

MEDICALERT • RESEARCH • CONFERENCES

PEM Lives

ISSUE NO: 3 • JULY 2021

Inside...

PROM-TEARS

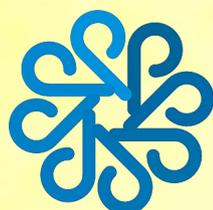
Children & PEM

24hrs in A&E

Virtual Meetings

And more!

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



PEM Friends
You are not alone

ISSUE NO:3
JULY 2021

IN THIS ISSUE:

Welcome

Events attended
in 2021

MedicAlert

Informing trial
development for
autoimmune
blistering diseases

24 Hours in A&E

Patient Reported
Outcome
Measures: The
Dry Eyes and
Ocular Surface
disease project

Experience of
Rituximab

Meet Felicity

Babies & PEM

Puzzle page &
Pets corner

Working with
other groups

Website details

PEM Financials

Spending wisely

Links to other
groups



PEM Friends

You are not alone

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

Welcome from our leader

A very warm welcome to the second edition of our magazine, PEM Lives. I hope you enjoy it. The first edition was very well received. We would welcome feedback about any of it as we are keen to make it as interesting and relevant as we can.

Last year was the culmination of a very exhausting and busy year when we were lucky enough, amidst all the challenges of Covid, to win 2 grants, one from the National Lottery Community Fund (Covid 19) and one from GlobalSkin. We achieved a lot (as reported in our last magazine) and hope to continue some of the successful achievements we had as a result of having some funding. For example, thanks to the hard work and endeavours of our webmaster, Ingrid, the website goes from strength to strength. And our membership continues to grow in leaps and bounds. The weekly Zoom calls we set up some 16 months ago are still popular and continue. We have also had more experts come and talk to us and answer questions on PEM. The most recent one of these sessions, with Ms Valerie Saw can be seen on our website on the Guest Speakers pages.

Those who have valiantly worn T-shirts and badges (paid for by the grants), on visits to hospitals and other appointments, have also done their part in 'recruiting' new members and spreading the word amongst patients and medical professionals alike. Well done to all of you who have participated! Some are pictured on these pages.

In this edition, we have a delightful story written by Felicity who has Pemphigus Foliaceus which reminds me of the suffering and also the enormous courage of those who have these autoimmune bullous diseases. And we have a wonderful message of hope from Siobhan

for those with these conditions wanting to bring new life into the world.

There is much more we could do to help others with PEM, so we hope to be more active in our support for research applications and studies and providing patient information in conjunction with specialists.

I hope you will take up the invitation by MedicAlert to participate in their survey and maybe win a prize. I find my own bracelet a source of security, knowing that, if I am injured or ill and unable to tell the medics about my disease and medications, there will be some way of them knowing.

And we have also included and update on the series of studies being done by the Centre for Evidence Based Dermatology at Nottingham University. There was quite a lot of information on the start of that research in our last magazine, and we hope this next part will give us much more data on the links between Bullous Pemphigoid and drugs. There is a lot of anecdotal information about the triggers for this nasty disease, and we hope this will prove or even disprove these belief.

And some very exciting information about the research by experts at Birmingham Eye Hospital, led by Ms Si Rauz, which was mentioned in the talk by Professor Dart late last year and featured on our Guest Speaker's page on the website.

But enough of my ramblings – do read on. And please do give us your feedback. We thrive on it. And any help you can offer, of time or even a small amount of funding, would be gratefully accepted. Details of how to donate are in the Financial report.

Stay well and safe in these ever challenging times.

Isobel

Events attended in Spring & Summer 2021



31st April and 3rd June EUROPADERM

GlobalSkin – an international organisation we belong to, is setting up a European network called Europaderm and we are involved in creating the aims and working rules for this group. This should allow us to ‘punch above our weight; in lobbying for the attention of other people particularly politicians making policy decisions, researchers studying disease and treatments and Biopharmaceutical companies developing drugs. We continue to input to the constitution of this new group which should be out in the Autumn. <https://globalskin.org>

6TH May PSG MEETING

We are now recognised as a Patient Support group by the British Association of Dermatologists and this was our first meeting. It was very interesting.

There was an update on the situation regarding funding of activities, the state of Dermatology services (which are returning to normal eventually), telephone vs face-to-face consultations, the availability of some drugs and emollients. There was discussion about the dependence on telephone appointments and a survey of patients and it was agreed that face-to-face is best but there is still a place for using the phone or video conferencing.

There was also a presentation on data protection. Each PSG member did a brief update.

We were also invited to attend the meeting that followed, which was the Dermatology Council for England <http://www.dermatologyengland.org.uk>. I wasn't aware of this group, but it appears to report (indirectly via a third party group called Decideum Ltd <https://www.decideum.com>) to an All Party Parliamentary Group (APPG) on Skin headed by Sir Edward Leigh. There was discussion about representation on the APPG. This will need further investigation. I am not sure how all of this works!

There was also a presentation on the topic of diversity in Dermatology which was very thought-provoking. Many descriptions of skin conditions are given from the perspective of white skin, leading to potential misdiagnosis of disease for those with darker skin. The sub-committee leading the charge on addressing this, reported on many actions to address this problem as soon as possible. Then there was further discussion about emollients, which is a subject that had been raised at the PSG meeting earlier, and also one on a study of topical steroid withdrawal by the National Eczema Society. Further discussion was mainly regarding the prescribing of drugs, etc.

All in all, it was well worth attending and understanding the issues and trying to get to grips with the complex organisational structures involved. The next meeting is in November.

17TH May ZOOM PRESENTATION BY MS VALERIE SAW, CONSULTANT OPHTHALMOLOGIST

We were very pleased that Ms Saw, who is an eminent specialist in the way that our diseases affect the eyes, could come and talk to us about taking care of our eyes or how to manage our eye conditions. Her talk is available on the website under Guest Speakers.

IPPF BACK TO BASICS PATIENT EDUCATION SERIES

Several of us have attended this excellent set of webinars arranged and run by the International Pemphigus and Pemphigoid Foundation. I would strongly recommend listening in to the recording of many of these as they cover both our diseases and treatments for these. They are, indeed, educational. <https://www.pemphigus.org/patient-education-webinars/>

Events attended continued.

3RD June GLOBALSKIN ANNUAL VIRTUAL CONFERENCE

GlobalSkin brought together over 91 dermatology patient group leaders and dermatology stakeholders from all regions of the world for a virtual half-day conference. The event was designed to strengthen connections and provide opportunities to collaborate and network.

This was a packed meeting and Trina and I attended for the day, visiting side exhibitions as well as the main event. There were opportunities to network too, but the whole thing was a little overwhelming so we tried to focus on the speaking elements. There was a presentation on Change and the opportunity (as well as the other consequences) of Coronavirus. We also the opportunity to hear about how we could work collectively to drive for positive outcomes as well as about the work of patients as advocates. Eurordis (<https://www.eurordis.org>) presented information about their one year open academy training programme to enable patients (and others) become a well educated and informed force for change. Finally, we were given an update on GRIDD – Global Research on the Impact of Dermatological Diseases – which is part way through it's very thorough process of collecting inputs and will, we hope, make a significant difference to the way specialists consider more than just the immediate and physical burden of skin disease. Many of our group have already contributed to the surveys conducted to collect the data.



6-9TH July BAD CONFERENCE

Although we are not delegates of this meeting which took place in early July, we are represented on their virtual patient and other group stands, and hope to get some attention from Dermatologists attending the conference. There was also a patient group quiz that delegates are invited to complete and we have input a question into the mix; *“What are the main sites for pemphigus and pemphigoid to appear?”*.

MedicAlert - needs your help... with a free gift in return!



MedicAlert is the UK's only charity providing life saving medical ID services. They have been protecting individuals living with medical conditions for over 56 years by providing access to their vital medical information in an emergency.

In order to better understand the needs of those with rare conditions, raise awareness of medical IDs amongst the general public and to highlight the needs of the group to government bodies, MedicAlert is undertaking research. This will cover individuals' concerns, impact on loved ones, emergency treatment and understanding, as well as experience and perception of medical IDs.

To thank those who complete the short survey, which should take less than 5 minutes, MedicAlert is offering a FREE medical ID bracelet when you become a MedicAlert member!

As the pioneers of medical ID services, the service remains unique to keep you safe when you need it most:

- Store your full medical record, including conditions, allergies, medications, scanned documents (such as clinical reports or Advance Decisions) and emergency contacts.
- Registered Nurses check your record when it is created or updated to make sure that it is medically sound and optimised for use in an emergency.
- 24/7 emergency helpline available worldwide, in over 100 languages and dialects.
- Ability to nominate one or more loved ones to help manage your record via the advocacy function.
- Update your record online, as often as required, to ensure it remains relevant to inform care decisions.
- NHS recommended.

“I feel so much safer wearing my MedicAlert bracelet, knowing that if I was ever in another situation when I was unable to speak, the details of my medical condition are only a phone call away. This means that I will get the treatment I need quickly, which could save my life.” - Isobel Davies, Leader of PEM Friends.

To complete the survey and claim your free medical ID, visit <https://forms.gle/A3zgpqSUgnpRbjn9A>



INFORMING TRIAL DEVELOPMENT FOR AUTOIMMUNE BLISTERING DISEASES



Dr Sonia Gran

In our last magazine, we reported on the very important research done, and continuing to be done, by the Centre for Evidence Based Dermatology. This report, by Dr Sonia Gran, Assistant Professor of Medical Statistics at the University of Nottingham, brings us up to date on this continuing work.

More information on the vital work being conducted at Nottingham can be found on their website at:

<https://www.nottingham.ac.uk/research/groups/cebd/projects/blistering-diseases/informing-trial-development-in-blistering-diseases.aspx> and the short videos are a must for those with BP.

PEM Friends continues to support the ongoing research in any way we are able.

THE RESEARCH SO FAR

Aim: To find out how people with blistering skin conditions are treated and how many people would be available to take part in future trials.

There were 4 stages completed so far in the study:

- looking at the feasibility of using Bullous Pemphigoid and Pemphigus Vulgaris records
- analysing the data, distribution and determinants of these diseases in the population
- reviewing the use of steroids in the treatment of Bullous Pemphigoid patients
- reviewing the feasibility of conducting trials on this latter population.

BACKGROUND

There are two serious, but rare, blistering skin conditions called 'Bullous Pemphigoid' (BP) and 'p=Pemphigus Vulgaris' (PV). They occur when the body doesn't tolerate its own skin tissues and attacks them. This results in painful blisters and open sores. There is no cure, only

treatments that aim to control the blistering and symptoms.

Steroid tablets are commonly used to control these diseases but they can cause serious side effects, including thinning of bones and fractures, diabetes and infections. There is an urgent need to conduct high quality trials to find better treatments but, because the conditions are rare, we need to gather as much information as possible from existing sources of information.

METHODS

We have determined whether routinely collected data from GP surgeries can be used to conduct research in BP and PV. We estimated how many people in England developed BP 2015-2017, and would be eligible to take part in a future trial. We have also described the dose and length of time over which people were prescribed oral steroid tablets.

KEY FINDINGS

We are able to use medical records from general practices to conduct research into BP. However, until the recording of PV improves, we are not able to use these records to look at PV.



BULLOUS PEMPHIGOID

Every year, about 8 people in every 100,000 are diagnosed with BP for the first time. This number has been rising slowly over the last two decades. BP more commonly affects older people, particularly older men. In 2017, about 50 in every 100,000 adults were living with Bullous Pemphigoid. Focusing only on older people (>60 years), just over 1 in every 1,000 older persons was living with BP in 2017. People with BP were more likely to die than similar people without the disease – three times more likely in the first two years after being diagnosed, and then 50% more likely following this.

About 70% of people with BP were prescribed oral prednisolone by their GP. The majority of people were on oral prednisolone for extended periods of time and at substantial doses.

Continued over...

INFORMING TRIAL DEVELOPMENT continued.

Many people with BP are receiving oral prednisone at levels that are high enough to cause serious side effects, such as diabetes and brittle bones. By making patients and GPs aware of this, we hope to improve the monitoring, prevention, and early treatment of these side effects.

We estimated that about 10,800 people are diagnosed with BP for the first time in England over a three-year period. The majority have pre-existing illnesses, although we believe that 5,100 may still be able to take part in a trial. A further 5,300 might also be able to take part, but have pre-existing illnesses that would need to be monitored during the trial. Less than 400 have pre-existing illnesses that make them unsuitable for trials. Finally, we believe that about 11-17% of people have pre-existing dementia.

We, therefore, believe there are substantial numbers of patients with Bullous Pemphigoid that might be eligible to take part in future trials in England. We hope that researchers will be able to use the results from our study to plan new trials, thereby improving the treatment options for people with Bullous Pemphigoid.

WHAT'S NEXT?

The next phase of the study is to find out whether people prescribed certain medicines or vaccines are at higher risk of developing Bullous Pemphigoid (BP) than those not taking such medicines or vaccines.

The proposal on medicines/vaccines associated with BP was submitted to the NIHR's Research for Patient Benefit funding scheme. We were successful at stage 1 and are waiting for the outcome for stage 2. We should hear the outcome some time this month. If successful, the project will start sometime between November 21-January 22 and last for 13 months. We hope we will be able to determine if any medicines/vaccines that are commonly prescribed in older people trigger BP. If there is an association, then GPs could look out for BP in older people taking these medicines/vaccines.



BACKGROUND TO THE NEXT PHASE OF RESEARCH

The cause of BP is unclear. Some studies show commonly prescribed medicines and vaccines may lead to BP but the findings are from small specialist hospitals. Stopping suspect medicines has been shown to help recovery from BP. There is, therefore, a need for better research to identify which medicines and vaccines are linked with BP, and to find alternatives that are less associated with BP.

Raised awareness of the risk of BP following the use of certain medicines or vaccines will offer the potential for earlier diagnosis of BP. Earlier diagnosis may mean disease control is possible with less aggressive treatment and enhanced wellbeing, for example by reducing discomfort from blisters. Withdrawal of suspect medicines and switching to alternatives, where available, may lead to recovery from BP. NHS costs may subsequently be reduced as fewer people may require advanced treatments (which have severe-side effects), or medical care for their BP.

DESIGN AND METHODS

We will use data which is routinely collected from over 600 GP surgeries across the UK to calculate the risk of developing BP for patients taking certain medicines and vaccines compared to those not taking them. This is an efficient way to undertake research on uncommon conditions like BP and it will reveal what happens in healthcare settings across the whole country, not just in specialist hospitals.

We will consider medicines or vaccines which are commonly prescribed for older people such as antibiotics, medicines for the heart and blood circulation, diabetes and dementia, and the influenza vaccine. We will also use a novel computer science technique called machine learning, which handles large amounts of data well, to allow us to corroborate our findings and identify other medicines associated with BP.

INFORMING TRIAL DEVELOPMENT *continued.*

PATIENT AND PUBLIC INVOLVEMENT

Patients with blistering skin conditions, including BP, have helped to develop this study and will help disseminate our results to the patient community. We are supported by PEM Friends. In the words of one patient, "So little is known about BP ...the more awareness of what could trigger BP, the better..."

DISSEMINATION

We will publish our work and specifically target England's national prescribing committee, the Royal College of General Practitioners, the British Association of Dermatologists, and PEM Friends to share details with healthcare professionals and patients.

Principal Investigator: Dr Sonia Gran, Centre of Evidence Based Dermatology, University of Nottingham

Research Team: Dr Monica Persson, Dr Karen Harman, Prof Sinead Langan, Prof Kim Thomas, Dr Yana Vinogradova, Dr Jo Chalmers & Prof Julia Hippisley-Cox

Future plans:

- The association between medication use/vaccines and Bullous Pemphigoid
- Delayed diagnosis in Bullous Pemphigoid
- Frequency of side-effects due to oral steroids in people with Bullous Pemphigoid.

Filming for 24 Hours in A&E



24 Hours in A&E shown on Channel 4, is a British documentary programme, set in a teaching hospital in inner London. Initially it was filmed inside King's College Hospital in Denmark Hill, Camberwell, but in the seventh series, the setting was changed to St George's Hospital in Tooting, Wandsworth and it has been filmed ever since.

Cameras film round the clock for 28 days, 24 hours a day in A&E (Accident and Emergency). This offers unprecedented access to one of Britain's busiest A&E departments.

Trina was diagnosed with Pemphigus Vulgaris in January 2015. In October 2020 she was taken by emergency ambulance to St George's Hospital following a huge flare of Pemphigus. This was her 3rd flare like this and each episode caused admission into hospital. This was the worst flare she had ever experienced. She

was finding it difficult to breathe after an eruption of blisters in her airway. She spent a further 4 days in hospital receiving IV steroids and antibiotics to treat the blisters. The episode featuring Trina is due to be aired this Autumn. The photos show Trina (and her husband Simon) fully recovered and filming for the programme, in a Covid secure way, in her home a few months later. The months following her admission into St George's were spent working with the producers and telling her story! The TV episode will certainly highlight this rare disease and raise awareness of the difficulties we all face on a day to day basis! So look out for it soon.

Trina has just completed Rituximab infusions to prevent this sort of flare happening in the future. She is much better now and hopeful that the treatment has put her into remission.



Patient Reported Outcome Measures: The Dry Eyes and Ocular Surface disease project (PROM-TEARS)

The following article is by Dr Anita Slade PhD, MPhil, DipCOT, ITM Research Fellow and the leader of this important research project at the Centre for Patient Reported Outcomes Research, University of Birmingham

PROM-TEARS Patient Reported Outcome Measures - Group concept mapping results

PROM-TEARS is part of an exciting new treatment for Dry Eyes and part of the new clinical trial being carried out by Saaeha Rauz (Consultant Ophthalmologist at the Birmingham and Midland Eye Centre) and her team at the University of Birmingham. A highly innovative fluid gel system has been developed which we hope will relieve eye pain and discomfort and reduce the frequency that drops need to be applied. PROM-TEARS is part of that project and we are developing a **patient reported outcome measure (PROM)** for use in the clinical trial.

What are PROMs?

Patient reported outcome measures, or PROMs are questionnaires that are completed by the person with the disease or condition being investigated. The questionnaires can ask about specific symptoms such as fatigue or pain, or the impact of your health on everyday tasks, such as driving, using a computer or working. Questions may also be asked about the effect on your quality of life or emotional well-being. PROMs are frequently used in clinical trials and research to ensure the person's experience of living with the condition is reflected in any outcomes being addressed by the research.

Group Concept Mapping

If you remember in a previous posting we asked for your support to carry out a group concept mapping (GCM) research project. We wanted to know what it was like to live with dry eye symptoms.

We had a fantastic response with 39 people from different groups consenting to take part and we would like to thank everyone who gave up their time to take part.

If you remember the GCM consisted of 3 parts:

Part 1

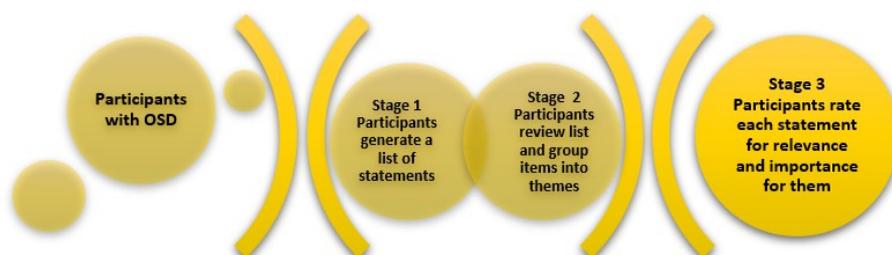
Participants were asked to make a list of common symptoms and how they affect your life. In total you generated 235 statements covering a wide range of issues. These were reviewed by two researchers. Duplicate ideas were either amalgamated or removed. Statements that related to other issues such as dry mouth were removed and we checked the statements for spelling etc. This left us with 125 statements covering: treatments, impact of dry eyes on tasks such as reading and driving etc., symptoms of dry eyes and the impact of the environment e.g. air conditioning.

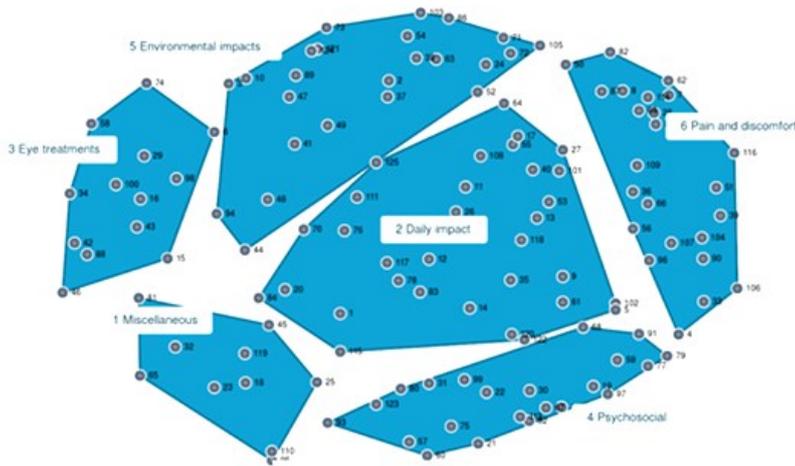
Part 2

Participants were asked to look at the 125 statements and sort them into groups and give each group a name based on its theme or meaning to them. This is a very important part of the study as the software uses this grouped data to create the clusters. Clusters are groups of statements that were frequently put together by participants.

Part 3

Participants then rated each statement for how important it was for the PROM and how much it reflected their own experience (relevance). The scores ranged from 1 to 3 with 3 meaning it was considered very important or very relevant. We can then see the average score given by everyone for each statement. This shows us which statements were thought to be most important and most relevant.





Dots and numbers represent statements

The 6 clusters generated by the GCM - What we found
 We identified 6 clusters that contained statements that were similar in their theme. We labelled them by looking at the statements within the cluster and looking at the labels participants used in part 2 of the GCM exercise. The labels we used were Miscellaneous, Daily Impacts, Eye treatments, Psychosocial, Environmental impacts, Pain and discomfort. Below is a table that shows an

example of a statement included in each cluster so you get an idea of the sorts of things that people were saying.

Participants were also asked to rate each statement on how important it was and how relevant it was to them. From this we can see which clusters were most important for use in a PROM and also individual statements within each cluster. This helps us make sure we are covering important information.

The Table below gives some examples of some of the statements in each cluster generated by participants and the average score given by all of you in relation to its importance for inclusion in a PROM.

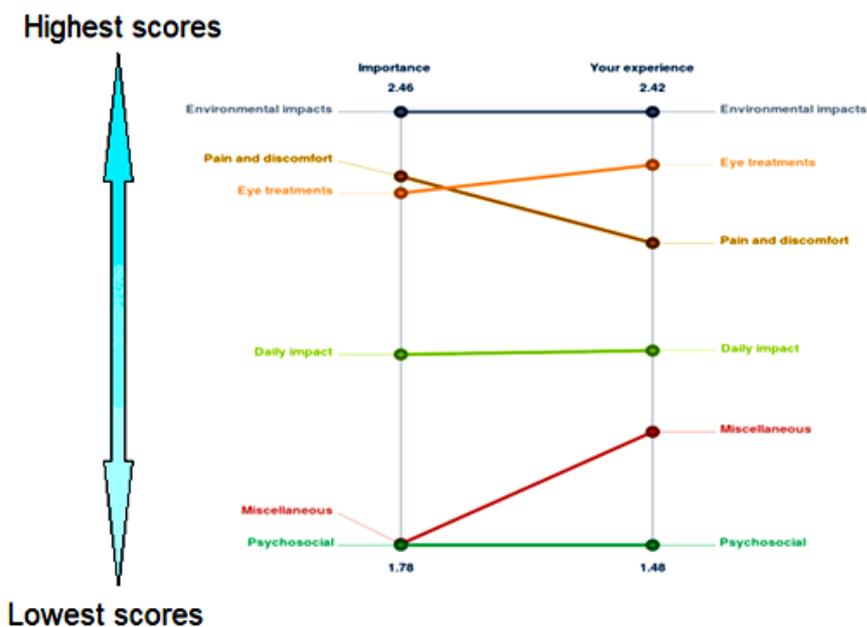
Cluster	Statements with high scores	Importance Average Score
Miscellaneous	I can cry if I am very upset. It makes my eyes feel so good once I start crying I don't want to stop.	1.33
Daily Impact	Aching stinging eyes make it hard to watch the television at night.	2.57
Eye Treatments	It would be great to have drops or a film that kept the eyes moist for longer.	2.87
Psychosocial	Not knowing the exact cause of my dry eyes is worrying.	1.95
Environmental impacts	Air Conditioning can be a real challenge as it dries my eyes out and can make it difficult to blink.	2.71
Pain and Discomfort	My eyes fluctuate between being painful and sore to just gritty.	2.73

The statement “It would be great to have drops or a film that kept the eyes moist for longer” got the highest score across all the statements for importance with a score of 2.87. Hopefully the new gel will help with this and we will make sure that a question relating to this will be included in the clinical trial.

(PROM-TEARS) Continued..

In the picture to the right, you can see which clusters were considered most important and most relevant.

As you can see the impact of the environment, pain and discomfort, and treatments were scored highest for importance and relevance closely followed by daily impacts. This means when we are thinking about the PROMS we are going to use in the clinical trial we will try and make sure these areas are covered as they relate to the new gel. We can also see which statements within all the clusters were given high scores as these will need to be covered as well.



So what next?

We are looking at some PROMs currently used in ocular surface disease and matching the questions included in them against the things you have told us matter to you. We want to make sure that any PROMs we use capture the most important issues for you. That way we can make sure that the benefits of the new gel are helping you with the symptoms and impacts of living with dry eye symptoms. We hope this brief outline of the results demonstrates how important your input has been to the PROM-Tears project. We couldn't have done it without you. So thank you to everyone who took part.

Dr Anita Slade and the research team at the University of Birmingham.

The project is funded by the National Institute for Health Research (NIHR) through the programme Invention for Innovation. The host organisation is the University of Birmingham, B15 2TT, Birmingham, United Kingdom. The Principal Investigator is Miss Saaeha Rauz.

Experience of Rituximab

Rituximab* belongs to a group of drugs known as 'monoclonal anti-bodies'. It is a biological medicine that works by 'targeting' specific proteins (receptors) on the surface of cells relevant to the cause of the disease. There is clinical interest in whether Rituximab may be effectively used to treat patients with immunobullous diseases which are not controlled by conventional treatment.

NHS England has carefully reviewed the evidence to treat Pemphigus and Pemphigoid with Rituximab. We have concluded that there is enough evidence to consider making the treatment available in adults and children who meet the defined criteria. *source www.england.nhs.uk

"After 4 years of PF and being very sore with blisters and in pain, both mentally and physically. I was referred to see a dermatologist in the RVI in Newcastle. After my first appointment he said I should have Rituximab and a couple of months later, after both my Covid vaccinations, I had 2 infusions. I was terrified at the thought but it went like a dream and 3 months later I have no bodily blisters (for the first time in 4 and half years), my face is still red and flares up but is so much better. My scalp has PF but I'm getting a new steroid cream to use. The constant and continuous aches and pains have lessened and I don't feel exhausted all the time, as I used too. I've recently seen the dermatologist who reassured me that it keeps on working. I am extremely happy so far and hope it continues to do its magic." **Helen Robinson in Alston Cumbria.**

Meet our youngest member - Felicity

Felicity is our very young and special member of PEM Friends and her own words tell her story so well. We think she deserves a medal for her bravery and occupying such a unique and rare position. Big cheers for Felicity!

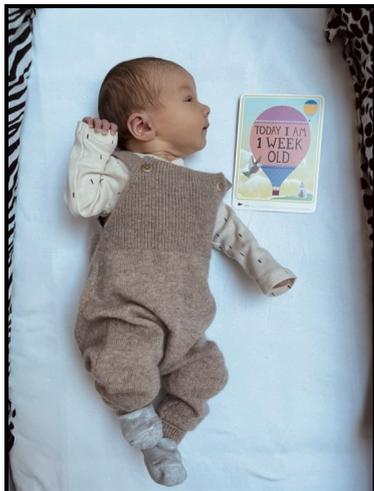


I AM Felicity,
I am 5 years old.
I have Pemphigus
Foliaceus. I get very
itchy and have spots.
I love dancing, tennis
and unicorns. I love
my PEM Friends
t-shirt. keep
Smiling.
X X X

Two colorful butterflies, one large and one small, are drawn at the bottom left of the handwritten note. The large one has pink, blue, and yellow wings, and the small one has yellow and blue wings.

Babies and PEM

Does anyone remember the beautiful arrival of Aoife mentioned in the last edition of PEM Lives? Here is Siobhan with her story.



Going into our first lockdown, back in March 2020, felt a bit like deja-vu for me. I had been diagnosed with PV the year before after being very unwell for quite some time. As a result I had given in to the fatigue and already ditched my social calendar for nights at home.

Azathioprine had caused me some problems around Christmas 2019, and it just so happened that as we went into lockdown, I was only taking a low dose of prednisolone to manage the disease.

Finding out I was pregnant was the most incredible feeling. With the amazing cross-disciplinary support of the teams at Guys & St Thomas' Hospital, I had a pretty gentle pregnancy. I had been warned to expect a severe flare-up, and we discussed how this would be managed, however I had no flare-ups. It seems pregnancy has worked in my favour and vastly alleviated my PV symptoms.

I counted down the days until I'd be able to be able to meet our baby, enjoying a much better

quality of life than I had throughout the whole of 2019.

Our daughter Aoife was born in December, a little earlier than we anticipated. I had worried that she might inherit a transient form of my condition, but she was perfect in every way. I

had some additional support during labour by way of IV steroids (to compensate for the potential of sleepy adrenals after having been taking prednisolone for an extended period of time), but other than this I breathed through labour and delivery without painkillers.

The physical endurance required in managing and living with the bad days that PV can bring, has left a permanent mark on my approach to

life generally. I have learnt to slow down (not that this is really feasible with a baby!) and to pay more attention.

Siobhan



Welcome to Alex

A very warm welcome to baby Alex and congratulations to his mum, dad and big sister Tara. His mum, Dr Antonia Lloyd Lavery is well known and in receipt of thanks from those people who attend her blister clinic at the Churchill Hospital and who read our website. Dr Lloyd Lavery was our resident guru in making sure our medical information was accurate and informative.



Working with

other groups

During 2021 we continue to engage with and been helped by other organisations.

Collaboration with other groups supporting people with PEM around the world has been facilitated by the [International Pemphigus and Pemphigoid Foundation \(IPPF\)](#) and in addition, our relationship with our French friends the [APPF](#) has grown from strength to strength. We are particularly grateful for their work representing our diseases on the [e-PAGS](#). These are the patient groups who work with the [European Reference Networks \(ERN's\)](#) – groups of medical specialists from across Europe whose aim is to pool knowledge to ensure better access for patients with rare diseases to highly specialised healthcare and to improve diagnosis and care in medical domains where expertise is rare. This type of collaboration can maximise the speed and scale of adoption and spread of innovations in medical science and health technologies. We are hopeful that, despite Brexit, UK participation in these ERN's, particularly the one relevant to us on SKIN and Autoimmune Bullous Disease in particular continues.



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.



International Alliance of
Dermatology Patient
Organizations



[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.

Several other organisations, including the [Coronavirus Community Support Fund \(CCSF\) Learning Hub](#) (a result of being provided with the National Lottery Community grant) have also provided us with much needed ideas, information, learning opportunities and an important boost to morale.



HM Government

In partnership with

THE NATIONAL LOTTERY
COMMUNITY FUND

And last, but not least, we are very pleased to be allied with the wonderful Penny at the PV Network - at last! Thank you to them all, as well as to those not mentioned here!

Pemphigus Vulgaris Network

www.pemfriendsuk.co.uk

The image shows a laptop displaying the PEM Friends website. The website has a navigation menu with 'About Us', 'Types of PEM', 'Managing PEM', and 'Resources'. Below the menu are several circular images representing different types of pemphigus. Overlaid on the laptop screen are several informational cards with green borders. One card is titled 'Texture of...' and shows a close-up of skin. Another card is titled 'Definitions and outcomes of pemphigus vulgaris' and includes a quote: 'The first international meeting on pemphigus and pemphigoid was held in London in 1984. It was a landmark meeting of the world with specialist knowledge and outcome measures.' A third card is titled 'Useful Links' and lists 'Food and nutrition'. A fourth card is titled 'Medications' and lists: Azathioprine, Ciclosporin, Dapsone, Doxycycline, Mycophenolate, Methotrexate, Nicotinamide, Rituximab, and Steroids.

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

PEM Financials

From Kalpesh Patel, our treasurer

Our bank account continues to be in the black to the sum of £1422.76. This is mainly due to the continued regular donations from our loyal and generous supporters, and we owe them our thanks.

We received an extraordinary amount of donations in memory of Suman's husband, Jag, who very sadly and unexpectedly died in April. Altogether, we contributed £90 in addition to those made by PEM Friends direct.

As a result of the popularity of the t-shirts to increase awareness of the group, we have decided to use funds to purchase more of them. Those already issued were paid for by our grant from the National Lottery Community grant which has now ceased. Some of our PEM Friends made a donation towards the postage and we will charge to cover the cost of future t-shirts. Other major items include website charges, postage and printing costs, etc.

Thank you again to those who keep us afloat. If you would like to make a one-off or regular donation, the details are 

Bank name: HSBC
Account Number: 51504525
Sort Code: 40-08-33
Account name: PEM FRIENDS

support us
 DONATIONS DONATIONS DONATIONS

Spending wisely..

Here are some images of proud t-shirt wearers, the magazines arriving from the printers and our new banner for events! We have also purchased a printed PEM Friends tablecloth and some badges, also worn by some here. Also, look at the amazing photo of the "PV Warrior" tattoo Ady has on his arm!



Links to other groups:

Rareconnect: <https://www.rareconnect.org/en/community/pemphigus-and-pemphigoid>

The International Pemphigus and Pemphigoid Foundation: <http://www.pemphigus.org>

NHS: <http://www.nhs.uk>

Findacure: <https://www.findacure.org.uk>

PV Network: <http://www.pemphigus.org.uk>

GlobalSkin: <https://www.globalskin.org>

CCSF Learning hub: <https://www.tavinstitute.org/projects/coronavirus-c>

July 2021

Editors: Trina Harris & Isobel Davies

Design and layout: Trina Harris

Facebook: <https://www.facebook.com/groups/www.pemfriendsuk.co.uk/>

Contact Information for next issue:

Isobel Davies: pemfriends1@gmail.com / **Trina Harris:** trinaharris@btinternet.com

ALL IMAGES TAKEN FROM PIXABAY - <https://pixabay.com>