

A HAPPY ENDING - MENTORING - PEM GRAND GET TOGETHER

PEM LIVES

ISSUE No: 8
CHRISTMAS 2023

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

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Puzzle page
Lily & Felicity
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Meet the PEM Council
And so much more...



PEMPHIGUS AND PEMPHIGOID
PEM Friends
You are not alone



PEMPHIGUS AND PEMPHIGOID

PEM Friends

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

Welcome to our Christmas edition of the PEM Lives magazine.

Another packed edition of our PEM Lives magazine awaits.

As always, we try to make this newsletter a balance of patient, organisation and medical inputs and a balance of reality and fun. I think the team has, as ever accomplished it.

The highlight for me, is always the contributions of our 2 little stars, Felicity and Lily. They always give us a perspective on our diseases, don't they?

Julie S has provided some great advice on the subject of hair products. This is an subject that regularly pops up in our conversations. I think we should make this type of review a regular item.

Lots has happened in the last few months and the British Association of Dermatologists Annual meeting was an important event in our calendar. You can read about that as well as the GRAND GET TOGETHER, held in September.

I can't wait to see the results of the current study into Bullous Pemphigoid and its triggers from the Centre of Evidence Based Dermatology and Dr Sonia Gran's team. Hopefully, her short summary will give you an appetite to go and find out more about their work on the CEBD website. There is much more already happened and more yet to come.

I'm sure you will also be tempted to order one of our PEM Journals. As Julie M regularly reminds us, keeping a record of our disease and treatment activity and all the other complexity that PEM brings to our lives is critical. As she always says, these diseases last a long time and there is such a lot to remember. I wish I had started all that time ago when my MMP started.

PEM Council members are keen to develop themselves and the organisation and Julie tells us about the mentoring programme she is undertaking and how it will benefit us all.

The ERN Skin/ePAG update from Laurence is a really important read. They have published a patient pathway for PV, amongst other things and their work will be the basis for a lot of what we will participate in in the future. We are lucky that BREXIT didn't isolate us from the good things going on across Europe in collaborating on our diseases.

Patient stories from Ingrid and Maggie also remind us about why we are here and why it matters. I think many of us share their experiences and it gives us hope for the future knowing how their stories turned out.

We want to ensure that PEM Lives remains interesting and relevant. Please let us have your feedback and do give us ideas about articles you'd like to see in our next edition. Or write something for us yourself. mail@pemfriends.org.uk

Enjoy reading PEM Lives Christmas 2023, and a Happy and Healthy New Year.

Isobel


PEM Council Report

By Isobel Davies

Phew! I think we seem to be doing more and more with less and less! It's been a very busy period, as always, but what a lot done!

We should all be very proud of what PEM Council achieve on our behalf – not to mention those kind and quiet volunteers who participate in Research Groups or provide 1-1 help with other PEM Friends who are struggling and need just a little more help.

Everything we do is done on a voluntary basis and from a place of compassion and care. We continue to run our weekly Zoom meetings, which are increasingly well attended. These hour-long meetings always seem to help those who attend, whether they are 'regulars' or people coming on the call for the first time or infrequently. (The Zoom meeting on 14th December is one not to miss. Mark will be taking over Andy's Quiz Master mantle. Better start revising!)

We now rotate the Zoom meeting hosting and UMBER has started to get us organised in terms of a rota. Despite being at a distance this winter, she has also helped with the production of this magazine, and her editing skills and eye for detail have allowed us to maintain a professional presence.

As well as taking Ocular MMP patients under his wing, Mark is also keeping an eye (no pun intended) on the research work at Birmingham being conducted by Professor Si Rauz. This, we believe, will be a huge step forward in the treatment of OcMMP and we wait with bated breath for successful results of the initial trial.



Julie managed to squeeze in a trip back to the US in between keeping our Facebook Group going (she is a fabulous gatekeeper) and organising the design and publication of PEM

Friends journals. She has been passionate about the need to record our disease and treatment journey for a long time and these journals are a good way to do this.

In addition to her work in maintaining our website, Ingrid took a short amount of time out for her son's wedding, in between representing our interests on the various medical working parties – the British Association of Dermatologists revision of their Bullous Pemphigoid Guidelines and the studies being conducted at the Centre of Evidence Based Dermatology into BP (Sue and Isobel are also involved in the latter). The results

of the Priority Setting Partnership (Blistering Diseases) have now been published with the final top 10 research priorities. This project also had a significant input from several of our very own PEM Friends.

Kal has now taken over from Andy in managing our budget and keeping us on track financially. He has been extra busy as we changed our bank account. It seems to be an extremely complicated and demanding exercise to find, set up and manage the move from one account to another and the 'fun' still goes on!

We met with our PEM Advisory Group once during this period and hope to establish a regular, twice a year meeting. It's good to know we have such eminent professionals who we can turn to whenever we might need their expertise and guidance.

One of the members of the PEM AG is Professor Jane Setterfield and, in November she treated us, as she has many times in the past, to a Q&A session via Zoom, to enable people to ask important questions about their particular case, or raise general queries about their disease or treatment. Over thirty people attended that call.



We hope that the next Zoom session will be by Dr Sonia Gran, another PEM AG member whose team are conducting important research into Bullous Pemphigoid (BP). The talk, in early 2024, will be about the most recent findings into medical triggers for BP. As always, PEM Friends have had an input into this research.

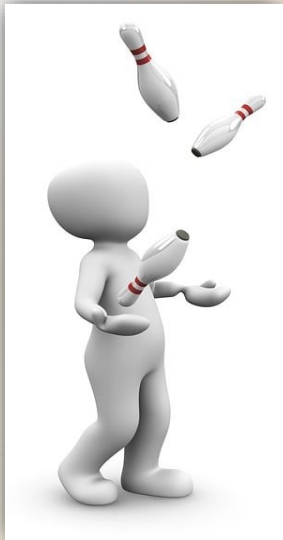
There have also been moments of real sadness and real joy in the last few months as Andy has left the group and Laurence has joined. I can't say enough about the strengths that Andy brought to the team. We are all very sad to lose him from PEM Council but we hope it is *au revoir* – not goodbye. And a very warm *bienvenue* to Laurence, who has joined us from the APPF – the French version of PEM Friends. Not only does Laurence bring a huge wealth of knowledge and experience to our group, her participation in various European activities, particularly the European Patient Advisory Group on SKIN, as well as being on the board of the IPPF is of enormous benefit to us.

Continued over...

PEM Council Report continued..

By Isobel Davies

The real highlight of the year was the Grand Get Together held in September. Some forty-five PEM Friends attended and we had 8 people attend in person while the others joined on Zoom. This involved considerable logistical demands and Trina, who was the host in Croydon, just about managed to avoid a nervous breakdown as she juggled all the elements, not least of which was a dodgy internet connection. PEM Council also spent many hours on Zoom, preparing for the event, the design, the technology, the scripts, the catering, etc.

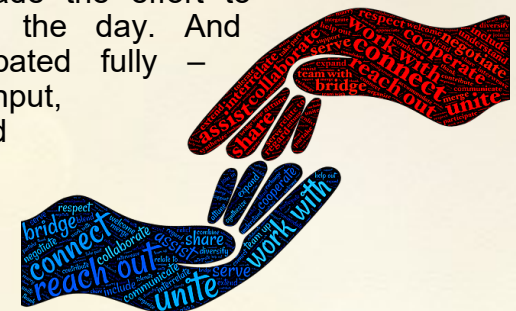


We were very thankful to the excellent session run by the delightful Rosie Hancock on Resilience, and to our hero Nigel Oakley who, despite falling downstairs the night before, ensured our multimedia miracle seemed like a normal day at the office. Thank you both.

PEM Council were magnificent. I am so proud of the work they do with no thought to reward or recognition. We met for the first time ever, face-to-face the day before and covered much of our important business, working as a team. Sadly, Laurence and Julie weren't able to be there in person but they stayed on the call for the whole period. The Grand Get Together was held together by the invisible strings being pulled by the PEM Council members as they stepped between their many functions – presenting, facilitating, feeding and trouble shooting.

And, last but not least, all hail those who attended and made the effort to travel down for the day. And everyone participated fully – with questions, input, comments and suggestions. Thank you to all that came.

I hope we can do it again next year.



www.pemfriends.org.uk

You will find a wealth of information as you look around the PEM Friends website.

Taking part in Beacon for Rare Disease's Patient Group Mentoring Programme



By Julie Martin

As a member of the PEM Council, I am participating in a year-long Mentoring Programme run by the charity Beacon for Rare Diseases. This is aimed at helping those involved in rare disease patient groups grow and progress the organisation. Participants start by choosing three goals they would like to achieve during the course of their development. I knew straight away what three goals I had in mind, especially my first goal, the result of which is now in boxes in my house waiting to wing their way to my fellow PEM Friends.

Goal 1 – Creating PEM journals for our group members.

My rare disease mantra is: 'keep a journal of your rare disease journey.' You can read the article I wrote about the importance of keeping a record of your PEM journey on our website. This benefits you and the medical professionals who treat you by providing a record of your day-to-day life dealing with your disease. Important information to include in your journal are your medications; if you are tapering or increasing; any side effects you are experiencing due to your medications; if you are in a flare or healing; what tests you've had and the results, etc. This will help you to keep track of the often long and convoluted journey through your life with PEM.

Thanks to a grant from The British Association of Dermatologists (BAD) fifty of our very own PEM logoed journals have now been printed and are available to our members in time for Christmas. We hope that most recipients will make a donation that we can use to invest in another print run.



Goal 2 – Forging links with Medics for Rare Diseases (M4RD).

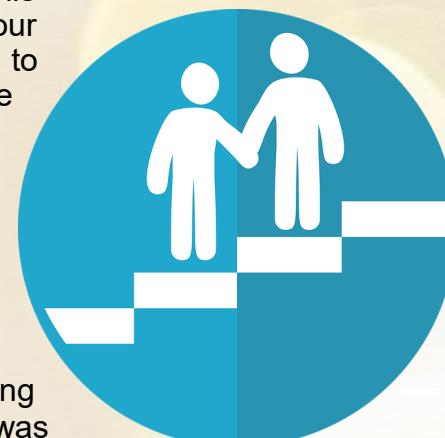
PEM Council benefits from forging links with other rare disease organisations, charities and patient groups. My choice to connect with M4RD stems from the need for people in the medical profession, especially those starting on their career path, to be aware of our rare diseases. Medics for Rare Diseases is a charity formed specifically to educate medical student and doctors in training about rare diseases. Our Photo Library, and Diagnostic tool on our website, is a perfect learning tool, and we want to spread the word. Now that the journals are finally here, I can concentrate on Goal 2.



Goal 3 – Creating Regional Groups and Buddy Networks.

The idea of regional groups and buddy networks has been in the pipeline for a while, and with the support from my two mentors, I will have guidance to help get these two concepts up and running, but this depends on the participation of our members. Do our PEM Friends want to connect with others who share their rare disease on a local basis? Would people like to link up on a one-to-one basis, especially at the start of their PEM journey? We will be looking for PEM Friends who might like to take part. Tell us if you are interested in getting involved.

I'm halfway through the Mentoring Programme now. The first challenge was getting the journals into production. Now that they're here and ready to find their way to our PEM Friends, I can concentrate on my two networking goals.





A PV story with a happy ending

By Maggie Zwirek



Maggie before



Maggie after

In 1998 I was lecturing at the local college in Kent and when, in the summer term, I developed a sore under my tongue, I assumed that I had a mouth ulcer. Little did I know that this was the beginning of a very unpleasant and painful journey, but luckily for me there has been a happy ending.

As the weeks passed the blistering in my mouth became more pronounced and more painful. I found it difficult to talk. My eyelids also began to blister and blinking was extremely painful. I had to go on sick leave, because talking was too difficult and my voice was reduced to a cartoonish, thin, high-pitched squeak.

Visits to various GPs were initially unhelpful. During a six-month period I was diagnosed with mouth ulcers, thrush, herpes, depression, anxiety and dental problems. At one point my dentist even suggested that it was my wisdom teeth causing the problem and I was booked in for extractions. The only benefit of the dental surgery was that the sedation took a while to wear off and it allowed me to eat my first solid food for months – two family packs of liquorice allsorts! The dental anaesthetic was the only form of painkiller that I had during my illness. I lost over three stone in weight, plummeting to under six stone. I had not eaten any solid food in four months and had been living on sips of tea and milk.

So how did it all change for me? A locum doctor I saw took just one look at me and made an urgent referral to a maxillo-facial consultant at the nearby Queen Victoria Hospital in East Grinstead.

Following a biopsy, Pemphigus Vulgaris (PV) was diagnosed in January 1999. I was referred

urgently to Professor Black at the St John's Dermatology Unit, Guy's and St Thomas' Hospital in London. He was wonderful. I will be eternally grateful to him and the doctors and nurses at GST and QVH as they saved my life. I was prescribed a huge dose of steroids and the steroid-sparing

Azathioprine. Fortunately, I did not have any serious side effects. Although my face became swollen, my steroid energy meant that I decorated our new three-storey house in a week and our lawn was perfect, because I mowed it furiously in the early hours of the morning!

I took the medication for about five years, gradually reducing it until I was taking ten milligrams of prednisolone. The last phase of reduction took time. If I reduced by 1mg I found that I would have a flare-up. My late mother-in-law suggested that I reduced the drugs more gradually. Cutting up the 1 mg tablet and reducing the dose by 0.5mg every three weeks worked and eventually I was drug and symptom free. Clinical remission came in late 2004. I have been well ever since. It may return but I will be prepared to seek medical treatment quickly as I now know what it is.

I went back to work as a lecturer and later returned to nursing, as I had a very rewarding and successful career. I retired in 2020, although I still teach occasionally at the Royal Marsden Hospital in London.

I still feel indebted the NHS for the wonderful care I received post-diagnosis. Their expertise and skill has afforded me a happy ending.



“Following a biopsy, Pemphigus Vulgaris (PV) was diagnosed in January 1999”

The First Annual Grand Get Together

By Isobel Davies

Once upon a time, we had a little group called PEM Friends. It was a small group and most people knew each other, everyone communicated by letter or e-mail and we would meet once or twice a year at the founder, Carolyn's home and for occasional lunches. A dermatologist (usually Dr Jane Setterfield) would come along and chat and answer any questions that people wanted to ask.

Then the Facebook group was formed — and PEM Friends got bigger and bigger. Today we have over 600 members. About 100 of these members are actively involved in the conversations we have, sharing their experiences and supporting the group.



Umber & Mark welcoming everyone

As the group expanded, I began to think about how to bring all these people together, regionally or nationally. I thought it would be wonderful to build close connections and to enable people affected by our awful conditions to talk about their experience and to exchange notes with each other.

And this year, we were able to make it happen.

It started in the Spring with a grant from the National Lottery Community Fund. This made my dream of getting people together a possibility.

PEM Council put many hours into planning the event. Trina was the real star. She was able to secure a fantastic venue in a good location (Croydon) and worked her socks off to ensure the internet was sufficient for a mass Zoom get-together. We all practised for hours to get the agenda right and to figure out how to manage the breakout groups. THANK YOU TRINA AND PEM COUNCIL!

We also had the fabulous Nigel. Nigel is a technology and audio/visual genius who helped us put the costing together for the original grant application and then offered, with huge generosity, to manage all the event equipment on the day. After an initial day of setting up the equipment, he horrified us by doing a backward somersault down a staircase in the evening (it was accidental!). He still got us through the main day, albeit with a very sore back and stiff neck. THANK YOU NIGEL!

We met in the Thornton Heath Evangelical Church. It was a fabulous venue for our meeting with a hall and breakout rooms and plenty of windows through which the blistering sun poured in.

Even though it was early September (the 9th) and it turned out to be the hottest day of the year and we sweltered in the heat.



Thornton Heath Evangelical Church



Isobel & Nigel

Eleven people made the journey to meet up in person while 38 people joined us via Zoom.

Trina, Mark and Umber were our hosts at the venue and Ingrid, Laurence and Kal facilitated the Zoom breakout groups throughout the day.

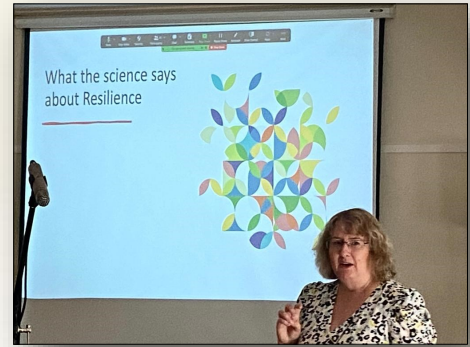
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During the day, we had several small surveys about people's experience of their disease. and there were several breakout sessions so we could chat in small groups about a particular item.

We started by explaining the objectives of the day:

- * Enjoyment
- * Sharing with others
- * Learning something useful

Our guest speaker, Rosie Hancock then ran a thought-provoking, educational and interactive session on Resilience.



Rosie Hancock

After the lunch break, we had a short video from Marc Yale of the International Pemphigus and Pemphigoid Foundation (IPPF).

We had conducted a survey of PEM Friends (the results are available on our website) about 18 months ago, and I presented the main highlights of the feedback collected through the survey.

We also had two smaller group meetings. One was according to disease type, with PEM Friends with PV/PF or with MMP or with BP chatting together, sharing experiences and things they had discovered which helped in managing their condition. The second small groups were divided by region. It was useful to start the regional conversation about the treatment and care situation in different parts of the UK.

It was a wonderful day, people were keen to talk to others, create new relationships and renew existing acquaintances. PEM Council, who had met for the first time ever as a team just the previous day, worked really hard to keep us on time and running smoothly. I think I speak for all of us when I say that, despite the hard work and heat, we left the event feeling quite a buzz.

The feedback from everyone who attended was constructive and very positive. If we can get more people to attend, we hope to have another GRAND GET TOGETHER in 2024.

A very happy ending. And also a very happy beginning!



Some of the zoom attendees



Trina & Isobel



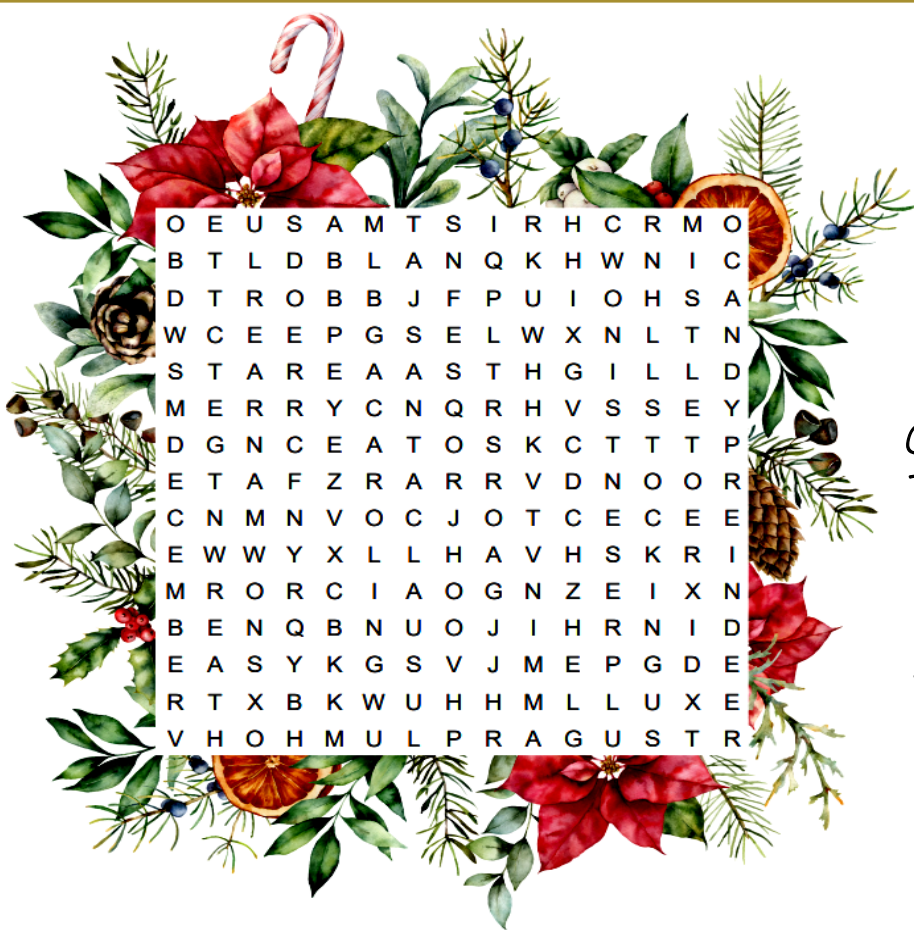
Ingrid leads one of the breakout groups



PEM Friends Cupcakes



After lunch stretching to get the brain back in gear.



Christmas Wordsearch

- | | |
|-----------|-------------|
| Candy | Peace |
| Cane | Presents |
| Christmas | Reindeer |
| December | Santa Claus |
| Holly | Sleigh |
| Lights | Snowman |
| Merry | Star |
| Mistletoe | Stocking |
| North | Tree |
| Pole | Wreath |

Christmas Code Breaker

Can you work out the message using the code?



Christmas Bauble Maze

Can you work your way through the Christmas bauble to get to the present?



Letters from Felicity and Lily

Dear PEM Friends,

I hope every one is excited for Christmas:
I've been a good girl and got invited to
Lapland U.K. It was really fun making gingerbread
and helping the ELVES make toys. I went ice
skating and met Father Christmas. Merry
Christmas Lots of Love Felicity Xx

by felicity

Felicity had an amazing time in Lapland!



Merry Christmas Pen-Friends! ❤️

I hope that everyone has a happy
and itch free Christmas and new year!

Lily

British Association of Dermatologists

Annual Meeting - Liverpool July 2023

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**BRITISH ASSOCIATION
OF DERMATOLOGISTS**
HEALTHY SKIN FOR ALL

We were keen to be present at the annual meeting of the British Association of Dermatologists (BAD) again this year as being at the event enables us to get up close and personal with dermatologists in the UK and also with other Patient Support Groups (PSGs).

This year, our stall was organised by Andy, although he wasn't able to attend in person for the main part of the conference as he had just received rituximab treatment and it isn't a good idea to expose yourself to crowds of people who may contain germs! (Last year, Isobel and Phil returned from the BAD conference with covid).

But that doesn't mean that Andy escaped heavy involvement as he was the one who set up and dismantled the stall and made sure we had plenty of materials useful to doctors there, as well as plenty of PEM Friends pens – which tend to go like hotcakes.

When Andy got to the hall he found that some 'kind' exhibition company had stacked about 30 chairs in the space allocated for the PEM Friends' stall. Nobody seemed to know why the chairs were there, so he 'enthusiastically' relocated the chairs, found our trestle table, set up the stall and left with his mask clamped on tight... time was of the essence!

Roshni, Alison and Pauline all volunteered to represent PEM Friends, be at the stall, chat to delegates and ensure we continue to build awareness of our autoimmune blistering diseases.

We created a WhatsApp group to allow our lovely volunteers to communicate effectively and therefore Andy was able to support from home, the PEM Friends at the conference. We also spent plenty of time prior to the date ensuring everyone was clear and well briefed.

Our volunteers were able to cover most of the meeting between them and did a fantastic job of building understanding and connecting with a very important audience. They also connected with the **Nottingham Centre of Evidence Based Dermatology**, who we work closely with, and the **Primary Care Dermatology Society (PCDS)** who had helped enormously with our own Diagnostic web pages and the Photo Library. The former

were also talking about the recent paper on the top 10 priorities for blistering disease research.

The whole 3 days of the conference went like clockwork and we achieved our objectives of 'recruiting' more dermatologists to our cause. Some were even persuaded by our 'sales' team to sign up as subscribers.

Pauline said about her experience:

Liverpool is just a short ferry ride across the water from my home town, but as the ferries weren't running I drove through the tunnel instead. "When it was my turn to man the stand for PEM friends at the BAD conference in I felt a bit of trepidation as I had never been to anything like this before.

I collected my pass at reception and proceeded to look for our PEM Friends stand. Shortly after I arrived people were milling around getting cups of tea so I managed to ask a few if they had ever heard of PEM friends and to those who hadn't I managed to explain a little about what we do, give them cards about the photo library and explain its purpose (to help with the diagnosis of our blistering diseases) and to help them access our website.

I wandered across to the Centre for Evidence Based Dermatology (CEBD) stand and spoke to Maggie (from the Nottingham Dermatology group) who gave me a copy of her leaflet on the top 10 research priorities for Pemphigus and Pemphigoid which I placed on our stand alongside Isobel's Hot off the Press leaflet on the same subject.

I visited Siobhan and Carol on the Primary Care Dermatology Society (PCDS) stand, next door but one to our stand, and had a chat with them too.

Although I only managed to get 3 people to sign up to our mailing list I felt that those I spoke to and gave photo library cards to showed an interest in what we do. Even though I had never done anything like this before I enjoyed it and would say to anyone that given the opportunity to help and volunteer in the future you should go for it as I felt it was really worthwhile to share our experiences of these awful diseases."

Roshni travelled from London and stayed for a day and a half. She said:

"I had a great couple of days at the BAD conference in Liverpool this year and it really made me feel good to give something back to PEM Friends when they had helped me so much over the past 2 years.

Continued over...

I arrived on my first day to be greeted at the stall by Alison who was already there. We spoke to lots of lovely medical professionals and told them all about PEM Friends and got them to sign up to the mailing list. The lunch provided on both days was very good and there was unlimited tea and coffee!

I stayed overnight in Liverpool not far from the venue and enjoyed some rare 'me time'.

On the second day in the morning I attended a couple of lectures in the main theatre hall. I listened to Dedee Murell's talk and it was so positive to hear about lots of research and trials that are going on for the different types of PEM that avoid long term B cell depletion."

Events like these are enormously valuable in

reaching audiences who we want to tell about our diseases and treatments. This does cost quite a lot of money and we value all the donations from our members as these help us to attend.

We also depend on the wonderful contribution of our volunteers. This year Andy, Roshni, Alison and Pauline did a great job (Umber had also volunteered and acted as a 'reserve'). It was hard work but I think the volunteers who attended would affirm that it is also good fun and interesting.

If YOU would like to get involved next year, please do get in touch. We would really like to have PEM Friends represented. The BAD Annual Meeting in 2024 will be in Manchester from 2nd to 4th July.

Meet the PEM Council - Ingrid

My name is Ingrid and I live in Leicester. In April of 2015 when I was 55, I was diagnosed with Bullous Pemphigoid. I had blisters all over my body when I was hospitalised on April 8th. 55 is comparatively young for the Bullous Pemphigoid as it is usually considered to be a disease of older people. The previous year had been extremely stressful and, although there is no proof, my friends, family and myself believe that stress played a big part in me developing BP. Towards the end of 2014 I developed an itchy red patchy rash. It started to spread so I went to my doctor.

I was given some gentle steroid cream but the rash spread and got itchier and various things were suggested for its cause, like eczema, contact dermatitis and scabies. Scabies is a quite common mis diagnosis of a bullous pemphigoid rash. Many family doctors know little or nothing about the disease, let alone having seen someone with it.

At the end of March 2015 I flew to the island of Madeira for a week's holiday. I still had the bad itchy rash and one (and I emphasise one) blister appeared on the day we flew out.

Hindsight is a wonderful thing and If I had known what was going to happen, I wouldn't have gone on holiday, but most of these "bullae" appeared whilst I was in Madeira, leading to one of the worst weeks of my life. Within the space of a week I had gone from 1 blister to being covered from head to toe in them.

The itch was appalling and I couldn't sleep. Having something so drastic happening and not knowing what it is is one of the worst feelings in the world. Indeed feeling alone is one of the worst factors in having a rare autoimmune blistering disease, and finding people with the same thing is such a relief and comfort, hence the need for patient support groups.

The flight home was horrendous (people staring etc.) and I waited three days for the doctor as it was Easter Saturday 4th when we flew back. On Tuesday 7th April I got an appointment with my doctor. He took one look at my skin and realised I needed help quickly. He got me an emergency walk in appointment for dressings to be applied. I still remember the look of shock on the face of the nurse who came into the room to dress my blisters. Next day at the hospital the clinician who saw me was nice and I found out is a top expert in the field of AIBDs. She asked the poor student who was with her to count my blisters. I had 467! I was immediately admitted to hospital, which was a relief to be honest, as I had found out that Bullous Pemphigoid can be fatal. I was put on a wheelbarrow full of drugs, including steroids which helped the blisters to disappear quickly but have side effects. I was given steroid creams but the pharmacist at the hospital did not realise the extent of my blisters and thought that one 20mg tube was enough! My blood pressure had to be taken on my ankle as that was the only area without blisters available, and the nurses had to aspirate the blisters meaning I needed a change of sheets every few hours!!

My diagnosis was Bullous Pemphigoid with gingival inflammation. My gums and mouth are also affected with inflammation and blisters. I knew I wasn't infectious but people stared and some even



Continued over...

asked!! It's very hard to deal with and I wasn't always polite in my response. In the end I spent nearly 3 weeks in hospital in 2015 and my whole life had changed. Medications, side effects, constant tiredness, retirement. The list is endless. The itch is so hard to deal with, but I found cool pads helped and once home I lay on sheets on my sofa which I got especially as the cream and weeping blisters meant that wearing clothes was very difficult.

It's been a bit of a roller coaster ride since I developed BP. 8 years on and I still live with the consequences of this condition. The disease has had a significant impact on my lifestyle, including early retirement. It's very hard when you no longer have blisters to explain to some people (including my work's occupational health), that it's a bit more than 'just a bit of a skin complaint'.

For the last few years I have been pretty stable, but tiredness is still a constant reminder that I'm living with an autoimmune disease. Steroid side effects have left me with diabetes and high blood pressure, but they saved my life. Quite a large part of my life is now taken up with maintaining the PEM Friends website. Helping others who have the same condition can be very satisfactory.



Hair product review by Julie Singleton

My name is Julie, I'm 41 and I have had PV for 3 years. Alongside all of the blisters and the chronic tiredness, the thing that I have struggled with the most is hair loss and hair quality. Drug induced alopecia took me by surprise, I had always had big wavy hair, which was now coming out in clumps. I thought I would share the products I have been using recently. Some of these products were to make me feel more "normal", others were to try and help with the alopecia.

Alongside my medicated pink shampoo (Dandrazol), I started using Aveeno Oatmilk Shampoo as a second wash, as my remaining hair was dry and straw-like. I then followed up with the Oatmilk conditioner and would leave it on for the rest of my shower, anything to try and get moisture into my hair. I have found the Aveeno hair products to be gentle on my scalp and my hair, they leave it softer and they have a nice smell, which when everything else smells medicated, makes a nice change. If you have fine/not frizzy hair and need a lighter version the Rosewater and Chamomile is a very good alternative.

I have used 2 different conditioning masks on my hair whilst I had blisters on my scalp. I liberally apply the product to the ends of my hair just once a week avoiding the scalp completely. The first, which has been a trusty hair mask for many years, is the Superdrug Extracts Argan and Amla mask. This is a very reasonably priced hair treatment that leaves hair feeling softer after use. It does have nut oil in it, so please check the ingredients before use to make sure you have no allergies. They have other versions in the range that may be more suitable.

The second one is Healthspan Intensive Repair Conditioner. This is a very thick intense moisturiser for hair and is not suitable if your hair gets greasy easily as it's very heavy. I have fine hair, and use this when my hair really needs the moisture, rather than every week. I really notice the difference when I have used this product.

Since my blisters at the front of my head have healed and cleared I have also been using a rosemary hair oil to aid hair growth. I did not try this on just one side of my head to compare, so I cannot



Oct 2022 - Nov 2023

guarantee the growth results, but I have included the photo to show the difference in a year. I was given the Hairsyrup Growsmary by a friend who had been secretly researching Alopecia for me. It's a pre-shampoo oil that you rub into the scalp and leave for an hour or two before shampooing out. Doing this twice a week and giving the scalp a massage as you apply is good for stimulating the scalp and encouraging regrowth. Hairsyrup also has an oil called Rapunzel which has grapefruit extract if you are unable to have Rosemary as an active ingredient.

WOULD YOU CONSIDER REPRESENTING PEM FRIENDS IN YOUR AREA?

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Help us:

- Have eyes and ears on what's going on in your area
- Build awareness with local medical professionals
- Know who the PEM Friends are in your locale.

This is a new endeavour and we will start with a discussion about how it might work. Come to a Zoom chat and offer us your thoughts with no commitment.

Contact us at: mail@pemfriends.org.uk



In Memoriam

We would like to mention the sad passing of two much loved Mothers in the last few months. Both struggled with the challenges presented by Bullous Pemphigoid in their latter years.

David lost his Mum, **Ethel Aston**, in October. Ethel was an accomplished seamstress and also enjoyed gardening, reading, cake decorating and was part of the Ladies Group at her local church.

Ursula Bowett left a devoted son and daughter after her struggles with the disease. James and Sarah were very generous in asking for the mourners at Ursula's funeral in September to donate to PEM Friends. We are grateful for their consideration during their time of loss.

Our sincere condolences to David, James and Sarah.



PEM Friends Financials



June 2023 to November 2023

By Kalpesh Patel, our treasurer

Thank you

Donations continue to keep us afloat. A huge thank you to all of you for your generous contributions whether one off or, especially, by regular direct debit.

We continue to offer our support to anyone who suffers from PEM (and their loved ones) for free. But voluntary donations enable us to keep our Zoom calls, Website and e-mails going. We depend on the funds raised to produce at least 2 PEM Lives magazine every year. I'm sure you will agree what good value for money we deliver!

Thank you, too, to those who have donated towards the cost of producing and posting the journal which is available to anyone who wants to maintain the record of their PEM journey.

We attended the British Association of Dermatologists Conference in Liverpool and although Pauline, Roshni, Alison and Andy waived much of their expenses, we covered all the main costs. This involved providing materials such as PEM Friends pens, etc, to ensure that the Dermatology delegates had a reminder of our presence. Insurance also continues to be essential to cover any liabilities such as conference attendance. These conferences are critical to building awareness amongst our most important audiences. As well as the exposure to these delegates that they offer, they provide opportunities to network and make new connections, and we learn a lot from medical professionals and from other patient support groups.

Where possible, we try to cover costs from small grants as we did when Trina attended the Global Skin Conference in Brussels. These are hard work and very demanding and we know that Trina's costs exceeded the small travelling bursary available. We appreciate the effort and expense committed by Trina and her husband, Simon, to build our presence with important contacts.



We started this period in a good shape, thanks to the additional income from Mark's Marathon contributions (and all who sponsored him) and also the grant awarded by the National Lottery Community Fund.

We are also indebted to the kind and generous gift of £426 from the mourners at the funeral of Ursula Bowett. Our gratitude to her son, James and daughter, Sarah for thinking of us during such a difficult time.

The Grand Get Together in September was made possible as a result of the grant of £4,000 from the National Lottery Community Fund. Almost a quarter was used to ensure that as many people could attend as possible via Zoom. Those who attended in person will agree, I'm sure, that the venue was excellent (if a little warm!). Most people who came along waived their expenses. Much of the remaining grant was used for travel and accommodation costs.

For the year so far, ending on December 31st, our income has been £8727, and we have spent almost £6,000 of that on the various areas mentioned above, including Zoom, Website, Grand Get Together, attending conferences, insurance and PEM Lives edition 7 (the one you are reading now still to be paid for). We accomplish a lot with very little. Your donations are always gratefully received and keep us going.

One very important change in the last few months is the transition to NatWest. This allows us to continue in business with more ease, as well as not having to pay the £5 monthly banking charge that HSBC made.

The new banking details are:

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NEW
BANK DETAILS

We would welcome any contributions to PEM Friends no matter how small. Regular payments are even more appreciated.

YOU CAN MAKE A DIFFERENCE
DONATE

PEM news from Europe

By Laurence Gallu

PAGE 16



Work continues on in the **European Reference Network SKIN** (rare disease network ERN SKIN), and, in our case, the one focused on auto-immune blistering skin diseases (AIBD). I'll also summarize what has been going on in the **RareDerm Committee**, a sub-group of the Global Skin patient organization (Global Skin is the popular name of the IADPO – the International Alliance of Dermatology Patient Organizations).

First, I should tell you that I have joined PEM Friends (<https://www.pemfriendsuk.co.uk>) who, along with support from Prof. Setterfield endorsed my continuing work in the ePAG SKIN group. These are the patient groups working with the ERN's mentioned above. I am also on the IPPF board, serving on it since 2021. I am still a member of the French patient organization, the APPF.

Got that? A lot of acronyms but all important groups working on the future of pemphigus and pemphigoid treatment.

Recap about the ERN SKIN AIBD – I am what is called an “ePAG” SKIN representative of the European Patient Advocacy Group.

November 6, I was supposed to attend the ERN SKIN board meeting in Paris. Trains were canceled due to the Ciaran storm; so I emailed our Health Care Professionals to let them have my inputs to what the ePAG SKIN plan for the next 5 years.

Here are our road map points:

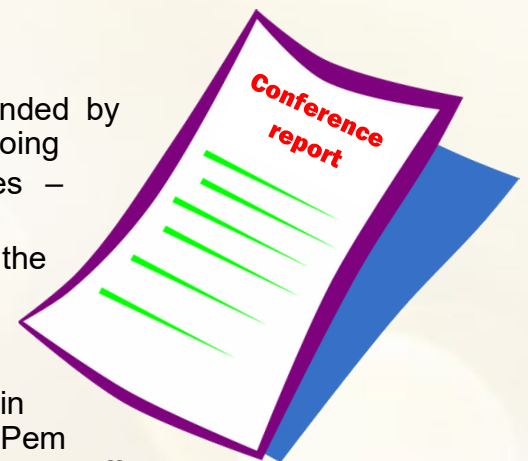
1. Improving patients' life by:

- a. Helping patients find the expertise they need and create a **map of expertise** for each of our rare diseases; this means gathering names & addresses of the experts/professionals we are used to work with and making a census of these experts. These lists will be used to create the map by 2026
- b. Working with Eurordis (a European Rare Disease organization) on **mental health** – this should be done by 2025 -<https://www.eurordis.org/mental-wellbeing/>
- c. Working on **palliative care** (pediatric & general) – should be done by 2025



2. Raising awareness on rare skin conditions by:

- a. Writing a **flash report** after each conference/congress attended by one of us – to put on the ERN SKIN website – this will be ongoing
- b. Informing about the patient burden in rare skin diseases – continue our shared work on **patient journeys**:
 - i. The Pemphigus vulgaris journey is done and is up on the ERN SKIN website as well as on the sites of PEM Friends and the IPPF
 - ii. We've started to work on the Bullous Pemphigoid (BP) patient journey with the French patient organization; I'm in the middle of translating it so that PEM Friends and other Pem patient organisations can add their input on the BP burden and difference in treatment – France being the only country (I think) who treats BP with topical CS as a first line treatment
 - iii. Then, we need to work on the MMP patient journey...
 - iv. This is an ongoing task since guidelines get updated
- c. **Pediatric** specificities – the AIBD group needs updated guidelines. The French have theirs but the ERN SKIN AIBD is still working on them
- d. **World Congress on Rare Skin Diseases**: 2024 & 2026 (Paris venue)



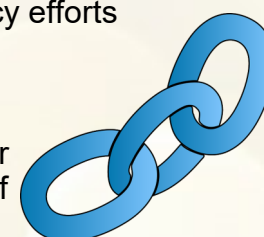
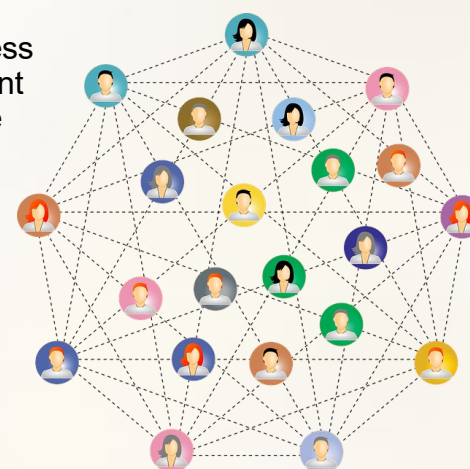
Continued over...

3. We're in **2 ERN Cross disease groups**: Pregnancy & family planning + mental health and well being
4. The **2 other issues** included in this road map are:
 - a. The lack of information regarding the impact of skin rare diseases on sexual life
 - b. The lack of information to teenagers who start their sexual life



Recap about GLOBAL SKIN/IADPO – RareDERM community (RareDERM = Rare Dermatological conditions)

1. **The Rare Skin Community** has been working on how it can address the challenges faced by both the patient community and patient organisations as well as provide what is needed to address these challenges:
2. **Key pains faced by the patient community:**
 - a. high physical, emotional and social burdens
 - b. significant stigmatization in many cultures
 - c. rare derm conditions are not taken seriously
 - d. inequities in access to rare derm treatments and care in comparison to more common conditions
 - e. lack of international treatment guidelines
 - f. lack of dermatologists specialised in rare derm conditions
 - g. lack of investment in rare derm research
3. **Key gains needed by the patient community:**
 - a. leverage collective power to address key problems faced by rare derm patient communities
 - b. more human, integrated, holistic care for rare derm conditions
 - c. clinicians and researchers interested in rare derm conditions
 - d. investment by pharmaceutical companies in research & devt
4. **Key pains faced by the rare derm patient organisations:**
 - a. lack of human and financial resources
 - b. many are volunteer-run organisations with limited capacity and capability
5. **Key gains needed by the rare derm patient organisations:**
 - a. secure funds to ensure organisational sustainability
 - b. connect with/reach people with rare derm conditions
 - c. have sufficient epidemiological data and patient evidence to support advocacy efforts
 - d. have sufficient advocacy know-how (e.g. engaging with pharma companies)
6. **Addressing these issues by sharing, connecting and acting:**
 - a. Sharing: provide the rare derm patient community with a platform for knowledge exchange, pooling of resources and the co-development of common resources
 - b. Connecting: connect the rare derm community to interested stakeholders and strategic opportunities
 - c. Acting: build a global registry for rare derm conditions; co-ordinate joint action to raise awareness about the burdens of rare derm conditions and the need for greater policy prioritisation of these conditions; provide a strong patient voice in global debates that impact on people with rare derm conditions



Most of these issues have been addressed by the GRIDD survey and are dealt with by the work we're doing in the ERN SKIN group.

Next issue, I'll write up an update of the October 2023 IPPF patient conference that I attended virtually.

Update from the Centre of Evidence Based Dermatology (CEBD): Research in autoimmune blistering diseases



Dr Sonia Gran

Completed research:

Dr Gran and team at the University of Nottingham have recently completed research funded by the National Institute for Health Research on **the association between medications/vaccinations commonly prescribed in older people and Bullous Pemphigoid**. The results are interesting and will be published soon. Please keep an eye out here:

<https://www.nottingham.ac.uk/research/groups/cebd/projects/blistering-diseases/medications-and-bullous-pemphigoid-risk.aspx>

It is hoped that the results will raise awareness among healthcare professionals of the risk of Bullous Pemphigoid following the administration of certain medications and will help patients to make informed decisions.

Current research:

Dr Gran and team are currently undertaking research, using GP records, on **the association between the Covid-19 vaccine and Bullous Pemphigoid, urticaria and shingles**. This work is funded by the National Institute for Health Research's School of Primary Care Research. We will be able to report whether or not there is an association between the different types of Covid-19 vaccines and these serious skin conditions. The project will end in September 2025 so please look out for the results on CEBD's website around that time.



Future research starting in January 2024:

2024

Dr Gran and team have also obtained funding from the National Institute for Health Research's School of Primary Care Research for a project to explore **the reasons for delay in, and barriers to, diagnosis in autoimmune blistering diseases (AIBDs) from the perspective of GPs as well as what tools could help GPs recognise AIBDs earlier**.

They will interview 15 GPs, from different parts of the UK, on a one-to-one basis for one hour online, to explore their views on the reasons and barriers associated with diagnostic delay and how to help GPs identify Bullous Pemphigoid earlier. We will make sure the GPs come from different backgrounds and types of practices and have different levels of experience. Patient co-applicants will help with writing the interview questions.



From this study, we hope there will be greater awareness of diagnostic delay for Bullous Pemphigoid amongst GPs, patients and dermatologists. The findings from this study will also contribute to a larger piece of research, involving patients and dermatologists, to help identify AIBDs. Earlier diagnosis is important as it may mean disease control is possible with less aggressive treatment and improved wellbeing, for example by reducing discomfort from blisters.



*Wishing all a Happy Christmas
& a healthy Happy New Year*

ORDER A PEM FRIENDS JOURNAL NOW!



Pemphigus and pemphigoid are long term chronic diseases. There is so much to remember along the way, from the initial symptoms, the various treatments and their side effects, the numerous Hospital appointment and conversations with specialists, etc, etc.

That's why we always recommend keeping a log of all the PEM related things that happen to you.

With the help of a very small grant from the British association of Dermatology, we have been able to produce our very own PEM Friends Journal

To order your own journal send an e-mail to:

Julie@pemfriends.org.uk

A generous donation of up to £15 would allow us to produce more journals for those who miss out on our first edition, along with covering postage and packing.

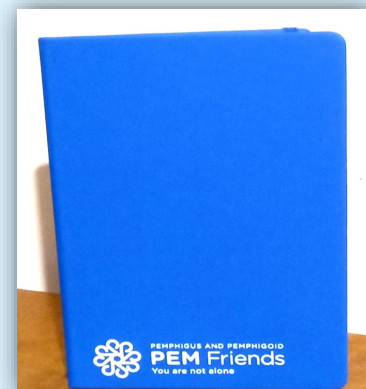
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Christmas 2023

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