

#25yearsofPEMFriends#1

#1 The Birth of PEM Friends by Carolyn Blain

In 2000, there the three of us were, having a mid-morning coffee in the cafe near to the Euro Star platform at St Pancreas Station. Due to the wonderful help from the organisation in America, later to be called the IPPF, they'd put me in touch with two people in the UK (fortunately in the S.E.) who had contacted the IPPF for help and advice. Coffee finished and after having a good old chat about our symptoms etc., we then felt comfortable enough with each other to do the following.

First to go was the lady who stood up and then raised her top so we could see the lesions on the upper part of her body, although now I can't remember whether it was the front or the back! I was next to go when the two of them had a good look in my mouth and throat. Finally, the man rose from his chair and pulled up his trouser legs and we had a careful inspection of his legs.

There had only been people at one other table the whole time we were in the cafe. But then, the three of us, realising how odd it all must have looked to them, had a good old giggle and I bet the other people 'dined out' on the story. It still makes me smile today when I think about it.

In August 1999, I was fortunate to be diagnosed very quickly with PV. By the early part of 2000, decided to start a support group and, as they say, the rest is history. Pemphigus Vulgaris, and its relations, are a terrible autoimmune disease to live with. I was fortunate to have a very caring family around me but very soon discovered that was not the case for all patients. This is why PEM Friends quickly became more and more important as a sounding board for non-medical advice and online companionship. In fact, many friendships developed and these were cemented at our social events.



PEM Friends lunch at Peter Jones – November 2014
Left: (Blue top and scarf) Isobel, 3rd from left, back row, Prof Jane Setterfield, front row at right end of those seated Carolyn.

Unfortunately, I can't remember dates, but I started to arrange lunches for us to get together when we'd compare stories and support each other. There would be one lunch each year held somewhere in the Midlands and one annually held at Peter Jones (top floor restaurant) in London. Patients then didn't have to feel so isolated, although they had to make an effort to attend. Quite a few came with their carers, which was beneficial for them too, to meet other patients. Relationships also were developed with highly regarded professionals in the field and I believe these have lasted for many years. Sometimes one of them would be able to join us for lunch.



PEM Friends AGM - June 2022
From L to R Ingrid, Carolyn, Isobel, Trina, Andy

Where I was living, was running three Airbnb's. One of these would sleep quite a few guests and for some years, we'd have an 'away weekend' when everyone could stay together in The Stables. As well as the UK PEM Friends, one year the lady from Holland who ran a support group there, joined us. In addition, a commercial pilot from America came and, on another occasion, someone else from America too. I like to think that no one who attended ever felt isolated again as they now had new friends.

I was running a separate business from the Airbnb's, was involved with various local organisations and wanted to hand over to someone else. Isobel Davies, I had got to know when she attended a few of the lunches in London. After I'd had a few hiccups with others who'd tried to run the organisation, Isobel (BLESS HER!) offered to take over. It was she who turned the group into a far more efficient and successful one. In turn, Trina came on board to assist Isobel. After many years of really hard work with PEM Friends, Isobel decided to retire and Saint Trina agreed to take over from her. Am extremely confident that Trina will develop and grow PEM Friends even more - the magazine is a shining example of something Trina and Isobel, have produced.

In my wildest dreams, I could never have imagined just how far PEM Friends could develop and grow. The organisation now participates in research opportunities with drug trials and partners with other patient organisations globally. Don't forget to donate, if you're able - it's such a worthwhile cause.



[At one time, someone in America told me that Harold Pinter, as well as the drummer in Blondie, had PV. The latter didn't want any contact with us. However, through a journalist friend on the New York Times, he drafted a concise and excellent email for me to send to Harold Pinter. It did the trick and he became our Patron sadly until his death. If any of you know of a well-known person who either had one of our diseases or knows of someone who has, would you be prepared to contact them with a request to become our Patron? In my appeal to Harold Pinter, I stressed that he'd never be asked to give money or participate in an event.]

Good health and love to you all,

Carolyn x