

PATIENT STORIES - CHARITY STATUS - LETTERS - STEROIDS

PEM LIVES

ISSUE NO: 9
JUNE 2024

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

Inside
Research
Charity Status
Conferences
Patient Stories
Rare Disease day
And much more..



PEMPHIGUS AND PEMPHIGOID

PEM Friends

You are not alone

Registered Charity Number: 1207029

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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 Summer 2024 edition of PEM Lives.

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.

I always enjoy writing the opening introduction. Not only is it a chance to see all the contributions our wonderful PEM Friends make, as well as updates from our medical collaborators, but it also makes me think about what we have achieved in the 6 months before publication. As always, it's a lot. Even more than ever this time.

Our Editor, Trina, takes a lot of time and energy in making sure we have a broad range of PEM related interests for a wide audience, including medical inputs and those of patients and carers. As ever, we have an update from our little stars, Lily and Felicity, who remind us that these diseases can affect anyone, young and old alike.

The BIG NEWS in the last few months, is that we have become a Charitable Incorporated Organisation. I always said that becoming a charity would result in more work from an already beleaguered group of volunteers, but we feel that the benefits outweigh the additional management that is involved. It will, hopefully, open more doors to support and funding than before. Not that we need lots more money to do what we do. As you will see in the Financials update, we hope to get sufficient donations and grant provisions to pay for the essential things we do and rely on the goodwill and expertise of volunteers like our own Andy Heath, who is re-vamping our website as we speak, to create the changes we need.

We can also introduce to you a new member of PEM Council. Mike tells you a little more about his story and shows the importance of knowing as much as you can about the disease, finding an expert and actively managing your care. We are delighted Mike has chosen to become one of the hardworking volunteers that make up the group. Please join me in welcoming Mike.

Another development is that we are starting to create Regional PEM Communities. Our lovely Helen is forging the way in the North East. Let us know if you live in that area and want to know more, or if you would like to set up a group in your own area. We can help.

It is the patient stories that are really important to us, though. David's and Melanie's experience of Mucous Membrane Pemphigoid give us all an idea of what they have experienced and how it relates to us. It is their stories and Sue and Hamza's sad journeys too, that keep us going. Ingrid and Gail also talk about the psychological aspects of our diseases, which can be very challenging. We are all different but everyone has a story to tell. I notice a regular mention of the intense fatigue that so many of us deal with and is seldom recognised by others.

Continued over....

Welcome CONTINUED

Have you seen the Patient Journeys that Laurence reports on too? PEM Council ensures they are in the midst of worldwide developments in our diseases and tries to keep up to date on what is happening. The PV journey is already on the European Reference Network's website to act as guidelines for Dermatologists across Europe (and, for the purposes of medical advancement, the UK is, thankfully still in Europe with inputs to the ERN Skin from Professor Jane Setterfield). Next stop, Bullous pemphigoid and we will be asking some of you with the disease to input to the BP Patient Journey. Do take a look at the PV one. It's very comprehensive and a help for patients as well as physicians.

One goal we have undertaken later in the year is to try and change the current England and Scotland commissioning guidelines on Rituximab. The current process requires 2 alternative medications to have failed before trying Rituximab. This situation is different in Wales (and most of the rest of the Western world) and there is very strong evidence that using these "biologics" is much more effective in cases of PV, PF and MMP if used as a first line treatment. As many of us know, steroids are a vital but awful tool in the treatment kitbag, and other options would be much better. Trina reminds us of the need to wear ourselves off prednisolone at an appropriate (usually very slow) rate.

The BP studies running at Nottingham's Centre of Evidence Based Dermatology continue apace. We were hoping that the very interesting conclusions from the recent study into medications and the correlation with new cases of BP would be published by now, but, at the point of this PEM Lives issue, the scientific press haven't produced their paper on the topic. We hope to tell you lots more before the next PEM Lives edition.

Julie's mentoring programme, run by Beacon for Rare Diseases, helps us develop our abilities to support PEM Friends. You can see how this useful development has helped shape our work with the introduction of the PEM Friends journal and our intent to build Region-based PEM Friend communities.

I'm sure that, in our next magazine, I'll be telling you more about the many more activities we have in our 2024 plan, including attending 2 conferences (one is the British Association of Dermatologists Annual meeting in Manchester in July). It's going to be another busy Summer and Autumn!

As always, we really love to hear what you think of our communications and welcome feedback and, even better, offers of contributions to our next PEM Lives magazine.

In the meantime, put your feet up and enjoy reading this edition.



IMPORTANT ANNOUNCEMENT

The PEM Council are delighted to announce:

**PEM Friends is
NOW A REGISTERED CHARITY!**

Registered Charity Number 1207029



PEMPHIGUS AND PEMPHIGOID
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PEM Friends Financial Update Start of 2024



By Kalpesh Patel, our treasurer

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 are also indebted to the generous friends and family of Mrs. Marjorie Ives, for the financial gift from the mourners at her funeral. Marjorie's contribution efforts persist, even after her sad passing. Our gratitude to Marjorie and her family for thinking of us during such a difficult time.

For the period Dec 2023 to Mar 2024, our income has been £2443, and we have spent almost £1200 of that on the various areas mentioned above, including Zoom, Website, insurance and PEM Lives edition 8 (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.

Our banking details are:

Account Name: PEM Friends

Sort Code: 55-70-06

Account Number: 76236226

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



IN MEMORIAM

STEFAN TAUSHANOV

I received this desperately sad message from Stefan's beloved wife, Vasilka, just before Christmas.. Stefan had developed Paraneoplastic Pemphigus (PNP) in 2021, as a result of Leukaemia. This awful disease can only be treated once the underlying cause (cancer) has been controlled. The biggest risk, as Stefan and his wonderful wife discovered, was serious lung complications called Bronchiolitis Obliterans. Stefan suffered enormously and his family, Vasilka, Kristina and Mila with him. Vasilka and Stefan married in hospital in March 2022 and then at church in June 2023. What a love story!



Stefan & Vasilka



Stefan & Vasilka's wedding in hospital

Stefan and Stefan married in hospital in March 2022 and then at church in June 2023. What a love story!

This is what Vasilka said.

"With broken heart I want to tell you that Stefan has passed away on 06.12.2023 in Addenbrooke's Hospital. We fought and fought and tried and hoped and believed but he is gone now. The lung disease from the Pemphigus was still progressing somehow. And at the end of September he started to test positive for Pemphigus again. I have left the group as is very difficult for me to see it. But if someone sometimes need any help or advise around Paraneoplastic Pemphigus be free to message me. Pray for Stefan's soul"

The hospital have contacted Vasilka since Stefan's death to get approval for his files to be used in medical research, published in medical journals, and shared amongst Doctors around world. We hope that they can investigate and, hopefully, find a way to help someone else in future, with PNP.

Hopefully, we will be able to post future research using Stefan's story to further our knowledge of this truly horrible disease.

IN MEMORIAM

MARJORIE IVES

PEM Council and me in particular, were so sad to hear about the passing of Marjorie Ives. What a woman! She did so much for the cause of PEM Friends, and we will miss her enormously. My only disappointment is that I didn't meet this formidable woman when she was alive. We also thank her wonderful daughters, Justine and Alyson for their contribution. Marjorie's funeral raised a whopping £1,135 for us. I think she would be pleased. Margie stayed in touch and one of her last messages in April last year was:

"Dear Isobel sorry been quiet for a while, had a persistent cough from last October treated as chest infection then February diagnosed with lung cancer, terminal, having chemo now, so no boot sale again but my donations when time comes will be split between lung cancer and PEM Friends x Ironic really never smoked but there are other causes obviously, wish you well in all your good work and hope you get charity status one day regards, Marj Ives x"

God bless you dear Marj.

From her daughters, Justine and Alyson

"A few words about Mum: this is tough as Mum is not that easy to sum up in a few words!

We knew very little of PEM until after we lost our Dad, Roy Ives. Mum was determined to raise awareness & funds for such a good cause. When Dad was first poorly with BP we struggled with a diagnosis & we were left floundering until Dad was hospitalised at St Thomas', he then received fantastic treatment from Guys. If only we knew about PEM Friends then!

Mum was a huge supporter of smaller charities that were close to her heart. She was a fantastic wife taking care of my dad during lockdown & after. He was one of the first people to survive Covid as we went into Lockdown. They even appeared on Good Morning Britain together with Piers Morgan. Sadly, we lost Dad in October 2021. Mum asked for donations to PEM Friends in lieu of flowers for Dad's funeral & continued to raise funds through boot fairs & selling things online. Mum then became poorly a year after Dad passed. She was diagnosed with Lymphoma in March 2023. She died at home, just how she wanted it, surrounded by her family in December 2023. She left instructions that she wanted no flowers but donations for PEM Friends & Lymphoma Action. She also made Alyson promise, once the house is cleared, to continue to sell items of hers in aid of PEM Friends which Alyson is doing.

Mum & Dad both lived life to the fullest, and they were at their happiest when enjoying family times, holidays & entertaining. Mum loved nothing more than throwing dinner parties; she loved to eat out & socialise. They are both forever missed by all who knew them. We were totally blessed to have them as our parents".

Marjorie and Roy are also survived by their sons, Ian and Martyn.



Rare Disease Day February 29th 2024

February 29th was Rare Disease Day. PEM Friends marked the day by adopting spots (nice ones!)



As ever, we are very busy. There is still so much to do to offer support to our ever-increasing number of PEM Friends and to get the word out, especially to the medical profession.

PEM Council is the small, but perfectly formed, group of people who keep the whole thing moving forward. That, and those who do remarkable things to support, like the lovely Helen who is starting our first regional group in the North East. And Maddy, who is diligently making sure our Finances are kept up to date and accurate.

We also look forward to having a good and very productive time in July at the Annual British Association of Dermatologists meeting in Manchester. Alison and Helen will be joining Isobel to tell as many delegates there as we can about our diseases.

Probably the most important thing to happen in the last few months is that we have become a charity. You can read about that in this edition. It gives us more to do, but we hope to reap the benefits.

Still to come and taking up a lot of effort is the work being done by Ingrid, with a lot of help from Andy, to re-design the website. You will soon hear about our new look website, packed with more information for patients and clinicians and an easy to navigate structure. Watch this space.

Alongside the numerous web pages being written, we are also creating and updating our policies to ensure that we continue to operate with the greatest integrity and openness. You will be able to see key policies on the website but will make any others available if you want to see them.

We were very sad that the result of becoming a charity meant that we lost Mark. The demands of so much reading material, etc, caused Mark, with

his increasingly problematic vision, to make the very difficult decision that he wasn't able to take on the commitment of becoming a Trustee. We miss you Mark and are very grateful for your continued support, particularly to others with Ocular Mucous Membrane Pemphigoid.

We do have a new PEM Council member, and hope to be able to announce a second addition soon. You can read a little about Mike elsewhere in the magazine but he is already making an impact and we are really excited to have him join our merry little band.

There is still a vacancy for any of you who would also like to become a PEM Council member. We are particularly keen to have a representative from Scotland, Wales or Northern Ireland. We support patients and their loved ones from all over the UK, but nearly all PEM Council are from England. Laurence, our very active and well networked member is in France.

A few facts might be helpful:

FACTS

We have 677 Facebook Group members and new people joining every week. Some are active and some are not. All are welcome if they are patients, loved ones of patients or carers and live in the UK.

The mailing list is 322 people with an interest in PEM – either patients or medical professionals. 264 of these are UK patients or their loved ones. We use this subscription list to ensure we follow UK data protection laws.

PEM Council are:

Kal Patel, Ingrid Thompson, Trina Harris, UMBER Khairi, Julie Martin, Laurence Gallu, Mike Burnett and Isobel Davies.



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

It's not just the body

By Ingrid Thompson 

Many of us with PEM know how it can affect the body physically. As research into PEM develops, we are finding out more about the symptoms and treatments and what it does to our skin, but what do we know about the effect on our mental health? So, these are my thoughts from the mental health side, and it may resonate with you.



Firstly, I wasn't in a good place when I was diagnosed with Bullous Pemphigoid in April 2015. I'd had an extremely stressful year before and still wonder if that played some part in me developing the illness. Then suddenly being covered in enormous blisters when I didn't know what was happening to me was a profound shock. I'm not exaggerating. It was Easter time and

every year, I still struggle at Easter as the memories come back, however hard I try not to let them. Being covered in blisters can have a profound effect on a person. Many people also live alone and dealing with this by themselves is very difficult. What is happening? Can it be treated? All questions that run through the mind. The sheer discomfort, pain and that itch! I know there are some who just wish they were dead.

Treatment can make things better physically but this is by no means the end to it. It sounds dramatic, but I think I had PTSD. This leaves mental health issues and a fear that things may get worse again if treatment is stopped. In recent years talking about mental health issues has got easier but there is still the feeling by some that it shouldn't be discussed and it's something to be ashamed of.

The blisters being gone are by no means an end to things. Body image is generally poor and there can be difficulties with people failing to understand. If you look O.K. then you must be O.K. Many diseases, PEM included, come with underlying tiredness and problems that aren't visible. It's not like a pair of crutches, for example, which are obvious.

Finally, the Covid pandemic caused more problems to mental health as many people with PEM are on immunosuppressants which meant they had to shield very carefully and thus couldn't mix with others or go out for many months. Hence loneliness got worse for some, and often no distractions such as not being able to go out and socialize meant all you did was sit at home and think bad thoughts. I know it affected me.

There is help out there, however. PEM Friends private Facebook group offers immense support for people who live in the UK, just by connecting with other sufferers who understand.

There is also the International Alliance of Dermatology Patient Organizations who ran a **World Skin Health Coalition's #NotJustMySkin Campaign**. It highlights how skin conditions can rule one's life. If you are struggling mentally, please never be afraid to talk to others. More people may understand than you think.

“Firstly, I wasn't in a good place when I was diagnosed with Bullous Pemphigoid”

facebook 

The Nottingham Evidence Based Dermatology Studies into Bullous Pemphigoid



University of Nottingham
UK | CHINA | MALAYSIA

Work is still ongoing on the investigations into BP reported in previous PEM Lives Magazine. You can read more about the work so far on their website at <https://www.nottingham.ac.uk/research/groups/cebd/projects/blistering-diseases/medications-and-bullous-pemphigoid-risk.aspx>.

The latest study is due to be published and will report on the results of their investigation into links between drugs (especially those used by older people) and the incidence of BP. The results, I think, will be of interest to many people with a connection to Bullous Pemphigoid.

The paper reporting the study results has been submitted for publication as PEM Lives goes to press but are still awaiting news. We hope to provide updates on this paper soon. As soon as the paper is published, we will be communicating a lot of the information currently planned by the hard working team at Nottingham.



Dr Sonia Gran



Felicity wishes everyone a lovely summer!

Hi Pem-pals,

Hope you all are itch free and doing well this summer. In July I was taken off steroids and I have lost most of the puffiness. I've also been taken off of the Methotrexate tablets and been put on the Methoject injections which is a little bit like an EpiPen that I take every week. At school I'm deputy head girl which is very exciting. I've had a few new blisters but my skin is so much better now than it was before. I'm a bit fed up with catching every cold that goes around but, I'd rather have that than another flare up. I'm going to Disneyland Paris again this August so let's hope that the sun doesn't cause a flare up. I hope that you have a happy and itch free summer! From Lily J.



PEM News from Abroad

by Laurence Gallu

ERN SKIN news - Auto Immune Blistering Disease thematic group



European
Reference
Networks



European
Patient
Advocacy
Group

1. Rituximab update

The European Reference Network - SKIN schedules yearly scientific webinars for each themed group. Our themed group is Autoimmune Blistering Disease, and in February (2024), Professor Joly presented the results of his study showing the efficacy of Rituximab. The results will soon be published, and we expect that these will be quite positive and hopeful for PV patients.

The objectives of his talk were:

- To assess the long-term efficacy and safety of the Rituximab 3 treatment regimen used as a first line treatment
- To compare the evolution of patients treated with Rituximab as a first line treatment versus a second line treatment (patients initially randomized in the prednisone group, who were secondarily treated with rituximab after they had relapsed)
- To evaluate the interest of biomarkers as predictors of short and long-term relapses in order to use a personalised maintenance treatment strategy with Rituximab to avoid relapses (biomarkers are serum samples collected for measurement of anti-Ds1 and anti-Ds3 IgG antibodies and more complex other biomarkers)

To be continued once these results are published.

2. ERN skin patient satisfaction questionnaire

In the UK, this would concern patients who consult Professor Setterfield and/or her team at Guy's and St Thomas' NHS Foundation Trust – Dept of oral Dermatology.

This questionnaire aims to measure the level of patient satisfaction after consultation in an ERN-Skin centre, in order to improve their quality of care and performance. It has been elaborated by SKIN ePAG advocates!

The questionnaire has 26 items and it is divided in 4 main sections:

- General information on the patient
- Consultation and follow-up (19 questions)
- Treatment prescription and therapeutic research (5 questions)
- Global satisfaction (2 questions).

A short blank section is available at the end of the questionnaire to add any comments.

The data will be processed by the ERN-Skin coordination team.

The survey should be given to every patient attending the clinic. Please let us know if you haven't been asked to complete it.

3. Patient Journeys

Developed by our SKIN ePAG (ePAG = European Patient Advocacy Groups, the patient's voice at the heart of the ERN activities, working in partnership with clinicians and researchers).

These journeys are an innovative approach to capture the natural history of a rare condition and the needs of patients through the day-to-day experiences and life-lens of people living with a condition. They offer a patient-driven view of a rare condition, identifying the common unmet needs to address healthcare gaps and enhance health services by concentrating on the patient's daily life perspective.

PEM Friends is working on the BP patient journey (elaborating on the French patient organisation, the APPF's ground work), and will then start working on mapping the MMP and the OCMMP journeys. We do need volunteers...

If you are interested in participating in the elaboration of these journeys, contact Isobel at mail@pemfriends.org.uk

Continued over...

IPPF patient conference days – October 2023

Isobel and I attended the virtual IPPF Patient Conference. Some of you may have also attended via Zoom. It lasted 3 days and was “action-packed” with speakers that are experts in the pemphigus and pemphigoid (P/P) field, and this year patient panelists were invited to share their perspectives during the Q&A section of the presentations. The patient perspective was one of the focus areas of the conference to go along with this year’s theme: “**Empowering the Patient Voice**” (IPPF Quarterly 4 - 2023).

It was a balanced mix of patient stories and doctors’ updates about our PEM diseases. These patient Conferences are quite informative and well worth attending if you have the time. You don’t have to be present at all sessions. Donations are suggested but there is a no pay option. People who can afford it will give more money anyway so that others can attend for free.

In 2024, the Conference will be “hybrid” (in-person at Newport Beach, CA, and virtual) and will take place on **October 26 & 27**. You can register now at <https://www.pemphigus.org/2024-patient-education-conference/>. We recommend it.

Highlights from last year’s event:

- **Oct 27:**
The Conference was introduced by Marc Friedman’s powerful story and his battles to get his PF & PV under control thanks to “rituximab or a similar biologic” and to “having a lust for life!”. Throughout the first day, we had presentations on:
P/P Disease Overview and Subtypes; the Trauma of Skin Disease and an Embodied Approach to Healing; Steroids and Managing Their Side Effects; Biologic Agents: IVIg and Rituximab Nutrition, and an IPPF Peer Coach panel
- **Oct 28: sessions on:**
Caring for Your Skin and Wounds; Antibody Recycling for Potential Treatment of Pemphigus Vulgaris; Immunosuppressive and Anti-inflammatory Agents – why do we use them?; Biosimilars; Oral Disease and Care; New Treatment Strategies for Ocular Disease
The final session of the day was a participatory event that connected attendees on Zoom
- **Oct 29: sessions on:**
Emerging Therapies in PV and in Pemphigoid; Understanding the Role of Patient Data in Drug Development; Patients and Clinical Trials

Other IPPF news:

The IPPF recently published the revised *IPPF Guide to Pemphigus and Pemphigoid*: it is intended to provide medically-reviewed information relevant to the most common questions people have when first diagnosed with Pemphigus and Pemphigoid (P/P), as well as educational information about ongoing disease management and treatment options. <https://www.pemphigus.org/patient-resources/> Do take a look. There is a lot of useful help published there, including a link to our own Photo Library.

The IPPF holds monthly *Patient Education Webinars* – this year, for instance, webinars about the following topics were proposed and can be watched in replay:

- Eye Disease and Treatment for Pemphigus and Pemphigoid (March)
- Skin Care for Pemphigus and Pemphigoid (April)
- Introduction to PV (February), to BP (January)
- Mental health when you have a skin disease (February)
- Tips & tricks by the IPPF peer coaches (February)

<https://www.pemphigus.org/patient-education-webinars>



Sue's Story

by Sue Abbott

I am aged 65 and my story began in May 2023. My face started getting quite blistering and I thought my Rosacea which I was diagnosed with in 2019, had flared up.

In Oct 2019 my husband passed away very suddenly and I was left in utter shock. Then in March 2020 Covid hit, and I found myself alone for a lot of the time. It was an awful couple of years.

In June, 2023, I was going to Spain with my friend, and I was very much looking forward to it, as I hadn't been away for so long. I boarded the plane with my face covered in spotty and blistering type things all over it, even a thick layer of foundation to disguise it didn't do a thing.

The heat in Spain made my face 10 times worse. I wouldn't go out in the sun and only ventured out at night. I even paid to see a Doctor privately, but he really wasn't sure the cause of my very bad skin. My scalp was sore and flaky, and I had blisters across my shoulders, behind my ears, and even in my eye sockets.

When I got home to England I went to A&E as I was so worried. I was referred by Queens hospital in Romford to see a Dermatologist ASAP. I had blood tests and photos taken and was given an appointment to have a biopsy of one of the larger blisters on my back. Within a few weeks I was diagnosed with Bullous Pemphigoid. It was something I'd never ever heard of. The Dermatologist explained what this rare disease was all about, and I was mortified.

Since my diagnosis, my condition has become very bad. I was put on Prednisolone 40 mg a day, Doxycycline x 2 a day and given gels for my face and body. At first my skin got a little better, and I was advised to reduce my steroids slowly. I saw my Dermatologist just before Christmas who said I did not have any immunity to Shingles and I needed to get this jab as soon as I could. I had to be steroid free before I could do this so carried on reducing my dosage until I was down to nil.

By now I was getting huge blisters on the back of my right leg. I had many blisters across my back and neck, my scalp was flaky and sore and itchy, I had tiny blisters in my eyes, back of my ears and even in my throat. My tongue has a continuous blister on the tip and I have lost my sense of taste and can no longer eat so certain foods. I have also lost 2 stone to

date.

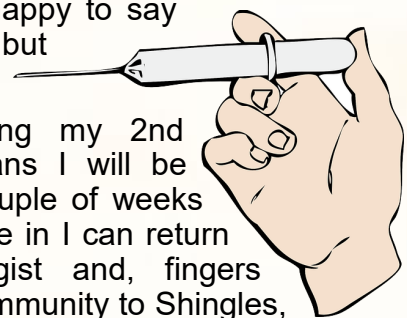
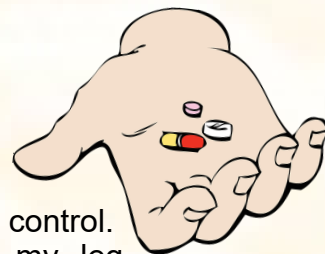
I had 7 months off work as I felt so ill, and the constant tiredness was impossible to control. The blisters on the back of my leg clustered and ulcerated. I was in so much discomfort. I needed painkillers before bed which was the only way I could get any sleep. The painkillers made me badly constipated which is yet another pain to endure, I even ended up in A&E with the constipation, I was in agony!

I was having my leg dressed twice a week by my Nurse at my surgery, but the stubborn wound would not heal. I am a type 1 Diabetic which was slowing the healing process. I was referred to the Tissue Viability Team and have been attending the clinic twice a week to have dressings and pressure dressings put on. I am happy to say that my leg is slowly but surely healing now.

Next week I am having my 2nd Shingles jab which means I will be having a blood test a couple of weeks later. Once the results are in I can return to see my Dermatologist and, fingers crossed, if I show some immunity to Shingles, I can be started on the autoimmune drug Mycophenolate Mofetil. I pray this medication agrees with me and that some if not all of my symptoms improve or even disappear. I retire on 4th July after being in my job as a Health Visitor Clerical Assistant for 32 years. I was so looking forward to having time to myself to go shopping, maybe join a club or two, help out with the Grandchildren and see friends.

At the moment though, I have lost my confidence and rarely go out alone. The disease has affected my sight and I have blurred vision, another reason I hardly go out. I was referred to see a specialist regarding the blisters in my mouth and eyes, but after 9 months I haven't heard a thing.

I hope my story has explained a little about this horrible disease that for me, came out of nowhere. Good luck to all that are going through a difficult time.



My year in Beacon for Rare Diseases' Mentoring Programme

By Julie Martin



Beacon for Rare Diseases is a UK-based non-profit organisation whose main aim is to offer training to help rare disease patient-led groups to grow, professionalise and forge links with the wider medical and rare disease community. This is achieved through their training programmes and events, in person and online. Each year they offer a year-long mentoring programme pairing members of rare disease patient advocacy groups (Mentees) with professionals (Mentors) in charity management, medicine, fundraising, communication, consultancy and other relevant occupations.

Further to my article in the last PEM Lives magazine, I've now finished my year-long mentoring programme with Beacon, where I met with my two Mentors, Ankita Batla and Andy Milligan, via Zoom throughout the year, working to attain my three chosen goals.

So, what was achieved in that year? The highlight has got to be my first of the three goals, the production of our own **PEM Friends logood journals** available to our members to record their disease journey. It can be very empowering to have all that information in one place, as these are chronic diseases that can last years, if not decades, and much can be forgotten on that long road. I hope those who have acquired a journal have found it helpful, and we still have journals available for those who would like to keep a log of life with PEM. If you are interested in a journal, please feel free to email me at julie@pemfriends.org.uk.

I even premiered the journals at a Beacon event in November, and there was much interest with the idea of journal keeping by those at the event, including other patient advocacy groups.



Isobel, Julie & Mentor, Ankita Batla

My second goal was to forge links with the charity Medics for Rare Diseases (**M4RD**), and I met up with some of their members at the Beacon event where we swapped contact details. I've had an initial Zoom call, and I look forward to working with them in the future. PEM Council is particularly interested in linking up with medics who have an interest in Dermatology and Dentistry, and they were very impressed with our photo library and diagnostic tool on our website.

Goal number three is just starting to take off, the setting up of regional groups, and I'm happy to say one of our core members, Helen Robinson, has taken on the organisation of the **northeast regional group**. She has organised the first face to face get together on May 18th. We look forward to hearing about the meet up in our next magazine.

Have you considered joining PEM Council ?

Join our great team and make a real difference to PEM Friends (and the world!)

- Contribute your ideas towards our future plans
- Ensure that PEM Friends delivers its support with care, compassion and efficiency.
- You may want to lead a specific activity or project.

To find out what's involved, e-mail us at: mail@pemfriends.org.uk

Becoming a charity

By Isobel Davies

It's official! On 15th February 2024, PEM Friends became a Charitable Incorporated Organisation (Foundation).

Being a charity was something we have resisted for a long time. We had anticipated that, at some time, we would need to face the need to formalise our work, and the effort involved was pretty daunting.

We have spent the last few years behaving as if we are a charity and creating the processes and policies that charities and small businesses adopt. We were told we had little re-organising and setting up systems in order to function as a charity because we were so well organised and reasonably disciplined.

Once our income went above £5000 due to grants and some very generous donations last year, though, the need to register became inevitable.

The first thing we had to do was to decide what sort of charity we should be. There are several types. It was quite a dilemma, and we are very grateful to the assistance given to us by Brian Seaton of Small Charity Support <https://www.smallcharitysupport.uk>. He gave us loads of reassurance and guided us through the options and implications. Thank you, Brian.

Eventually, we decided to apply to be a Charitable Incorporated Organisation (Foundation). That meant all of PEM Council being Trustees and the main decision makers for our plans and operations. We are unusual in that the Trustees and the people doing the main work in keeping PEM Friends operating are the same. I can't emphasise enough how much commitment and effort this small team of volunteers provide to keep PEM Friends going.

Completing the Charity Commission registration application with a deadline of the day before Christmas Eve was a daunting task, but we managed to get the form in with an hour to spare. The reward was a positive response and registration commencing on 15th February.

As I write, we have applied for HMRC registration too, which will enable us to claim Gift Aid on any donations we receive from UK taxpayers.

We hope that, by becoming a charity, we will be able to access more support than before and that the increased workload isn't too challenging.

The PEM Friends Board of Trustees is:-

- Kal Patel (Treasurer)
- Trina Harris
- Ingrid Thompson
- Umber Khairi
- Julie Martin
- Laurence Gallu
- Isobel Davies (Chair)

And we hope to add our new PEM Council members to the list soon.

Editors note: On behalf of the PEM Council and PEM Friends we would like to publicly thank you Isobel, for all the time you spent, especially during the Christmas period, to get all the paperwork in order ready for the day before Christmas Eve deadline! Thank you Isobel xx



Update on the Birmingham and Midlands eye hospital research

By Isobel Davies



We reported in the third edition of PEM Lives about the research being done by Ms Saeeha Ruaz at Birmingham. This is intended to help people with Ocular MMP and, we hope, will stop the scarring that causes the eye damage. You can read more about this work on the Sight Research UK's website, as well as a blog from our own Mark Noble in support of the funding application. <https://www.sightresearchuk.org/research/ocmmp/rauz/>

You will read in this edition of our magazine about the awful consequences that OcMMP can cause.

Firstly, for those waiting for a referral to Ms Rauz's clinic, for numerous unavoidable reasons, there is a long wait list, but she and her team of specialist ophthalmologists are trying to work through this as quickly as possible. Please be

patient. Our usual advice to call her secretary is unlikely to help in the circumstances.

The research is currently on a brief hold called for a final inspection by the Medicines and Healthcare Products Regulatory Agency (MHRA). As soon as this is concluded, they (and we) will be announcing the start of the study, hopefully, at the end of June. Once announced, work will be full on to enrol trial subjects at Birmingham (and probably Liverpool and Moorfields) as the timescales will be very tight. The team needs 12 months to analyse samples, so they hope to complete patient visits by the end of October, although this may have to slip due to the time pressure.

We will try to keep you updated so you know when they are recruiting for the study.

Watch this space.

Would you like a unique Journal?

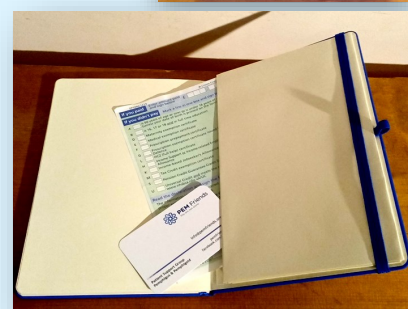
Pemphigus and Pemphigoid are long term chronic diseases. There is so much to remember along the way, from the initial symptoms, the various treatments and their side effects, the numerous hospital appointments and conversations with specialists, etc, etc. That's why we always recommend keeping a log 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.

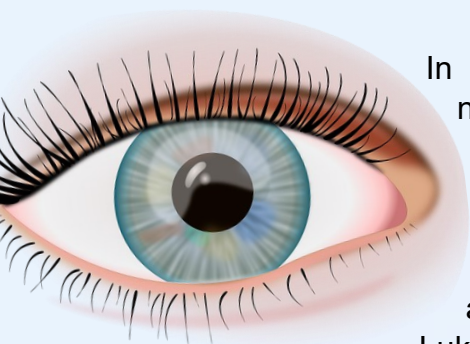
Bank: Natwest
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Sort Code: 55-70-06
Account Name: PEM Friends
Please put '**Journal Donation**' in the reference.



It comes with a handy pocket!!!

Melanie's Story

By Melanie Hunt



In January 2021 I noticed a few inward turning lashes on the lower lid of my right eye which were causing irritation. I arranged to see Mr Luke Clifford at

Basingstoke Hospital for a course of electrolysis to try and kill off the lashes. These sessions continued regularly to coincide with the growth cycle of the lashes.

In Spring 2021, I started to experience spontaneous and progressively worsening nosebleeds (right side only). I made absolutely no connection between these two things. I didn't believe the nose bleeds to be serious and as it was during Covid, I didn't consult a doctor about it. I felt perfectly well.

In May, at a lash appointment, Mr Clifford noticed some scarring inside the lower lid of my right eye. I had noticed this myself a few days prior to the appointment although I had no idea what it was. I had also noticed that it was getting very difficult to put my contact lens in that eye. Mr Clifford mentioned MMP (Mucous Membrane Pemphigoid) - of course I'd never heard of it - and referred me to Mr Thomas Poole at Frimley Hospital.

I first saw Mr Poole in August and he also suspected MMP, although he said it was extremely rare and that I was young to have it. He checked my eyes and mouth and asked a lot of questions about my health. I underwent an inconclusive eye biopsy (both eyes) in September. I'll always remember him sitting down next to me in the waiting room and saying "we're going to take really good care of you". Thinking back, I'm so grateful to him because he has.

I started taking Mycophenolate after the biopsy. This immunosuppressant takes about 4 months just to even start to kick in, so in the interim I was using steroid drops in my eyes to help combat the inflammation. Mycophenolate was his preferred

choice of treatment to avoid the use of steroids, if at all possible. I have 3 monthly blood tests to check my liver function and, luckily, I seem to tolerate it. He advised me to have all the Covid jabs I was offered and to get a pneumonia jab as soon as possible. I use Thealoz Duo eye drops during the day and Hylonight gel at night to help ease the intense symptoms of dry eye that I now experience. Obviously, I can no longer have electrolysis as this would cause more inflammation and scarring, so I self-epilate any emerging lashes with specialist tweezers.

The damage to my eyes cannot be reversed so it's a case of managing my symptoms and regular check ups. Mr Poole also referred me to Ms Anurahda Jay who is an Ocular plastic surgeon. I see her twice a year to see how I'm managing my lash epilation. When the time comes that it becomes too difficult there are a couple of surgical options to consider.

My eyes often feel tired, sticky - a whole host of sensations difficult to describe. They definitely don't feel normal anymore. I'm always aware of my condition - it's impossible to forget about it. I have to regularly check for new lashes and epilate as once the lashes start to poke my eye the pain is intense and of course I risk scratching my cornea.

People can't see my illness and I've been in a very dark place emotionally. It's affected my self-esteem, my confidence, the way I look, and my energy levels. When I was first diagnosed my anxiety levels were sky high and I couldn't eat or talk to anyone. I completely withdrew. I've had counselling and I've tried Sertraline - which I had to stop quickly as Mr Poole noticed it seemed to be causing inflammation - always read the bit about side effects! I titrated off and inflammation settled again.

There are still unanswered questions, I get angry and I get low, but I know I'm so lucky to have the help of three wonderful specialists who do the very best they can for me.

effects
withdrew
counselling
inflammation
anxiety
Sertraline high
levels

Tapering Steroids - 'step by step'

by Trina Harris



Please note, this article is my personal journey and the opinions of others in PEM Friends, who have shared their experiences of tapering steroids.

Steroids (glucocorticoids) are usually prescribed initially to reduce blistering and inflammation. There is little else that possesses the fast acting and positive impact these drugs can have when you are in pain from your blisters, but they come with very serious negative side effects. Steroids can be delivered in a topical form (creams or lotions to apply to the skin or liquid drops or sprays or foam applied into the eyes, nose or mouth, etc), or in a "systemic" form, i.e. taken as tablets or intravenously. They can also be delivered via inhaler. In the UK, oral corticosteroids are usually called "prednisolone", and the various creams used have different names, but these vary on the basis of their strength.

The factual and scientific information is shared in the

links at the bottom of this article. Most, if not all of us, take or have taken steroids for our AIBD (Autoimmune Blistering Diseases). Steroids tend to be the first line treatment for newly diagnosed patients with AIBD, to get the symptoms under control. This is why it is important to recognise what tapering is and how to do it. You must not stop taking your steroids without talking to your doctor.

So what is 'tapering'? This is to gradually reduce or discontinue your steroids over days, weeks, or months to prevent medication withdrawal or 'adrenal insufficiency'. Adrenal insufficiency is where your adrenal glands do not make enough cortisol.

People on long-term steroid medication have the greatest risk for withdrawal symptoms. However, taking steroids short term can sometimes affect people. We are all different so you must discuss your dosage with your doctor. They will be the best person to advise and keep an eye on you.

Stopping steroids abruptly can lead to several nasty side effects such as adrenal problems, which can cause severe tiredness, body aches, and nausea. If you don't give the adrenal glands time to recover from taking steroids your body will have a severe deficit of cortisol and experience a cascade of symptoms recognized as steroid withdrawal.

Your doctor should instruct you on how to take your steroids in a planned tapering schedule, especially if you have taken

high doses for a long period of time. Everyone is different and your plan will be personalised for you.

Tapering may not always prevent withdrawal symptoms. There is no way to predict who will experience withdrawal and to what degree. This is why it is important for you to contact your doctor for personal advice and they can adjust your tapering schedule accordingly.

Information can also be found on the NHS website:

<https://www.nhs.uk/conditions/steroid-tablets>

Information can also be found on the National Institute for Health and Care Excellence (*Evidence-based recommendations developed by independent committees, including professionals and lay members, and consulted on by stakeholders*) website below (NICE):

<https://bnf.nice.org.uk/treatment-summaries/adrenal-insufficiency/#:~:text=Patients%20with%20established%20adrenal%20insufficiency,vomiting%20or%20diarrhoeal%20illness%20persist.>

For further 'scientific' reading please review the article below, from

the National Library of

Medicine: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8510692>



Firstly a bit of background about myself. I am 85 years old and all my family originate from Lochwinnoch in Scotland. I went to Dunfermline High School and then to Harrow County Grammar School. I did an HND in electronics and a science degree course before doing a public sector Chartered Accountant Course. During the war my father was in Mauritius where as a Chief Quantity Surveyor he was involved in constructing the air strip which is still used today. I did not see my father since a baby until the end of the war. I have had 32 moves in my life as my father got moved every year and a half and I joined the civil service and also got moved frequently. I suffered asthma badly as a child. A friend of my father visited us when I was about 15 and I had a bad asthma attack and the Mauritian visitor said this may help and produced a Brovon inhaler and within minutes my attack stopped. So the small island seemed more up to date on medical cures than England. I do also wonder if all these moves, particularly at a young age with changing schools, have contributed to my condition.

When I got to 60 my dentist kept referring me the dental hospital as I had bleeding gums. I had carried out the dentist's and hygienist's instructions and more. The dental hospital were at a loss as to the reason for the sore gums.

At 62, I went to see my doctor about what I can only describe as a crease on the surface of my eye. I was referred to an eye specialist who was on secondment from an African country. He said "Your condition is quite rare in the UK but more common in dry sandy climates. He asked if I could think of anything that may have caused the condition. I recalled that the computers in the office had ceased up and when we looked at the hard discs they were coated in a fine metallic dust. A metal turning factory was adjacent to our building. I was given drops. However, on reflection, this may have been the cause of my MMP causing gum problems

extending to OCMMP.

Subsequent to that I saw 3 other eye specialists with various diagnoses of Conjunctivitis. Pterygium and Blepharitis. Eventually, I saw a specialist in Redditch who said "I think I know what this is" and referred me to a surgeon at Worcester Hospital. He took two biopsies resulting in a diagnosis of Ocular Mucous Membrane Pemphigoid. He had a handful of patients with the condition and consulted with Professor Dart at Moorfields on the best treatment. I was originally prescribed Cyclophosphamide 50mg tablets and Prednisolone 5mg tablets. I was also sent to see a dermatologist, a rheumatologist and an ear nose and throat specialist as my condition was known to affect sites other than my eyes.

I was weaned off these two drugs gradually which I was very pleased about as I was getting very tired and run down. I was then prescribed Mycophenolate 500mg which I now take at the level of two per day. I get ingrowing eyelashes which are removed at the hospital. An optician at Boots opticians removed the eyelashes initially but she left. Specsavers in Redditch only have the one optician qualified to do this but she did not do it well so I rely on my 4 monthly visits to the hospital. I did have surgery for removal of eyelash follicles in my left eye but these have come back again. I also have symblepharon which is pronounced in my left eye and looks almost identical to the picture on your website.



I had two cataract operations pre-Covid. The first one on the left eye took 3 days as I had to have an infusion before and after surgery and on a follow up the day after surgery. This was to prevent any rejection. After conferring with Ms Rauz (a specialist at the Midland Eye Hospital) my surgeon was happy that I only need one infusion before the next cataract surgery. When I saw Miss Rauz she mentioned clinical trials on new drops and medications for OMMP, and I opted to be

Continued over...

included in the trials. Unfortunately, this has not progressed because of lack of funding.

I had laser eye treatment at a private unit in Birmingham to "Zap" small particles in my eyes which did improve my eyesight a little. Following this I went to Specsavers to have my eyes tested for new glasses and seemed to be the centre of attention as I had 3 opticians including the manager looking at the scarring on the surface of my eyes as none of them had seen this condition before



In summary my condition took 10 years to diagnose. In the meantime, I have lost all but one of my teeth and the condition progressed to OCMMP which may have been triggered by metallic dust irritant. The mycophenolate medication seems to be

stabilising my condition although I have had some side effects in my regular blood tests such as iron and vitamin b12 deficiency. These have been counteracted by supplements. I am due to see the doctor at the end of this month as my most recent blood test shows my Haemoglobin is lower than normal. Hopefully, I can be prescribed medication to counteract this. I do not want to discontinue taking mycophenolate as eyesight is so important to my well-being particularly as I am very involved in bridge club activities and update their website.

Can I end by saying that I have always lead an active life and before my condition played tennis and was a member of Shaftesbury Harriers athletic club. I do enjoy dancing and went to Zumba gold and play bridge twice a week – so remain healthy in mind and body as far as I can.

Positive thinking By Gail Windows

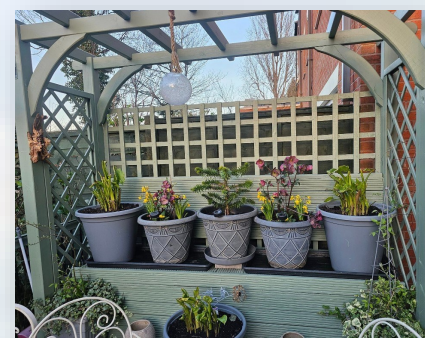
One thing many of us seem to have in common despite the different conditions we have is the exhaustion & itching! I think we can agree that both 'get us down', especially over the winter months when bad weather keeps us cooped up at home!

After a difficult time with Mum having falls and going back and forth to hospitals, she had to go into a care home. The stress created a flare up of my PF and little if any sleep which 'got me down'. One slightly sunny day a few weeks ago I looked out on my garden & thought, THINK POSITIVE! Some days when I wake, I have a 'burst of energy' to do something with those few hours! Something that will enable you to enjoy the fruits of your labours, even though the next day you will be shattered, but hey! You will be shattered anyway) We have a local garden centre I love to visit and browse around the plants and have a nice pot of tea. One day, I saw some lovely new plants and so my THINK POSITIVE idea started.

Over the next weeks, I purchased a few plants on my visits to start preparing my garden for summer. The rain we've had did quite a bit of damage so there was a lot to get replaced, so bit by bit I did it, with hubby's help of course! Though the work is still ongoing, it is becoming a haven for birds, squirrels & a robin who now follows us around knowing his 'dinner' will be more easily available. We even have a Robin 'mom' to be that has taken up residence in one of the bird boxes we have put up & the blue tits who nest here are back too. We have more varieties of birds now – it's like the word has got round. Our crazy squirrel has worked out how to climb the squirrel proof tree feeder and we have a stare off as to who moves first, me or him! (usually me)

Yes, the following day I'm even more exhausted, but the pleasure I get from seeing the birds, Squizzly 1,2 and 3 chasing each other feeding & playing in the garden gives me immense pleasure. It's like small victories scored in the battle of Pem. It has boosted me in other ways too, my mental health is a little better' the 'negativity' has eased feel and I am soooo looking forward to being able to sit out in the garden in the summer (suitably 'protected').

Your own 'victories' may be different; perhaps you go out for a walk, a tidy up of the garage or kitchen cupboards, but they are VICTORIES! Sometimes, these things will make you feel better in yourself more than you realise. I hope you like the start of my garden makeover photos.



My Pemphigoid Journey by Mike Burnett

I recently joined the PEM Council and was asked to share my Pemphigoid journey for the magazine.



It all started in 2021 when I had my Covid booster in the middle of November. A couple of weeks later I noticed, whilst cleaning my teeth, the gums started to bleed. I examined my mouth and saw a number of white lesions. The following week I had a few red and clear blisters.

I made an appointment with my dentist who examined my mouth and said she had never seen anything like it in her thirty odd years of dentistry. She referred me immediately to the local hospital.

In January I had an appointment at the ENT (Ear, Nose and Throat) Department of Boston Pilgrim Hospital and was seen by a very experienced consultant. After a thorough examination, she also told me she had not seen anything like this before and wasn't sure what I had. She said "let's leave it for three weeks and hopefully it will go away on its own accord". I asked what the next steps would be to identify my condition if it didn't go away, and she explained that I would have a biopsy.

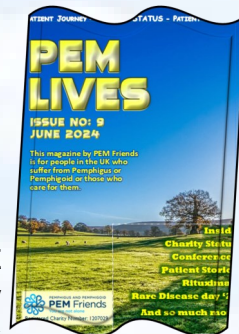
My mouth became extremely uncomfortable, and I realised quickly that consuming certain foods made my mouth either bleed or become very sore. I also noticed that I had what I thought was conjunctivitis in my eyes.

I rang the Consultant's secretary, and a biopsy was arranged for late January. Two weeks later I received a telephone call asking me to come in the following day as the Consultant had a treatment plan. Full of enthusiasm, I arrived at the hospital the following morning, believing we may be able to treat the mouth very quickly and return to normal. I saw a locum consultant, who re-examined my mouth and asked me a bucket load of questions. After about 15 minutes, he told me I had Mucous Membrane Pemphigoid (MMP), explained the condition, and referred me to the Charles Clifford Dental Hospital, Sheffield and to a local eye specialist.

Two months later I had a referral to Spalding Hospital for my eye but had not heard from Sheffield, so I rang them and established they had not received a referral. I followed this up with ENT and persuaded them to email the referral again. A few weeks later I had an appointment with Charles Clifford in May.

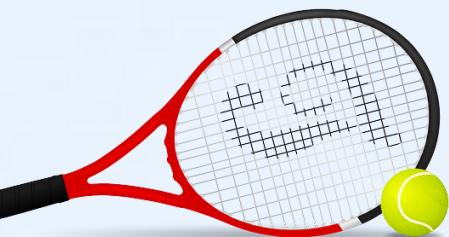
In the meantime, I had to persuade ENT to begin a course of steroids to treat the MMP. I travelled to Sheffield and I saw a specialist called Dr Jurge who specialises in Pemphigoid and for the first time I felt I was in expert hands. She explained fully my condition and the road ahead. I started on steroids and had blood tests to establish if I would be suitable for Mycophenolate and booked a further appointment for a month's time.

A few weeks later I had my first appointment with the ophthalmologist. My eyes were becoming uncomfortable and I began to take eye drops to prevent dry eyes. My eyelashes were now growing inwards. I had blepharitis, as well as sticky eyelashes every morning and had my eyelashes treated by electrolyte therapy. Meanwhile my nose was bleeding regularly and blistering, and I began to feel fatigued. I saw Dr Jurge who prescribed a course of steroids and Mycophenolate. It was early May and I had just played tennis for Wales in the 4 Nations, and we had managed



"I rang the Consultant's secretary, and a biopsy was arranged"

Continued over...



to win. I carried on with my tennis coaching at my local club but had to pace myself. I found this very hard to do, but very necessary.

I saw Dr Jurge regularly up to December and had regular blood test. My mouth was slowly improving, but my nose was now completely blocked, and I had no sense of smell.

ENT at Sheffield unblocked my nose but, after a couple of months it was completely blocked again. The bleeding was intermittent, and I was using Breathe Easy and E45 to try and keep my nose moist.

I visited an Ophthalmologist at Spalding and saw another consultant who clearly had no understanding of MMP, and I left very frustrated. I planned to see an Ophthalmologist privately and stay with ENT at Sheffield for the time being. My next appointment was 3 to 4 months' away in June 2023.

I had an appointment with Ms Saw, the Ophthalmologist, in Harley Street in late February and my MMP journey was about to change. I had met a specialist who had a vast amount of experience in MMP. Ms Saw examined me in depth and explained the plan for my treatment. I had a cataract which needed a lens replacement, which I had in April, and monthly appointments with my local optician to remove the eyelashes. I bathed my eyes twice a day and also used an eye heat pad for twenty minutes twice a day. My eye stabilised and everything was going to plan.

I returned from a trip to Ireland and several days later developed a cough and then started to cough up blood. I felt really unwell. The following day I was treated at the Urgent Treatment Centre in Boston and found I had developed a chest infection. I was no better after five days and went to A & E where I was diagnosed with Pneumonia and spent a week in hospital. Unfortunately, I had to come off the immune suppressants for a month, which allowed the MMP to develop and move forward especially in my eye.



In July I visited Dr Saw and her colleague Dr Fayers at the Western Eye hospital. My eyelashes were continuing to grow into the eyeballs, especially in my left eye. The consultants decided to treat the lashes by removing the roots. I was continuing to have two monthly consultations with Dr Jurge at Sheffield, and ENT became more involved after the pneumonia. They suggested I might have nodules in my nose which could account for my nasal problems and suggested an MRI.

I revisited the Western Eye hospital in early September and was examined by Ms Saw. Unfortunately, I had developed symblepharon in my left eye and a little in my right which meant my eyes were now at stage 3. I was a little dejected and frustrated. Ms Saw also referred me to Guys Hospital to be considered for Rituximab infusions.

I saw the consultant in early October, and we discussed my condition and she initially indicated I would be declined the infusion. Fortunately, I had recorded over approximately 6 months of my visits to various consultants, and she changed her mind and liaised with her head of department. I would have the infusion in early December.

I went on holiday to Spain in mid-October and after a few days I developed a stomach upset. After a week, I noticed I had conjunctivitis, and on my return, Ms Saw managed to see me at short notice. I had contracted viral conjunctivitis which took me about 3 weeks to shake off. My main concern was to be fit enough to have the infusion.

I attended Guys on 5th December for my initial infusion which took about 6 hours. The

Continued over...

second infusion took about 4 hours. It's worth noting that Rituximab doesn't always work for everyone, and it can take between 2 & 4 months to feel the benefits of the infusion.

In mid-December at an appointment with ENT, the blockage in the nose was confirmed as being due to the MMP, and they wanted to operate. I have delayed the procedure until May 2024.

I also travelled to Sheffield in mid-January to visit Dr Jurge who confirmed my mouth was in remission. I had a private consultation with Professor Sandhu in London In February, an ENT specialist and had the good news that the nose involvement was in remission, but I would need a procedure to clear the nose. I spoke to my local GP who after a lot of discussion referred me to Charing Cross hospital. I have not heard from them as yet.

I think the Rituximab is working as I haven't felt fatigued since early January. At the end of March, I went on a competitive golf holiday to Spain where you play five rounds in 6 days, something I would never have imagined I could do three months ago. I am hopeful that I may be in full remission.

I have really battled MMP and followed the treatment plans. You have to be extremely respectful of the disease, and the mind plays a big part in all of this. Always negotiate with medical professionals, especially when they are not sure of your diagnosis. Persuade them to take the next steps to confirm your illness and treat it accordingly or refer you to specialists who can treat this rare autoimmune disorder.

My journey continues and I will do my best to beat MMP and I believe I can, with the help of my brilliant medical team of Ms Saw and Dr Jurge.

Hamza's Story by Hamza Shaikh

In December 2020, Hamza, a Deaf Muslim man, received a diagnosis of Bullous Pemphigoid, an autoimmune condition, amid the challenges of the coronavirus pandemic. Despite the pain and uncertainty brought by his condition, Hamza found a newfound resilience within him.

As time passed, Hamza felt the need for a fresh start away from the busy streets of Birmingham. In October 2021, he left and moved to Derby, seeking solace and a sense of belonging.

Hamza found his new home in a small village, just twenty minutes from Derby's city centre. It was a ground-floor maisonette that offered both comfort and accessibility. Embraced by the warmth of his diverse community, he felt at ease.

Although he faced challenges due to his Deafness and autoimmune condition, Hamza thrived in his new environment. He immersed himself in village life, connecting with his neighbours and finding purpose through acts of kindness.

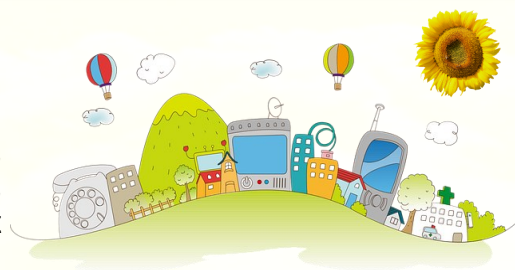
From exchanging greetings with the elderly couple next door to lending a helping hand to those with mobility difficulties, Hamza's quiet strength and optimism inspired others.

As the seasons changed, Hamza remained grateful for the blessings around him. Simple pleasures like a walk in the village square, the laughter of children playing in the nearby park, or the rustle of leaves in the breeze brought him joy.

In his new home, Hamza found belonging beyond language and culture.

He knew he had finally found the peace and serenity he had been searching for - a place to call home, where his heart could honestly be at ease.

Note from the editor: Hamza didn't mention his contribution to the Priority Setting Partnership for Blistering Diseases mentioned in previous PEM Lives editions or his help with copy reading this magazine. Thank you, Hamza.



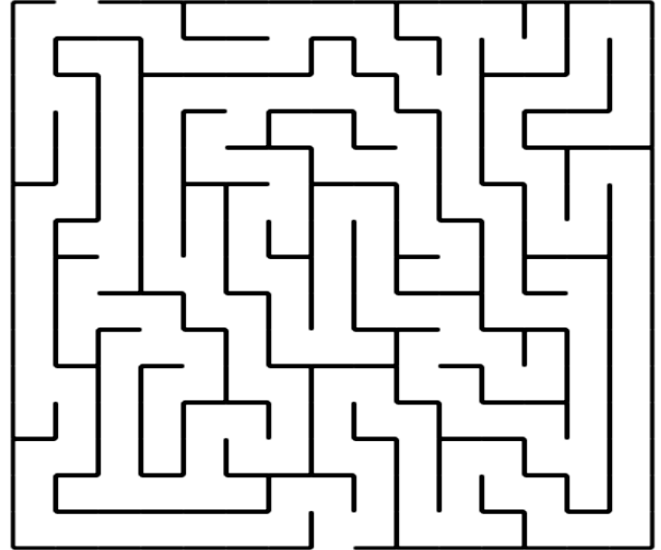
Summer Word Scramble

This Summer themed Word Scramble features 10 Summer themed words which have been scrambled. See if you can unscramble them to see what they are.

- umswisit -----
- nkbiii -----
- tabniog -----
- eraptrawk -----
- cigmnpa -----
- fna ----
- tehnseigigs -----
- spead -----
- sneaadtslc -----
- wims -----

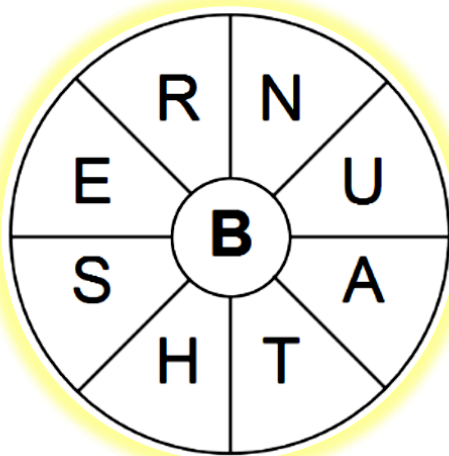
Summer Maze

The little girl wants to swim in the ocean. Help her through the maze so she can go for a swim.



Summer Word Wheel

This Summer themed word wheel is made from a 9 letter Summer themed word. Try and find that word, then make as many words of any length as you can from these letters. You can only use each letter once, and each word must include the letter **B**.



Summer Sudoku

It's our Summer "sunbather" Sudoku. Fill in the grid with the letters: **S, U, N, B, A, T, H, E, R**. Make sure no letter is repeated in every row, every column and within each mini grid.

n							r	
r	u	b				h	e	n
	h			n			b	
		t	h	s	n	r		
a	e		t		u		h	s
h			e	r	a			u
s	r		n	e	b		u	a
		u	a	t	s	e		
t			r	u	h			b

Summer Sunflowers

How many sunflowers can you find on the pages of this magazine?



Working with other groups

We are engaged with and helped by other organisations. Our relationships with (and gratitude to) many of these friends continues to develop.

Collaboration with other groups supporting people with PEM around the world has been facilitated by the **International Pemphigus and Pemphigoid Foundation (IPPF)** .



The International Alliance of Dermatological Patient Organisations, better known as **GlobalSkin** (we are a member) has, with the IPPF, provided us with information, advice, links to other groups and access to potential new treatments and trials. Following the IPPF Conference, we have spoken to several Biopharmaceutical Companies who are doing great work on new treatments for Pemphigus and Pemphigoid. GlobalSkin also has a European network to which we are active contributors.



Beacon (formerly known as Findacure) in the UK has also helped a lot. They run training and information exchange sessions which keep us informed and building (some) expertise in important areas such as social media marketing – important if we are to grow awareness.



PEM Friends are also a part of the BAD PSG (British Association of Dermatology Patient Support Groups) and Dermatology Council of England groups, which enable us to keep up to date on changes in Dermatology practices in the UK and also give us access to their grant funding, another benefit for which we are very grateful.



Thank you to them all as well as to those not mentioned here!

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Editors: Trina Harris & Isobel Davies

Design and layout: Trina Harris

Proof readers: Julie Martin, Phil Davies and Hamza Shaikh

Website: www.pemfriends.org.uk

Facebook: <https://www.facebook.com/groups/>

Contact information for the next issue:

Isobel Davies: isobel@pemfriends.org.uk

Trina Harris: trina@pemfriends.org.uk

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