**Registered charity number: 1207029**

**Company number: CE035255**

# PEM Friends

# Trustees' report and accounts

# for the year to 31st December 2025

# PEM Friends
# Report of the trustees
## for the year to 31 December 2025

The trustees present their report and unaudited financial statements for the year to 31st December 2025. As the charity has an income of less than £25,000, the accounts have not been independently examined or audited.

**Reference and administrative information**

**Charity name:** PEM Friends

**Charity registration number:** 1207029

**Principal office:**

c/o SWEET BRIARS COTTAGE
HOGGESTON
BUCKINGHAM
MK18 3LQ

**Trustees:**

| | |
|---|---|
| Trina Harris | Chair |
| John Kendrick | Treasurer |
| Umber Khairi | (resigned 18/05/2026) |
| Kalpesh Patel | (resigned 16/06/2026) |
| Isobel Davies | |
| Julie Martin | |
| Ingrid Thompson | (resigned 18/05/2026) |
| Hugh Gardner | (appointed 18/06/2026) |

**Bankers**
National Westminster bank plc
Chatham Customer Service Centre,
Western Avenue,
Waterside Court,
Chatham Maritime, Kent,

# Report of the trustees
# for the year to December 2025

## Structure, governance and management

The company is a Charitable Incorporated Organisation formed on 14th February 2024 and registered as a charity with the Charities Commission on 15th February 2024.

### Induction and training of trustees

Trustees are encouraged to read the online information on the Charity Commission website relating to their responsibilities.

### Organisational structure, including recruitment and appointment of trustees

The charity is strategically managed by a board of trustees who are recruited for the support, knowledge and experience that they can bring. All trustees have lived experience of PEM rare diseases, although this is not a requirement to be a trustee. The board is supported by a council of volunteers in the operation of the charity, as well as by a small group of medical advisers.

After the yearend, 3 trustees resigned. We thank Umber Khairi, Kalpesh Patel and Ingrid Thompson for their help and support for PEM Friends before and after it became a charity. In addition, Hugh Gardner was appointed a trustee, bringing legal expertise to the board.

All trustees and advisers are volunteers with no payment for their services.

## Aims, objectives and activities

### Aims

The aims of the charity are set out in the governing document as:

*TO RELIEVE THE NEEDS OF INDIVIDUALS DIAGNOSED WITH PEMPHIGUS AND PEMPHIGOID, AND BY EXTENSION THEIR FAMILIES AND CARERS, IN PARTICULAR BUT NOT EXCLUSIVELY BY THE PROVISION OF SUPPORT AND INFORMATION RELATING TO THESE AUTOIMMUNE DISEASES AND BY RAISING AWARENESS AMONGST THE WIDER PUBLIC*

### Objectives

The objectives relate to delivering support and advice to Pem sufferers and/or their carers via a private Facebook group, a comprehensive website, half-yearly magazine and increasing awareness amongst the medical profession in order to improve early diagnosis.

### Activity of volunteers

The charity is run entirely by volunteers of which there were 9 active at the year-end.

## Activities undertaken for public benefit in relation to objects

In planning our activities for the year, we kept in mind the Charities Commission's guidance on public benefit and the work was planned with reference to the trustees and monitored through the council meetings of trustees

**Achievements and Performance**

During the period, PEM Friends continued to provide information, support and advocacy for people living with the rare autoimmune skin diseases pemphigus and pemphigoid, together with their families and carers. The charity continued to develop its role as a trusted source of information, a provider of peer support and an advocate for the patient voice within the wider medical, research and pharmaceutical communities.

2025 was a significant milestone for PEM Friends as we celebrated its 25th anniversary. To mark our Silver Jubilee, we shared 25 stories and examples of our work over the years, reflecting on the history, achievements and development. These included the birth and evolution of the charity, the development of its website and diagnostic resources, regional meetings, PEM Lives, Zoom sessions, its involvement with the British Association of Dermatologists and its participation in international and regulatory initiatives. The anniversary provided an opportunity to recognise the contribution of the many patients, carers, volunteers and healthcare professionals who have helped shape PEM Friends and to demonstrate the progress made over 25 years.

Our private Facebook group now has approximately 1,000 members. The group provides a valuable and supportive environment in which people affected by pemphigus and pemphigoid, and their carers, can exchange experiences, practical information and knowledge. This peer-to-peer support complements the information provided through the charity's website and other resources and helps reduce the isolation that can accompany living with a rare and often poorly understood condition.

Our programme of regular Zoom meetings, both general and disease specific, provides an opportunity for people living with particular forms of pemphigus or pemphigoid to share their experiences and discuss the challenges they face in their daily lives. They provide a welcoming forum for anyone to share experiences, ask questions or simply listen, with participants able to engage at their own pace.

Our website continued to be developed and upgraded, with the aim of making it a comprehensive and accessible source of information and links relating to pemphigus and pemphigoid. It provides access to disease information, diagnostic resources, patient information, medical research papers, clinical guidance and links to organisations including the British Association of Dermatologists (BAD). The website also provides access to current news and information about the charity's activities. During the year, we continued to develop its diagnostic information and resources, supporting its objective of improving awareness of these rare diseases and helping to reduce delays in diagnosis.

We continued to develop PEM Lives, our half-yearly magazine. During 2025, the magazine was redesigned and moved to an A5 format, providing a more modern and accessible presentation while also making it easier and more economical to distribute by post. The magazine continues to include a wide range of material, including patient and carer experiences, research developments, medical information and community news. It provides an important means of keeping people affected by PEM informed, connected and supported.

We also started the process of redesigning our Patient Information Leaflets to ensure that they are clear, accessible, accurate and up to date. By improving access to reliable information, we aim to contribute to earlier recognition and diagnosis and better support for patients and their families.

A key area of activity during the year was ensuring that the lived experience of patients was represented within professional education. In July 2025, our chair, Trina Harris recorded a video for the British Association of Dermatologists Education Hub, sharing her personal experience of pemphigus vulgaris. She discussed the potentially life-threatening challenges associated with airway blistering, the emotional impact of living with the condition and the experiences of others affected by pemphigus and pemphigoid. She also emphasised the importance of clear communication and coordinated care in helping patients feel supported, understood and listened to. The video provides healthcare professionals with valuable insight into the reality of living with these rare diseases.

PEM Friends also contributed directly to the education of healthcare professionals, working with the Education Nurse of the British Dermatological Nursing Group in the development of an educational module for nurses. Patient experiences and real-life examples of wound care were incorporated to demonstrate the significant practical and emotional burden associated with managing chronic pemphigus and pemphigoid. This collaboration demonstrated the value of combining clinical, evidence-based information with the lived experience of patients and supported our aim of encouraging more informed, empathetic and patient-centred care.

The patient voice was further promoted through Trina's contributions to professional publications. She authored an editorial for the September 2025 edition of the Dermatological Nursing Journal and a patient-voice article for the December issue. These contributions provided an opportunity to communicate the realities of living with pemphigus and pemphigoid to a professional audience and to encourage greater understanding of the needs and experiences of patients.

Research engagement remained an important part of the charity's activities. In January 2025, PEM Friends hosted a patient and public engagement event with the University of Birmingham and collaborating research centres. The event focused on research into ocular mucous membrane pemphigoid and potential approaches to preventing scarring. Patients were able to hear directly from the research team about the scientific background, the patient journey and the clinical trial, and were able to ask questions about what participation would involve. A recording of the event was subsequently made available through the PEM Friends website, extending access to this information to the wider patient community.

The charity strengthened its international engagement during the year. In April 2025, Trina Harris represented PEM Friends at the GlobalSkin Conference in Prague. The conference provided opportunities to learn about patient engagement, clinical trial design, health policy advocacy and collaboration between patient organisations and industry. Trina used the opportunity to raise awareness of pemphigus and pemphigoid, build relationships with other patient organisations and contribute the patient perspective to wider discussions about improving outcomes for people living with dermatological conditions.

Trustees and volunteers also continued to attend important medical conferences, including the annual British Association of Dermatologists conference and international pemphigus and pemphigoid meetings. Conference participation enables us to maintain our profile within the dermatology community, keep abreast of developments in research and treatment, establish and strengthen professional relationships and raise awareness of the particular needs of people living with PEM diseases. It also provides opportunities for the charity to seek to influence the provision of appropriate medical advice, treatment and support for patients and carers.

PEM Friends continues to develop relationships with pharmaceutical companies and other organisations involved in treatment development. These relationships provide opportunities for the charity to contribute patient and lived-experience perspectives, including information that can support discussions around new treatments and NICE applications. Through this work, the charity seeks to ensure that the experiences, priorities and needs of people living with pemphigus and pemphigoid are represented when new treatments are being considered.

Overall, during the year PEM Friends continued to build on its 25-year history by expanding its role in patient support, information provision, professional education, research engagement and patient advocacy. We continued to try to ensure that the patient voice is heard and that people living with these rare and challenging conditions have access to information, support and opportunities to influence the development of their care.

**Financial**

The charity is reliant upon income raised from donations and sponsored activities plus the occasional grant. Total income of £12,281 included a grant of £935 for the purchase of a laptop for which we thank the British Association of Dermatologists.

During the year, we received £1,980 in regular monthly donations, which are the bedrock of our income. In addition, at the start of the year, a sponsored charity dinner in Scotland raised £5,400 and we have also benefited from a number of sponsored walks and runs.

On occasion, we are nominated as the charity of choice in remembrance of a deceased family member for which are very grateful.

Expenditure supports the cost of the printing and distribution of the PEM Lives magazine (£2.2k) and the website and systems (£0.5k). Also, it also includes the cost of attendance at the various conferences noted above (£2k) with the BAD conference being more expensive this year as it was located in Glasgow. Attendance is important for keeping the medical profession aware of the issues relating to the rare PEM diseases and making them aware that PEM Friends is there to support their patients.

Overall, the charity remains in a sound financial position.

**Reserves policy**

The charity is dependent upon donations and fundraising activities. The trustees have built up the unrestricted reserves across the period and are able to meet the financial commitments that the charity plans for the year ahead.

As the charitable Incorporated organisation has an income less than £25,000, its accounts have not been independently examined or audited.

**Aproved by the trustees at a board meeting on 12th October 2026 and signed on their behalf by:**



Trina Harris (chair)

# PEM Friends
# Financial report of the trustees
# for the year to 31 December 2025

| | Unrestricted funds | Restricted funds | Total funds 2025 | *Total funds 2024* |
|---|---|---|---|---|
| **Note** | **£** | **£** | **£** | ***£*** |
| **Receipts** | | | | |
| | | | | |
| Donations | 11,263 | | 11,263 | *5,336* |
| British Association of Dermatologists | | 935 | 935 | *584* |
| Other | 84 | | 84 | *500* |
| | | | | |
| **Total Income** | **11,347** | **935** | **12,282** | *6,420* |
| **Payments** | | | | |
| ***Charitable expenditure:*** | | | | |
| Computer/internet/website | 458 | | 458 | *2,306* |
| Printing/postage/publicity materials | 2,532 | | 2,532 | *1,954* |
| Conference costs | 1,988 | | 1,988 | *1,144* |
| Travel/Insurance/sundries | 385 | | 385 | *1,235* |
| | | | | |
| **Total expenditure** | **5,363** | **0** | **5,363** | *6,639* |
| **Net income/ (outflow)** | **5,984** | **935** | **6,919** | *(219)* |
| **Bank & cash balance at start of period** | | | **9,837** | *0* |
| **Transfer from unincorporated association** | | | **0** | *10,056* |
| **Bank & cash balance at end of the year** | | | **16,756** | *9,837* |

**Statement of Assets and Liabilities as at 31st December 2025**

**Liquid funds**

Cash at bank - current account £6,672 (2024: £ 9,837)

- deposit account £10,084 (2024: £0)

**Liabilities**

There were no liabilities incurred as at 31st December 2024

**Approved by the Trustees on 12th October 2026 and signed on their behalf by:**

**Trina Harris**



# PEM Friends
# Notes to the financial report
# for the year to 31 December 2025

**1 Accounting basis**

The financial statements have been prepared on a receipts and payments basis.

**2 Trustees' expenses**

Expenditure included £2,007 (2024: £448) for trustees' out of pocket expenses, generally incurred on attending Glasgow BAD conference. No other payments were made to the trustees.

**3 Unrestricted cash reserve**

The unrestricted cash reserves at the year-end were £16,756 (2024: £9,837)

**4 Restricted**

There were no restricted reserves at the end of year-end.