

## **Blistering Skin Diseases Priority Setting Partnership Steering Group biographies**

### **Patient representatives:**

#### **Ingrid Thompson**

Ingrid was diagnosed with Bullous Pemphigoid, at the age of 54, in April 2015. The disease turned her life upside down and resulted in her taking early retirement from Leicester libraries in 2016. Ingrid is still on medication but currently only experiences the occasional blister. She wishes to help with research into pemphigus and pemphigoid illnesses and hopes to increase awareness of these conditions.

#### **Isobel Davies**

Isobel developed the early stages of MMP when she was working in a senior HR Role. It continued to develop into a significant nose and sinus problem, initially diagnosed as an allergy. She was 39 when she then erupted in blisters on her hands and feet and spent some weeks in Hospital. The MMP was diagnosed at this point. Isobel has had many operations on her nose, (including the removal of part of her septum), her larynx and some on her eyelids. She has also had a serious airway obstruction caused by blistering. Her voice has been affected by the MMP and, despite several attempts at voice therapy, she can speak, at best, with only a croaky voice.

#### **Jagdish Barha**

Jag Barha is married with 3 children. She was diagnosed with Pemphigus vulgaris (PV) approximately five years ago. Despite having this condition she works full time in the NHS. Jag joined PEM Friends, a support group on Facebook and found the support from other PV sufferers to be invaluable.

#### **Lisa Shendge**

Lisa is 76 years old and has had Bullous Pemphigoid for four years. She has other disabilities but manages well. Lisa worked as a senior Occupational Therapist later serving as a Disability Qualified Member of Disability Appeals Tribunals. She was a Magistrate and has sat on several disciplinary committees including the General Medical Council.

#### **Sharon Hockey**

Sharon is a Freelance Business Manager specialising in Rail Engineering and Agriculture and a keen horse rider. She was diagnosed in November 2018 with Pemphigus Vulgaris, after 4 years of possibly related symptoms.

Sharon's late Mother suffered 30 years of autoimmune connective tissue disorders and associated treatments, so Sharon is keen to participate in any opportunity to improve treatments for future patients. As a former carer and now herself a patient, Sharon has been using the PEMfriends Patient advocacy online group to learn more about this disease.

#### **Badruj Rahman**

Badj was diagnosed with MMP after 9 months of tests in 2015, aged 48 while working as a Civil Engineer in London. This extended to his oesophagus creating strictures, and causing rapid weight loss through his inability to eat. Badj has worked closely with his dermatologist, Gastrologist ophthalmologist, dietician and dentist to lessen the blistering on both his skin and in particular his mouth. He has had 3 dilatations performed by a Gastrologist to help stretch the oesophagus which have been successful and undergone two courses of intravenous Rituxumab.

## **Clinical representatives:**

### **Karen Harman – Dermatologist**



Karen is a Consultant Dermatologist in Leicester and a Clinical Associate Professor at the University of Nottingham. Karen has a longstanding research interest in autoimmune blistering diseases. Her doctorate involved establishing ELISA assays for the diagnosis and investigation of pemphigus and the technique is now used in routine care. She was the development group leader for the management of Pemphigus Vulgaris BAD guidelines in 2017 and is currently a member of the group updating the bullous pemphigoid guidelines. She has

worked on research projects in partnership with the patient support groups PEM Friends and the PV network.

### **Jane Setterfield - Dermatologist**



Jane is a clinical academic dermatologist and oral medicine specialist. She has an active interest in research into autoimmune blistering diseases, in particular; improving diagnostic techniques for PV/MMP, devising clinical outcome measures for oral PV/MMP, and identify biomarkers for disease severity in MMP.

Jane is a clinical advisor for the patient support group – Pemfriends, and an active member of the European networks for rare blistering diseases.

### **Ruth Murphy - Dermatologist**



Consultant Dermatologist in Sheffield, including the Department of oral medicine, Sheffield and Nottingham Children's Hospital. Ruth has been a consultant Dermatologist since 2001 and is Associate Professor University of Nottingham. She is a Fellow of the International Society of Vulvovaginal Disease and the British Association of Vulvovaginal disease. Her interest is in chronic inflammatory skin disease affecting the skin and the mucous membranes in adults and children. Blistering disorders often affect the oral and genital regions and affect people considerably. Ruth is also involved at national level in medical education.

### **Gudula Kirtschig - Dermatologist**



Gudula is a Consultant Dermatologist based in Germany and Switzerland. She studied medicine at Ulm University & Muenster University in Germany and previously practiced dermatology in Nottingham and Oxford, UK and Amsterdam, NL. She has special interest in vulval skin disease, pregnancy associated skin disease and blistering skin conditions. With a strong research interest her work has contributed towards more than 80 peer reviewed scientific articles, national/international clinical guidelines, and patients' information leaflets. Gudula works with the Cochrane skin group to deliver systematic reviews and sits on oversight committees of clinical trials.

### **Philip Hampton – Dermatologist**



Phil has been a Consultant at the Royal Victoria Infirmary Newcastle, since 2007. He has a special interest in people with complex immunobullous diseases and runs a joint Oral Medicine-Dermatology clinic. He was a member of the group that produced the 2017 BAD Pemphigus guidelines. Other research and clinical interests include psoriasis, hand eczema, Hidradenitis and Tele-dermatology.

He is co-founder of an app to improve skin self-monitoring ([myskinselfie.com](http://myskinselfie.com)).

### **John Dart - Ophthalmologist**



John is a clinical scientist and has been a Consultant Ophthalmologist at Moorfields Eye Hospital since 1989 and an Honorary Professor of UCL, at the Institute of Ophthalmology, since 2011. His research has been focused on microbial keratitis and scarring eye diseases including mucous membrane pemphigoid. He has published over 30 peer reviewed studies related to pemphigoid.

### **Saaeha Rauz – Ophthalmologist**



Saaeha Rauz has been an Academic Consultant Ophthalmologist at the Birmingham & Midland Eye Centre since 2003 and Reader of Translational Ophthalmology at the University of Birmingham. She has a specific interest in immune-mediated ocular surface diseases and immunosuppression for conditions such as mucous membrane pemphigoid and Stevens-Johnson Syndrome.

### **Antonia Lloyd-Lavery – Dermatologist**



Antonia is a Consultant Dermatologist at Oxford University Hospitals NHS Foundation Trust. She has a specialist interest in blistering diseases and runs the regional immunobullous service in Oxford including fortnightly blister clinics and joint oral dermatology clinics.

She is currently leading the BAD's national guidelines on the management of bullous pemphigoid and sits on the UK Dermatology Clinical Trials Network Trial Prioritisation Panel. She was previously involved in the BLISTER trial for bullous pemphigoid and has conducted national surveys assessing the impact of this study on clinical practice in the UK.

### **Sharleen Hill – Dermatologist**



Sharleen is a dermatology registrar and UK DCTN Fellow with an interest in immunobullous disorders. She has experience in clinical trial development specifically in blistering diseases after a fellowship in Australia and the United States.

### **Debbie Brown - Nurse**



Debbie is a Clinical Nurse Specialist in Medical Dermatology at St John's Institute of Dermatology at Guy's & St Thomas' NHS Foundation Trust and Lead CNS for Hidradenitis Suppurativa, inpatients and SJS/TEN. She was a member of the BAD Guidelines Committee developing guidelines for pemphigus vulgaris and has been working with patients who have immunobullous conditions for many years.

### **Melanie Westmoreland - Nurse**



Mel is the lead research nurse in Dermatology at the Churchill Hospital in Oxford. She recruited patients to the Blister study and realised what a devastating impact blistering conditions can have on patients and their family's lives. She feels that working with patients to identify the most important questions is vital to developing research in this field.

### **Christina Waistell - Nurse**

Christina is a Dermatology Specialist Nurse at the University Hospitals of Leicester NHS Trust. Initially working with dermatology inpatients, she then moved to outpatients and set up nurse-led clinics for patients with inflammatory skin conditions. Recently she has been part of the multi-disciplinary team in a complex medical dermatology clinic which specialises in immunobullous conditions. She has also assisted in developing their service for patients with Hidradenitis Suppurativa.

## **The Partnership and the priority setting process is supported and guided by:**

### **Douglas Grindlay**



Douglas is an Information Specialist in the Centre of Evidence Based Dermatology, University of Nottingham, working on various aspects of evidence-based medicine, systematic reviews and database searching, and developing methods for disseminating research and assessing impact. Douglas has an MA from Loughborough University and a PhD from the University of Nottingham, and is a member of the Chartered Institute of Library and Information Professionals.

### **Joanne Chalmers**



Joanne spent five years in clinical research in the pharmaceutical industry then joined the Centre of Evidence Based Dermatology in 2003. As a Senior Research Fellow, Jo has been involved in the design and implementation of several studies including an RCT to determine whether prophylactic antibiotics can prevent cellulitis, an RCT to compare doxycycline and prednisolone for bullous pemphigoid, and more recently an RCT to investigate whether regular emollient use from birth can prevent the onset of eczema in high risk babies.

### **Maggie McPhee**



Maggie is co-ordinator of the UK Dermatology Clinical Trials Network and provides support to both the Clinical Trials Development Manager and Network Manager. Her role involves co-ordinating submissions of research ideas to the network and supporting subsequent pilot/ feasibility work (surveys, focus groups). Maggie has been involved in several priority setting partnerships, including eczema, hidradenitis suppurativa, cystic fibrosis, hyperhidrosis and psoriasis.

### **Sheela Upadhyaya**



Sheela is an experienced expert facilitator with over 17 years of experience in the NHS. She has undertaken work in many different areas of the NHS including cancer, dermatology and rare diseases. She supports James Lind Alliance PSPs as a facilitator and has a history of working in situations where she brings together patients, clinicians and other stakeholders to establish common goals and objectives.