Leading with purpose: PEM Friends past and future

Trina Harris

It is both an honour and a responsibility to lead as the volunteer Chair of PEM Friends, a UK-based charity supporting individuals affected by the rare autoimmune skin conditions pemphigus and pemphigoid (PEM). I took over the role in October 2024, following the dedicated leadership of Isobel, who helped shape the organisation's direction. I'm proud to continue this important work as we move into a new chapter.

PEM Friends was founded in 2000 by Carolyn Blain. After experiencing pemphigus herself, Carolyn recognised the urgent need for emotional support, community, and practical guidance. What began as a small, informal support group has grown into a respected and trusted organisation for patients and carers alike.

In February 2024, after nearly 25 years of committed work, we became a registered charity. This milestone has helped formalise our operations, strengthen our internal structure, and expand our ability to advocate for people living with these rare diseases.

The charity is guided by a team of dedicated volunteer trustees, many of whom are also members of the PEM Council. Several live with pemphigus or pemphigoid themselves, bringing invaluable lived experience to the table. The Council plays a key role in research engagement, forward planning, and ensuring patient needs remain central, all shaping decisions and driving our strategy.

Trina Harris is Chair of PEM Friends

Our mission is rooted in compassionate, knowledgeable support. We aim:

- To offer emotional and practical support to those living with Pemphigus and Pemphigoid
- To provide accurate, accessible information and encourage patient education
- To reduce isolation through Zoom meetings and peer support
- To raise awareness among healthcare professionals and the public
- To ensure UK patients have access to the same first-line treatments available internationally

This last goal remains especially urgent. While highly effective treatments exist, access in the UK is often delayed or limited. These barriers can seriously impact health and quality of life. We are committed to advocating for equal, timely treatment regardless of location.

In 2025, we're marking '#25YearsOfPEMFriends' by sharing 25 stories that celebrate the resilience of our community and highlight the importance of connection, education, and support.

We also publish PEM Lives, a magazine filled with patient stories, updates on treatment and research, and news. Current and past issues are available at www.pemfriends.org.uk/pem-lives-magazine.

We're proud to work with a dedicated Advisory Board of medical experts who guide us in complex cases and help ensure our efforts align with current clinical thinking. Their expertise supports informed decision-making and effective long-term planning.

With the help of a grant from the British Association of Dermatologists, we created a diagnostic photo library, supported by our Advisory Board of clinicians, to aid diagnosis. You can access the photo library here: www.pemfriends.org.uk/diagnostic-photo-library.

PEM Friends is the only UK-based support organisation dedicated solely to rare PEM autoimmune blistering diseases. We believe that greater collaboration between patients, carers, and healthcare professionals leads to better outcomes. Patient voices are crucial in shaping care, treatment access, and research priorities.

We invite nurses, especially in dermatology and wound care, to partner with PEM Friends by sharing our resources, referring patients, or contributing to education, your support can make a real difference.

Looking ahead, we aim to expand our reach, grow our network, and raise awareness of Pemphigus and Pemphigoid. Every patient should find PEM Friends, feel supported, and know they're not alone. As Chair, I'm proud to lead with empathy and lived experience, there's more to do, and together, we can build a stronger, brighter future.

At PEM Friends, our message is simple and enduring: You are not alone.

To learn more about PEM Friends, visit www.pemfriends.org.uk.