be used. I had to make complaints about ward staff who refused to aspirate blisters (and also would not let me do it myself), meaning that 50p-sized wounds were again allowed to become 15 cm.

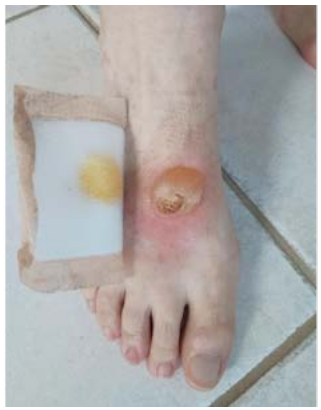
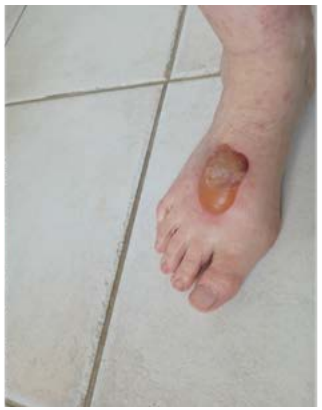
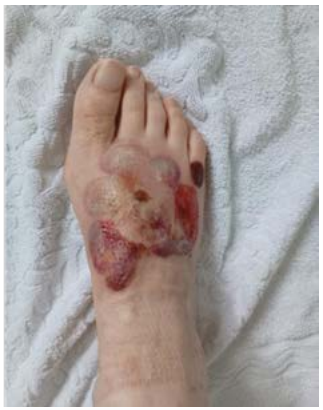
I'm in remission now, and my skin is completely clear (thank you MMP and Doxycycline). However, because I spent about five months in hospital, I have lost the ability to walk and am having to relearn. I do wonder whether that long stay would have been necessary if I had received appropriate dressings from the start. It was very upsetting when the damage was caused by the wrong dressings, especially when a small wound was made unnecessarily larger.

Annemarie Xavier

Personal Story:

A Blister That Wouldn't Heal: My Journey to a Bullous Pemphigoid Diagnosis

Alison Jane

A Holiday Blister

I got a small blister on the top of my foot a week before we went on our annual family holiday to Tenerife in 2024. During the week it got bigger, filling with fluid. I couldn't wear shoes, but hey, we were on holiday, so I wore flip-flops and thought the sunshine and fresh air would cure it.

The blister was a bit unusual, but I thought it might be due to the new trainers I wore. As the week went on, the blister increased in size and was very uncomfortable. By the time we flew home, I couldn't get my shoe on.

Seeking Help

Once home, I immediately requested an appointment with the doctor for the blister and the rash on my body. Where I live (in Leeds), you now have to request an appointment online, giving details of the problem and uploading photos of the condition. I was triaged to the practice nurse to dress the foot blister; the body rash was ignored.

Things got worse and the following week I requested another doctor appointment and got it. By this time the wound was covered, having been dressed by the nurse, and the young GP didn't want to look at it (she had photos of it) and concentrated only on my incredibly itchy rash, which was put down to eczema/dermatitis.

When Things Got Worse

I had an appointment with the nurse every Wednesday for her to re-dress the wound. I became increasingly terrified of what would be revealed when she took the dressing off. There would be more blisters and bleeding. The size of dressing required increased. It was difficult showering because I had to keep the dressing dry.

Eventually a swab was taken, which revealed the wound was infected. It was getting so bad I feared losing my foot—I couldn't even wear flip-flops. I had to fashion footwear out of a sheepskin insole, attached to a cardboard shape of my foot, inside a sock.

The nurse couldn't fit me in one week and made an appointment for me to see her colleague. On the second week I saw her, she started to think this wasn't a regular blister. She asked the doctor to come and see it. He just said to check for infection.

But the next time I saw the new nurse, she said she thought it was an autoimmune condition called bullous pemphigoid, which she had seen once before. She called the doctor in again, who by then thought it was serious enough and, on the nurse's advice, referred me for an emergency dermatology appointment at the hospital.

This was now May 2025, seven months after I first consulted the doctor about my insanely itchy body rash.

Things are currently under control with medication. I feel so grateful to that nurse, whose experience of BP was limited, but far superior to that of the two doctors I saw at the medical centre.

The dressings used were Mepilex Border Comfort. They come in different sizes, and I got them on repeat prescription. It would have been helpful if the nurse could have aspirated the blisters, but that was never suggested.

Alison Jane

Meet Hazel PEM Council Member

Hazel Marsden

My name is Hazel. I'm a wife, mum to two wonderful sons now in their thirties, retired nurse and former care regulator living in Scotland, where I seem to feel cold most of the time! Since retiring early in 2022, I've been enjoying walking and have recently taken up golf lessons, mostly with the hope of spending more quality time with my husband as we embrace retirement together!

I do not personally live with a PEM disease. Instead, my connection to the PEM community began through my youngest son, Scott, who was diagnosed with Pemphigus Vulgaris (PV).

Like most parents, all I have ever wanted is for my children to be healthy and happy. I am immensely proud of both my sons, they are kind, funny, ambitious young men with big dreams and caring hearts. Watching Scott become suddenly unwell in March 2023 was therefore devastating.

At just 28 years old, he developed painful, infected blisters on his scalp and in his mouth. Despite numerous courses of antibiotics, the blisters would not heal. Gradually, every aspect of his daily life became affected by pain, exhaustion and uncertainty. As a mum — and someone with a nursing background — I found it incredibly difficult to witness his suffering while feeling so powerless to help.

After months of perseverance, appointments and worsening symptoms, Scott was finally diagnosed with PV. Before this, I had never even heard of the disease. Like many people facing a rare diagnosis, I turned to Google searching for answers, although that can sometimes feel more frightening than reassuring.
Thankfully, that search led us to PEM Friends — and for me, that became a genuine turning point.

Although I am not a patient myself, I was warmly welcomed into the PEM Friends Facebook community. Suddenly, there were people who understood. People willing to answer questions, share experiences, offer encouragement and simply listen. Joining the Thursday Zoom calls helped me feel connected to real people navigating the same challenges, and I quickly realised I had become part of an extraordinarily supportive and compassionate community.

Last year, through the PEM Friends website, I discovered that the British Association of Dermatologists (BAD) Conference was being held in Glasgow. As a Scot determined to learn as much as possible about PV, I asked if Scott and I might be able to attend. Fortunately, PEM Friends Chair Trina was looking for volunteers to help on the PEM Friends stand, and we were delighted to get involved.

It proved to be an incredibly inspiring experience. The conference brought together an enormous range of dermatology organisations, professionals and patient groups. What stood out most to me was not only the growing interest in PEM diseases among dermatology professionals, but also the passion and dedication shown by the PEM Friends council volunteers. Their commitment ensures that patients and carers no longer have to feel isolated, frightened or alone while navigating these rare conditions.

At the same time, the experience highlighted how much work still needs to be done to raise awareness and improve understanding of PEM diseases within healthcare and the wider public. That realisation strengthened my desire to become more involved.

Feeling so grateful for the support we had received, I wanted to give something back — initially through fundraising events and sponsored activities, and later by joining the PEM Council itself.

That was less than a year ago, and so much has changed since those dark early days following Scott's diagnosis.

Through the support, confidence and connections gained via PEM Friends, both Scott and I learned how important self-advocacy can be in a medical world where experience of rare diseases is still limited, despite a genuine willingness from professionals to learn and help.

After not responding well to several steroid-sparing immunosuppressant medications, Scott was approved for Rituximab treatment. He received

infusions in September last year and thankfully experienced no significant side effects. While he remains on Prednisolone, he has successfully tapered from 80mg to just 7mg daily — something we once could hardly have imagined.

Although fatigue and achy joints remain an ongoing challenge at times, life today feels immeasurably brighter.

We understand this is a long journey, often with twists, turns, setbacks and uncertainties. But compared to those early days filled with pain, helplessness and fear, we now move forward with hope, knowledge and positivity.

What this journey has taught me most is the importance of community, advocacy and awareness. We must continue speaking up, educating others, supporting one another and raising awareness of these rare diseases — and thankfully, through PEM Friends, none of us has to do that alone.

Hazel Marsden

Letter from Our Star – Felicity

Advocacy and Call to Action

Financial Update up to April 2026

John Kendrick, Treasurer

Introduction

The last update was around October and since then, we have been through the yearend.
At 31st December, we had £16,757 in the bank, which provided a solid basis to move into 2026.

Current Financial Position

As of April 2026, we have £16,667 in the bank.
We have put £10,000 into an interest-bearing account, as it is not currently required for day to day expenditure.

Summary of Income for the 4 months to end of April

• Overall, our income for this period was £2.5k, of which £540 is regular monthly donations – the bedrock of our income.

Income Highlights

1. Clive Jay Berkley Foundation – a Scottish charitable trust donated £500 to recognise our support of Scott Marsden, who is one of our younger Pem patients. This is the second donation and we are very grateful.
2. £400 was received in memory of Lee Moodie, a pemphigoid patient. We very appreciate when relatives think of us at such a difficult time.
3. Regular Monthly Donations - 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!

Expenditure Overview

Spending for the period to April was £2.6k, the major items being the December magazine costs (£1.2k) and the complete redesign and print of our new disease specific information leaflets (£0.7k)

It is during the next 3 months that the bigger costs come through:

- Attending the British Association of Dermatologists conference is key to lifting awareness of our diseases. We have a stand, manned over the full three days, handing out leaflets etc and engaging with dermatologists wherever possible. This year it is in Manchester and our attendance will cost upwards of £2k
- This June issue of our magazine will cost circa £1.3k for printing and distribution

Overall financial position

PEM Friends remains in a sound financial position and we thank all our supporters for everything that they do to enable us to continue to ensure that Pem sufferers are not alone.

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. Justgiving or Give as you Live websites - enter PEM Friends in the search bar and follow the links.

Thank you.

John Kendrick.

Fundraising Update

Mark

Mark will be running again, to raise money for PEM Friends, in September 2026!

On Sunday 6 September 2026, The Big Half will take over East and South East London – Mark will run 13.1 miles from Wapping to Greenwich, whilst raising money for PEM Friends.

Mark was diagnosed with Pemphigus Vulgaris in 2021, and with the support of PEM Friends, was able to find excellent NHS medical help and saw the finest doctors in London. He responded very well to treatment and has been able to run to raise money for PEM Friends since. He has previously raised money running the London Vitality 10k in 2022, the London Marathon 2023, and the 2024 Big Half.

Mark and PEM Friends would be truly grateful to receive any donations if you can manage.

donate.giveasyoulive.com/fundraising/mark-bighalf-2026

Mark

Thank you, community recognition

As we head into summer, I just wanted to take a moment to say how grateful I am for every single one of you, the people we support, your carers, and your families. The honesty you share with us, the stories you tell, the moments of humour, frustration, courage, and connection… it all shapes who we are as a community. You remind us every day why this work matters.

To the carers and families who quietly hold so much together, your support, patience, and love make an enormous difference. Even when it isn't always said out loud, it's felt deeply.

I also want to give a heartfelt thank you to our PEM Council. You keep everything moving behind the scenes with your time, your ideas, and your commitment to supporting this community. We simply couldn't do any of this without you. If you ever want to share an update or something you're working on, we'd love to highlight it.

And to everyone who has raised money for PEM Friends this year — thank you. Whether it was a run, a walk, or a quiet personal donation, your kindness helps us continue supporting people, creating resources, and keeping this community connected.

Summer can feel different for everyone. Some enjoy the warmth, others find it challenging. However it looks for you, I hope you find small moments of comfort and joy, a gentle walk, a quiet cup of tea, a chat with someone who understands, or simply a bit of rest when you need it.

Thank you for being part of PEM Friends. Thank you for your strength, your kindness, your humour, your resilience, and the way you show up for yourselves and for each other. Wishing you a gentle, hopeful summer ahead.

Trina

Patient Information Leaflets

We are delighted to share our newly redesigned Patient Information Leaflets, which are now available to view and download from the PEM Friends website. The leaflets have been updated to provide clear, accessible and practical information for patients, carers and healthcare professionals.

Below, you will find our new leaflets together with a link to download them and share them with anyone who may benefit from them. We hope these resources will help improve understanding of pemphigus and pemphigoid and support those affected by these rare conditions.

Looking ahead, we would like to undertake a nationwide distribution of relevant leaflets to dental practices across the UK to help raise awareness of oral pemphigus and support earlier recognition and referral. This is a significant undertaking and will require additional administrative support and resources, but it remains an important aspiration for the future.

www.pemfriends.org.uk/raising-awareness

Discover our new patient information leaflets

Designed to help people living with pemphigus and pemphigoid better understand their condition, treatment and support options.

Visit: **www.pemfriends.org.uk/raising-awareness**

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: **www.pemfriends.org.uk/**

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