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You are not alone

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

Who are we?

PEM Friends is, principally, a support group for people in the UK who have been diagnosed with either Pemphigus or Pemphigoid, or those who care for them.

We do not have any funding, so any help offered comes from other sufferers who can offer personal advice or experience. Most people find there is someone out there who has or is going through a similar experience to them or their loved one.

We try to keep up-to-date on any research or medical updates related to the diseases, but we do this on an ad hoc basis, (unsupported by any personal medical expertise, although with access to some excellent specialist advice). There are usually 2 main issues that our members report – the difficulty in getting a diagnosis and the problem of finding a local expert who understands the diseases and can provide the best and most up-to-date treatment.

There are many options on the sorts of treatment regimes and products that ease the symptoms. We have a new website: <https://www.pemfriendsuk.co.uk/>

where we have tried to offer some information on these on the 'Resources' page, but we are always open to further suggestions. Everyone is unique – what works for one may have no impact at all on another. Some of the side-effects can be dramatic, too.

Most support is via e-mail, but we do meet for lunch every so often, usually with an expert Dermatologist or another specialist available to chat about the diseases and any recent development.

We trust you will find the content of the newsletter helpful. Please feel free to suggest future topics for inclusion using Isobels' & Trina's contact details on the back page.



Some PEMFRIENDS at a recent meetup.

A warm welcome from Isobel

It's been some time since my last Newsletter. Many thanks to Trina for picking up the mantel and getting us galvanised.

I hope you and yours are all healthy and pain free and heading towards remission. It's a long and hard journey but it is achievable. Some of us have already arrived there and we are happy for all of those who have been able to put the disease behind them.

You will, no doubt, be worrying about the Corvid 19 crisis at the moment, and we include advice from the experts below about how best to deal with the risk.

Those of you in the PEM Friends Facebook group will know our editor, Trina. If you are not in the Facebook group, which has proved very valuable and supportive to many people, then I would recommend it to you. It is at:

<https://www.facebook.com/groups/1501381213444947/> And with over 250 members, there is plenty of experience to share.

During the last year, we have attended a major conference in Milan, run by Globalskin.



International Alliance of Dermatology Patient Organizations

Globalskin is the face of the International Alliance of Dermatology Patient Organisations and we and the International Pemphigus and Pemphigoid Federation are members. Our own Sharon and Trina attended and had the opportunity for creating a great point of collaboration and Sharon tells us more about the event below.

We continue to build alliances with other groups. The APPF in France, in particular, has a lot more resource and material than we do and have been extremely helpful and supportive. We met them at the European Association of Dermatology Conference 18 months ago. Their representative, Laurence, has been a great ally and she also is one of the main representatives on the European Patient Advocacy Groups. These are split

into sub-groups, one of which is devoted to skin related ailments and aimed at creating collaboration between medical specialists and researchers across Europe to understand and treat disease better. Hopefully, the UK participation will continue despite Brexit. For more information, and there is a lot, go to



[https://www.eurodis.org/
content/epags](https://www.eurodis.org/content/epags)

Another great opportunity to be involved has been taken up with the Nottingham Dermatology Trials Network. One of the studies (and I hope you have completed the survey!) is outlined below and is called the PEM Priority Setting Partnership. They are also conducting other research and analysis related to our diseases. The group is led by Dr Karen Harman, who many of you will know for her care and treatment at the Leicester Royal Infirmary Dermatology Clinic.

As you can tell, we have been busy trying to connect with other groups who can provide support, information, resources and advice. Another group is Findacure, who help small groups like ours have a bigger impact. We are hoping to do more with them, using their training and mentoring. I attended one of their annual workshops recently where the topic was Drug Repurposing. More on that later too.



*From L to R : Fellipo Lattuca, Italy; Marc Yale, IPPF;
Trina Harris, UK PEM Friends; Laurence Gallu, France;
Sharon Hockey , UK PEM Friends
at Global Skin in Milan 2019*

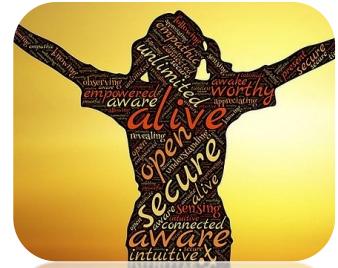
A warm welcome from Isobel

Continued...

Finally, we are sad to say that Professor Dart, who has done so much for people with OCP is retiring from clinical practice although he will continue with research into the disease. And Jane Setterfield at Guys, who is also a strong supporter of our group and who continues to deliver the highest level of care and expertise to patients and other medical specialists has been made a professor.

As you can tell, we have been busy. But there is so much to do if we want to

- Build awareness and reduce the period before a diagnosis is given
 - Improve knowledge and expertise in the treatment of PEM and
 - Reach out to more patients who feel they are alone and suffering the awful impact of Pemphigus and Pemphigoid.



I do hope you enjoy the newsletter. We are all working through the impact of **Covid 19 as well as** our own disease while we produce this and try to make an impact for the benefit of us all. Any feedback would be gratefully received. Please do let us know using the contact details on the back page.

Food & Nutrition

There is absolutely no evidence that there are any foods that contribute to Pemphigus or Pemphigoid, however, particularly for those with mouth involvement, eating can be difficult and certain foods can aggravate the situation.



It is best to avoid:

Onions, garlic, chives, leeks, salt, oranges, tomatoes and tomato and brown sauce, marmalade, lemons, pizzas, pickles, vinegar, salad dressings, pre-prepared foods, some cheeses (with high salt content), toast, crusty bread, berries, e.g. strawberry, blackberry, including strawberry yoghurt, all herbs and spices, fizzy drinks, crisps, nuts and hard food such as apples. Alcohol can dry out the mouth, particularly red wine.

When mouth lesions are particularly painful, try:-

eggs, fish, custard, ice cream, soft small pasta shells (take care about the sauce), soft vegetables (steamed to retain nutrients)

Eating Out

This can be difficult, although some restaurants will prepare a special simple dish omitting certain items. You need to be pro-active and ask for a dish without a certain item or sauce and check menus carefully for what is in each dish.

It is important to make sure you try to eat, even when it is difficult. Try using a small plastic spoon as it is softer on the mouth than metal cutlery

British Association of Dermatologists*

The British Association of Dermatologists (BAD) is a charity whose charitable objects are the practice, teaching, training and research of Dermatology. It works with the Department of Health, patient bodies and commissioners across the UK, advising on best practice and the provision of Dermatology services across all service settings. It is funded by the activities of its Members.

The BAD works with many other organisations to achieve its aims of supporting patients and improving standards. These include Patient Support Groups, Special Interest Groups, International Dermatology Groups and the Medical Royal Colleges.

Social distancing: What should I do?

Working from home



Advised

For anyone aged 0-69

Strongly advised

Anyone 70+

Those with an underlying health conditions

Pregnant women

Use less public transport



Advised

For anyone aged 0-69

Strongly advised

Anyone 70+

Those with an underlying health conditions

Pregnant women

Visits from friends and family



Advised against

For anyone aged 0-69

Strongly advised against

Anyone 70+

Those with an underlying health conditions

Pregnant women

Socialising outside home



Advised against

For anyone aged 0-69

Strongly advised against

Anyone 70+

Those with an underlying health conditions

Pregnant women

Those with serious underlying health conditions: as above but further guidance will be provided by the NHS

On this site we provide information sheets about skin diseases, written and approved by our dermatologists, as well as general information about the skin, current issues in skin disease along with changes to dermatology services in the UK and those areas experiencing problems with providing access to care for their patient population.

Dermatology Advice Regarding Self-Isolation and Immunosuppressed Patients: Adults, Paediatrics and Young People can be found following the link below:

<http://www.bad.org.uk/.../covid-19-immunosuppressed-patients>

*Source www.bad.org.uk

Coronavirus tips and tools

"As COVID-19 spreads, so do all sorts of bizarre and dangerous myths like "the new coronavirus is man-made" or that "handwashing isn't effective". In the face of an international public health emergency, it's crucial that you get your information in the right places.

Avoid using social media as your main source of news or health advice, especially from accounts, organisations or individuals with no medical qualifications or backing.

Lots of trustworthy websites, including [Patient](#) and [Public Health England](#), are staying on top of the latest news about this coronavirus outbreak to help you protect yourself and your community."

Dr Sarah Jarvis MBE, Clinical Director at Patient

*"it's crucial
that you get
your
information
from the
right places"*

How and when to get help?

You should use the [NHS 111 self-check tool](#) to see what action you need to take if within the last 2 weeks:

- You have returned from mainland **China, Thailand, Japan, Republic of Korea, Hong Kong, Taiwan, Singapore, Malaysia or Macau** and have fever, cough or shortness of breath, no matter how mild.
- You have returned from **Italy, Vietnam, Cambodia, Laos or Myanmar** and have fever, cough or shortness of breath, no matter how mild.

- You have returned from the **H10 Costa Adeje Palace Hotel (Tenerife)**, even if you don't have any symptoms.
- You have returned from **Iran, specific lockdown areas in Northern Italy or special care zones in South Korea**, even if you don't have any symptoms.
- You have returned from **Wuhan or Hubei Province of China**, even if you don't have any symptoms.
- You have been in contact with someone with a **confirmed case of coronavirus**.

This tool is designed for English users. If it recommends that you contact 111:

- In England and Wales ring 111.
- In Scotland, ring your GP during opening hours and 111 (NHS24) out of hours.
- In Northern Ireland, ring the coronavirus 24/7 helpline on 0300 200 7885.

Do not visit your GP or pharmacist if you are concerned you might have coronavirus - they do not have facilities in place to isolate you and prevent transmission of the infection to others.

How to protect yourself.

Like many viruses, there are lots of things you can do to reduce your own risk of contracting COVID-19. These measures will also reduce your risk of contracting the [common cold](#) or [flu](#), both of which are spread by cough and sneeze droplets.

- Carry tissues at all times and use them to cover your mouth and nose when you sneeze. Bin the tissue (preferably in a bin with a lid) and wash your hands or use hand sanitiser. If a tissue isn't available, cough or sneeze into your elbow rather than your hands.

Wash your hands frequently and properly. This means using the WHO [recommended handwashing method](#), hot water and soap. If you can't wash your hands, use a hand sanitiser containing at least 60% alcohol and wash your hands at the earliest opportunity.

- Avoid touching your face, especially your mouth, eyes and nose, with hands that haven't been washed.
- Avoid contact with people who are unwell.

Wearing surgical face masks makes little difference outside of hospital environments as they must be worn and removed correctly, changed frequently and disposed of safely to be effective. Rising demand from the public for protective face masks is also causing shortages for hospitals around the world.

There isn't yet a vaccine but various teams of scientists across the globe are in the process of developing a vaccine to protect against COVID-19. There also isn't a specific treatment yet available, although many people will recover from mild infections following rest and fluids. Those who go on to develop pneumonia will have their symptoms managed and treated.

"Know the signs and symptoms"

It's important that we're able to spot the signs of COVID-19 so that we can act quickly if we need to. As COVID-19 is part of the coronavirus family which includes SARS, MERS and the common cold, many of its symptoms are respiratory and flu-like.

If you do not have a fever, it is relatively unlikely you are infected, although some people are able to be infected and pass on the virus without symptoms. Typically, a runny nose and sneezing are not symptoms of this virus.

According to a study published in The Lancet, the proportion of infected people with the following symptoms of SARS-CoV-2 infection is:

- Fever - 98%.
- Cough - 76%.
- Shortness of breath - 55%.
- Muscle ache or tiredness - 44%.
- Coughing up sputum - 28%.
- Headache - 8%.
- Coughing up blood - 5%.

Obituary - Gordon Pirie (1936-2019)

We were very sad to hear about the death of Gordon who, with his wife Maria, has been a longstanding member of PEM Friends, contributing both on e-mail and Facebook as well as providing much needed financial support.

Gordon died in August last year but we missed his obituary in the Times. Gordon has had a very impressive history in the diplomatic service and he and Maria seem to have shared a very exciting and eventful life together. His adventures included a significant involvement with the Iranian Hostage situation in 1979.

Maria remains a much appreciated member of PEM Friends.

Maria and Gordon attended the last PEM Friends lunchtime meeting in London, Maria is in the centre front and Gordon third from the right.



Obituary - Rosemary Pratt (1950 -2020)

Rose came from a large family and was 1 of 6 children born in Wiltshire. She lived a simple life and struggled throughout with depression after the loss of her son, Anthony, at 2 days old. She lived for her Husband George, Daughter Sally and Grandchildren Theresa and Paul.

Rose was initially diagnosed with Pemphigoid Bullosa Vulgaris just over 12 months ago, starting with blistering in her mouth. This progressed to very large blisters on her hands and feet. She dealt with these better than I would have and took them in her stride. After further tests she was diagnosed with Epidermolysis Bullosa Acquisita. She was at a routine dermatologist appointment when the Dr noticed a lump in her neck, within days she had blood tests, biopsies and an ultrasound, a diagnosis of Lung Cancer followed shortly, which had spread to her lymphatic system.

The staff at GWH Swindon have been awesome and Chemotherapy arranged post haste along with IV immunoglobulin therapy for which funding had to be sought.. Still the blisters came and the skin thinned. After the first Chemotherapy Rose seemed to weaken in body strength dramatically and continued to weaken over the next few weeks. Chemotherapy was halted but IVIG continued, after 3 days of this she became far to weak to continue her daily struggle to the hospital. On the 3rd day my wife jokingly refused not to take her home because her arms, legs and body were covered in lesions, all raw, sore and weeping. Wounds dressed, the hospital rallied around and arranged delivery of a bed, mattress and various aids for mobility.

Rose continued a downhill journey, palliative care was arranged but a care package could not be sorted due to the lack of nurses in the community. Somehow Prospect found some care and a nurse turned up for a waking night. In the morning the community nurse decided she was showing signs of agitation and needed morphine. An injection was given and a pump was conjured from nowhere.

Family were sitting talking to her as she slipped away peacefully, she looked calm and content her family sat with her one by one saying there goodbyes. Emotions were high and Covid-19 was at the back of everyone's minds just for short time.



Where can I find some help?

If you have any concerns about your mental health or coping with your skin condition, please see your GP, who may be able to refer you on for further support. You may also find the following resources helpful:

Skin Support: Website developed by the British Association of Dermatologists containing emotional support resources and patient information leaflets for people with skin conditions. Visit www.skinsupport.org.uk.

Mind: Mental health charity that provides advice and support about mental health problems. Tel 0300 123 3393 (Mon-Fri, 9-6), text 86463, email info@mind.org.uk or visit www.mind.org.uk.

STRESSED? By Trina Harris

We all know what that feels like! The immune system is one of the first protective mechanisms to be activated when you're exposed to stress. When this happens, a major part of the brain and many hormone-producing glands are activated.

I am certain that anyone reading this article will relate to being stressed and noticing increased disease flare ups! Often the time it takes to be diagnosed and waiting for appointments can cause us so much stress that we get an even greater flare up? Is this true of you? When we feel anxious, our bodies release hormones called cortisol and adrenaline. This is the body's automatic way of preparing to respond to a threat, you have probably heard of the saying, 'fight, flight or freeze' response. This is what is happening to you when you are stressed and are producing high levels of these hormones. Well, since I was diagnosed with Pemphigus Vulgaris in 2018, I have realised that to be stressed means more blisters!



What is the answer?

Well, we know that we simply cannot remove all of the stress but the more we change some of the things that cause us stress the better our blistering condition will be. I used to be a special needs teacher and although the job gave me so much joy, making a difference to young children's lives. Teaching, watching and observing the tiny steps they were making but were huge at the same time.. I knew that the position of responsibility was causing me so much stress (although I couldn't really admit it at the time) I decided the best thing I could do was QUIT!

Which is what I did. I made a huge step! I now have low key part time job and can work from home as often as I like! Yes, the pay is less than half of that I used to receive but my health was more important than the money! What steps can you take to alleviate the stress in your life to trigger the possibility of reduced disease activity?



Have you heard of Headspace? This is a very helpful tool for stress: <https://www.headspace.com>.

In a year you'll barely remember why you felt so stressed, so why stress about it now? Take care
Trina x

DRUG REPURPOSING FOR RARE DISEASES CONFERENCE

by Isobel Davies



In February this year, Findacure held their annual Drug Repurposing for Rare Diseases conference.

I attended and learned a lot about the process for licencing drugs originally designed as a treatment for one ailment so they can be used for another – usually a rare disease for which there were no drugs under development.

I was surprised how many organisations were interested in and funding this area. There were Clinicians, Researchers, Rare Disease groups and Pharmaceutical organisations speaking and attending.

For many rare diseases, there are no drugs available at all. Finding a suitable treatment can vary from a rather hit and miss process to a very complicated computer analysis.

In Europe, they consider a disease rare if it affects 5 or less people in every 10,000. They also told us that only 400 of the 7,000 rare diseases have licenced treatments.

Since the total number of people with a rare disease adds up (around 3.5 million people in the UK with a rare disease), there is sufficient and mounting interest to find better ways of diagnosing and caring for these people.

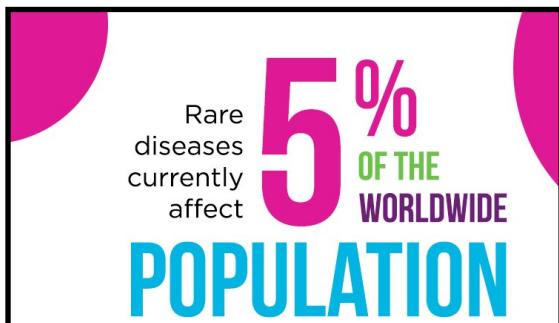
Government has, since 2013 built strategy and policy in this area.

One of the speakers was from NICE (<https://www.nice.org.uk/>) and she spoke very powerfully about her interest in rare disease, and the view from NICE that we need to speed up and use different, simpler approval processes to get helpful drugs to patients.

I was encouraged and also somewhat overwhelmed by the work and interest going on in this area.

I can offer many points of reference if you want to contact me for further information.

E-mail me (Isobel) at: Pemfriends1@gmail.com



Head over to the PEMFRIENDS website



<http://www.pemfriendsuk.co.uk> Most of the information on the website is copied from other resources. We are particularly grateful to the IPPF, with whom we are allied. We strongly advise investigating more sources of information about Pemphigus and Pemphigoid via all the links and al-



so other resources. On this site, we can only offer summary information and advice and we may not be 100% up to date on current thinking or treatments.

Another useful source of shared information and possible support is Rareconnect. Links for these and other websites is on the Resources page. (Links also on back page of this newsletter.) Many thanks to Ingrid Thompson for all her efforts in relaunching the website and for trying her best to keep the information relevant and up to date.

SETTING RESEARCH PRIORITIES FOR THE TREATMENT OF PEMPHIGOID AND PEMPHIGUS IN THE UK by Isobel Davies

Late in 2018, PEM Friends, the UK support group for people with immune-bullous diseases, was invited to participate in a Priority Setting Partnership.

As we discovered after eagerly agreeing to something we knew absolutely nothing about, this is intended to survey the patient and medical community connected to our diseases. The intent is to establish the top 10 or so issues related to treatment that these communities see as requiring investigation or research into Pemphigus Vulgaris, Bullous Pemphigoid and Mucous Membrane Pemphigoid.

We patients on the team (about 6 of us), were aiming to change the world and conquer our diseases but were guided towards a more modest and much more achievable target of improving treatments. A still very exciting and motivating goal and the important work on finding out what causes immunobullous skin diseases will carry on.

The Priority Setting Partnership was initiated by the UK Dermatology Clinical Trials Network (UK DCTN) which develops research ideas into high quality, independently-funded clinical trials of treatments for skin disease in the UK.

The 900 or so members of the network consist of dermatologists, dermatology nurses, researchers and patients throughout the UK and Ireland. It is coordinated from the [Centre of Evidence Based Dermatology at The University of Nottingham](#)

The intention of a Priority Setting Partnerships is to enable clinicians, patients and carers to work together on an equal footing to identify and prioritise particular areas of health and care that could be answered by research. The partnership is facilitated by the James Lind Alliance, but the funding and organisation is being done by the Priority Setting Partnership team and the UK DCTN. The Nottingham Hospitals Charity provided

funding to carry out the Priority Setting Partnership.

We started by refining the communications and the wording for the first survey. A surprisingly tough and demanding task. We were anxious to speak to as many medical professionals, patients and carers affected by the disease as possible and finding the right words that persuaded/explained/informed as simply as possible was a challenge.



Despite the fact that the Priority Setting Partnership includes, as well as PEM Friends and patients, eminent dermatologists, ophthalmologists and dermatology nurses, our very biggest challenge is in finding the contributors to the survey. Clinics run by experts in these diseases in the UK are few and far between and they will hand out leaflets and copies of the survey, but we need to reach as many people as possible and there are no lists of patients with our rare diseases. We hope that we will get as many UK based patients, carers and healthcare professionals as possible by Spring 2020.

Once we have got enough contributions, we will be able to carry out the second survey which will ask people to prioritise the questions about treatments that have been raised to create a shortlist. Finally, those patients and clinicians who indicate an interest in doing so, will be invited to a workshop to consolidate the final top 10.



Continued over...

SETTING RESEARCH PRIORITIES FOR THE TREATMENT OF PEMPHIGOID AND PEMPHIGUS IN THE UK

Continued..

Collecting inputs to the first survey closes at the end of March and now need to step up our efforts to get as many respondents as we can. Although we have a rare disease, there is an opportunity

to gather a representative sample and really get valuable data on what patients and medical experts alike, see as the most important aspects of pemphigoid and pemphigus treatment.



The survey simply asks for up to 5 questions that people have about the treatment of their disease.

In parallel with the Priority Setting Partnership, members of PEM Friends are also involved in other work being led by researchers at the Centre of Evidence Based Dermatology.

One study will show how many people in England have developed bullous pemphigoid in the last 20 years, and whether the number of people affected is changing or varies by geographical region. We will

also describe the dose and length of time over which people are prescribed steroid tablets, and any reasons why patients might not be able to take part in a future trial."

We hope that this is the start of something really important in what feel like neglected and little understood diseases. The results will be used to inform future research and investigation.

If it raises awareness alone, it will be a big step forward.



For more information about the DCTN and the James Lind Alliance, go to :

<http://www.ukdctn.org> and <http://www.jla.nihr.ac.uk/priority-setting-partnerships/>

And to see the survey, go to <https://www.surveymonkey.co.uk/r/PEM-PSP>.

Please do take a look and provide your inputs to the survey.

Every contribution makes a difference and the more we can get, the more informed future research will be.





GLOBALSKIN 2019 - Milan

Conference June 7-9th & RareDERM Forum 5th-6th June

June 2019 I was invited to represent PEM friends by attending my first ever medical Conference: GLOBALSKIN 2019. No, I had no idea what this would entail either - I don't think anyone else was available at the time!

I went with a totally open mind and the idea that, every committee has a "novice" in it's ranks - the person who knows nothing at the start but has to learn on the job. Eventually one day, that person becomes an experienced and useful committee member and be able to show someone else the ropes. Well, I decided, the worst I could do was to be that newbie, at least I would learn a few things and hopefully take something useful back to PEM friends.

Luckily the lovely **Trina Marie Harris** from PEM Friends had arrived before me with her wonderful husband and although I'd never met them, I knew it was Trina's first time too so I wouldn't be completely alone.

Hosted by an organisation called IADPO (see above) I was immediately struck by variety among the 180 Delegates representing 60 Skin diseases and from 42 different countries, each identified by a conference badge bearing our name, our Country and the organisation we represented. I confess I was overwhelmed by the professionalism and scale of it all and very amused to learn that the standard greeting for the event was: "Hello Sharon (squinting at my badge) what's your disease?"

Funded by 5 major pharmaceutical Companies, the aim of the conference was to bring together Representatives of Dermatology patients from around the world to show us how we could work with our fellow patients and learn from each other to better represent our Patient members around the globe.

The whole point of representing patients, I learned was that with time and organisation, a group of patients with the same disease become interesting to the medics of the world. Between them, these patients hold the answers to many medical conundrums and the route to finding a treatment and maybe even a cure. When there are enough of these patients, the Big Pharmaceutical Companies become interested. Now these guys have a lot of funding to invest and are constantly looking for new drugs to research and opportunities for breakthrough treatments. There's big money to be made in this business but they need patients (customers - us) to identify our needs to start the ball rolling.

The programme was 4 ½ days packed with plenary sessions, Forums, break out sessions, and networking sessions. Trying to teach us different ways to attract research interest and then Pharm funding to improve our disease situation.

Many of our fellow delegates were patients themselves. Several had turned their interest into their job and become professional representatives working for major charities (Psoriasis UK, for example). Others were simple patient advocates like Trina and I looking for a starting point. Well, the organisers did a terrific job of making us all feel relevant. The starter groups were encouraged as well as the very professional organisations, everybody was keen to share advice, experience and funny enough, symptoms;



funding proposal to a Pharmaceutical company (early days for PEM friends maybe?) We participated in some research into the psychological and social impact of having a skin disease (Globalskin.org/GRIDD). For this we talked about the many effects of suffering with a skin disease: Isolation, depression, feeling a lack of control, the need for coping skills, The social stigma with the visible symptoms, the financial burden and the demotivation suffered. The researchers from Cardiff And Hamburg Universities clearly had a good understanding of the difficulties faced by our fellow patients. They are working towards using their data to influence the access to care for patients at country or regional level. We were happy to help.

I learned many things from this conference and hope to be able to share them with you in later articles. One of the very special moments was when we 5 Pemphigus patients from 4 countries held a side meeting and pledged to assist one another in any way we can. As a result of this meeting we had some good discussions with Marc Yale, executive Director of the IPPF International Pemphigus & Pemphigoid Federation based in the USA and himself a PV patient. IPPF seems to be the largest PEM organisation worldwide and is the route that many UK patients have followed to eventually find PEM friends. We hope to collaborate more with Marc and his team in the future but he assures us that his resources are available to us in the UK as and when needed. Laurence Gallu from the French APPF with her perfect English joined us and we learned about the French organisation and that her own PV appears to be in remission as she takes part in an exciting clinical trial for a Rituximab bio-similar drug being developed by Leo Pharmaceuticals. The charming Italian Fellipo Lattuca made up the 5th member of our side meeting. (See photo below)

But in order to keep this piece short, I will summarise by saying that we learned that the starting point for an effective Patient Organisation is very much to bring together patients with a shared disease. Support one another, share symptoms and signs, share tips and advice. Open your arms to new members and their families. Together we can get through this and hopefully make improvements to our lives.

- Disease advocacy matters
- Pharma industry is increasingly including the patient voice as disease experts
- Patient voice needs to be included in key health care decisions

If we keep learning and listening, keep contributing to research whenever possible then one day, the information will fall into place and maybe, just maybe a cure could raise it's head.

Sharon Hockey (PV)

Globalskin.org

One Skin

One World

One Voice

We found we had a lot in common.

I learned that skin dressings are really hard to obtain in South Africa, the Netherlands have a sophisticated database of skin disease pictures that they hope to make globally available for diagnosis one day. How to write a

funding proposal to a Pharmaceutical company (early days for PEM friends maybe?) We participated in some research into the psychological and social impact of having a skin disease (Globalskin.org/GRIDD). For this we talked about the many effects of suffering with a skin disease: Isolation, depression, feeling a lack of control, the need for coping skills, The social stigma with the visible symptoms, the financial burden and the demotivation suffered. The researchers from Cardiff And Hamburg Universities clearly had a good understanding of the difficulties faced by our fellow patients. They are working towards using their data to influence the access to care for patients at country or regional level. We were happy to help.



**Sharon Hockey, Trina Harris,
Marc Yale & Laurence Gallu**

PEM FRIENDS ACCOUNTS



As ever, we have managed to stay solvent.

We currently have a balance of £616.88 in the account, with huge thanks to those of you who have donated. Most money goes towards paying for the costs of running the website, Any “surplus” will go towards additional means of extending our membership and establishing us as a more influential force with the medical profession. We have also been invited to join a few conferences in this country and abroad (if the travel ban has ended), and the information and collaboration this offers is very useful as you can see from this Newsletter. The greater our number and the more connected we are, the more influence we can bring to bear and the more help we can provide to people who suffer from these horrible diseases.

If you would like to contribute, donations can be made to:

HSBC

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Sort Code: 40-08-33

Account name: PEM FRIENDS

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Links to other groups:

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

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

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

Pemphigus in Remission: <http://www.pemphinremission.com/>

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

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Design and layout: Trina Harris

Contact Information for next issue:

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



If anyone is interested in organising a get together, then let Isobel know. She'll be happy to help.