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## **Lichen Sclerosis Priority Setting Partnership**

### **Steering Group Member Biographies**

#### **Patient representative/s:**

#### **Suzanne Larsen**



Suzanne is the Founder and Chairman of the Danish Lichen Sclerosis Association. The Danish Lichen Sclerosis Association was founded in 2010 and it is a patient association for all patients suffering from lichen sclerosis, genital lichen planus and plasma cell vulvitis/balanitis. They currently have 378 members, mainly women but also 8 men, 8 children and 3 support members from all over Denmark including Faroe Islands. They cooperate with other associations in Europe. Their aim is to create awareness of the diseases, gather knowledge, inform and support the patients and their relatives. They also aim to take care of patients interests in relation to the political system. Suzanne is 41 years old and was diagnosed with lichen sclerosis in 2008. Her work for the Lichen Sclerosis Association is voluntary and unpaid and it takes place in her spare time. She has no medical background and works as a banking advisor for private clients in her professional working life.

#### **L.H.**

LH was diagnosed with lichen sclerosis aged 9, after 2 years of intrusive investigations and different treatments for similar presenting conditions. She then had appointments every couple of months until the age of 18 and although she became more used to it, the difficulty she experienced in attending those appointments, and the time in between didn't really wane over the years of her adolescence. Although she is able to do a lot more than originally expected, and is significantly more improved than her original prognosis allowed for, it has stuck with her into adulthood, and she still attends hospital a few times a year. The experience of the condition and her time as a young person attending hospital has greatly affected her throughout her life, and so she is here in the hope that sharing her experience might help to alleviate the difficulties for other people whether they have a paediatric or an adult diagnosis.

#### **M. D.**

MD was diagnosed with lichen sclerosis over 25 years ago but has had the condition for more than 30 years. She found it very difficult to get a diagnosis and relevant treatment and was originally told she had vulvodynia and then vestibulitis. It was only after consulting a number of gynaecologists and dermatologists that she eventually found a professor of dermatology who diagnosed lichen sclerosis.

MD was appointed as a patient representative for the British Society for the Study of Vulval Disease (BSSVD) in autumn 2014. The BSSVD is a UK based international society currently numbering over 160 doctors and drawn from a range of specialities such as Dermatology, Gynaecology, Genitourinary Medicine, Histopathology and Sexual Health. MD is one of two lay members who sit on the Council and provide input from a patient's perspective. MD is delighted that this piece of research is to be undertaken on lichen sclerosis and is hopeful that it will generate interest and funding for further research into this much neglected disease.

### **S.S.**

SS is a parent of a 7 year old daughter who has had lichen sclerosus since January 2017. They are under the supervision of a consultant dermatologist but it has been hard to keep symptoms under control. SS hopes to contribute a parent's perspective to the steering group.

### **H.B.**

HB is 41 and has had lichen sclerosus since she was a child. She was diagnosed at age 16. She is really pleased to have the opportunity to bring the patient perspective to this very important piece of work, which is desperately needed.

### **S.R.**



SR is a Research Fellow at Warwick Medical School (University of Warwick). She is a sociologist with research interests in women's health, gender, and experiences of health and illness. She completed a PhD in Health and Social Studies about young women who had breast cancer in 2015. Her expertise is in qualitative research methodology. She has a personal as well as academic interest in lichen sclerosus because a close relative has the condition. Last year she submitted a NIHR fellowship application on the topic of vulval skin conditions.

## **Clinical representatives:**

### **Rosalind Simpson**



Rosalind is the lead for the Lichen Sclerosus Priority Setting Partnership. She studied at the University of Nottingham Medical School, U.K and completed a BMedSci degree in 2002 and BMBS degree in 2004. In 2008, Rosalind commenced Dermatology specialist training. She has taken time out of her registrar training program to pursue a career in Academic Dermatology and completed a program of clinical research into vulvovaginal erosive lichen planus (ELPV) funded through the NIHR Doctoral Research Fellowship scheme. She has a research interest in trial methodology, especially for vulval skin disorders and rare conditions; diagnostic criteria development and selecting suitable outcome measures for clinical trials and clinical practice. Rosalind became a Fellow of the International Society for the Study of Vulvovaginal Disease ISSVD in 2011. She is a trainee representative on the British Society for the Study of Vulval Disease Executive Council.

### **Sandra Lawton**



Sandra is Nurse Consultant Dermatology, at Rotherham NHS Foundation Trust and Past Chair of BDNG (British Dermatological Nursing Group) 1998-2000. She is also a specialist advisor for Care Quality Commission (CQC). She qualified as a general nurse in 1981 and as a children's nurse in 2001. Sandra has worked in dermatology for 30 years previously at Nottingham University Hospitals NHS Trust and developed the role of dermatology liaison sister in 1990, the first post of its kind in the UK. Her areas of interest include paediatric dermatology, care of children and their families with atopic eczema, nurse led services and vulval skin conditions. She has contributed to the field of dermatology through her publications, presentations and research at national and international level. She was awarded Public Servant of the Year in 2003, the title of Queen's Nurse in 2007, Stone Award presented by the British Dermatological Nursing Group in 2010, Alumni Laureate Award from The University of Nottingham in 2011, Fellow of Queen's Nursing Institute in 2012 and an OBE for services to nursing in 2014.

## David Nunns



David Nunns is a Consultant Gynaecological Oncologist at Nottingham University Hospitals, Nottingham, UK. He runs the vulval service in Nottingham and completed a research MD in vulval pain in 1995. He established the Vulval Pain Society charity in 1994 to provide care and informal support to women with vulval pain and is a Trustee of this group. He is a member of Council of the British Society for the Study of Vulval Disease and is currently Chair of the Education and Training group. The outcomes of the group have included changes to postgraduate training and development of clinical standards for vulval disease.

David is also Cancer Lead at Nottingham for the East of England Genomic Medicine Centre 100,000K Genomics Project and Macmillan Recovery Package Lead.

## Susan Cooper



Susan is a Consultant Dermatologist at Oxford University Hospitals and an Honorary Senior Clinical Lecturer at the University of Oxford. She trained in Bristol and then completed vocational training in General Practice. After a short spell in General Practice she embarked on Dermatology training in the Oxford Region. She leads the vulval and contact dermatitis services in Oxford. She has had an interest in vulval disease for some years and submitted her research thesis on a clinical and laboratory study of vulval lichen planus. She has participated in two Cochrane reviews: Interventions for lichen planus and Interventions for Paget's disease of the vulva and has been part of the team that published a European review of treatments for lichen sclerosus. She has written several book chapters on vulval disease and in 2016 co-authored a new text book on vulval disease: Gynecologic Dermatology. She is a member of the International Society for the Study of

Vulvovaginal Disease and is currently chair of the British Society for the Study of Vulval disease.

## Gudula Kirtschig



Gudula is a Consultant Dermatologist based in Germany and Switzerland. She studied medicine at Ulm University & Muenster University in Germany and has previously practiced dermatology in Oxford, UK and Amsterdam. She has special interest in vulval skin disease, pregnancy associated skin disease and blistering skin conditions. Gudula has a strong research interest. She works with the Cochrane group to deliver systematic reviews and sits on the oversight committees of clinical trials. She is committed to excellence in clinical dermatology and her work has contributed towards the production of national/international clinical guidelines, producing of patients' information leaflets and developing national registries for surgical and vulval disease patients. The Lichen Sclerosus Priority Setting Partnership fits well with Gudula's clinical and research interests and she will be increasing awareness of the project through her international links.

### **Chris Bunker**



Chris is a Consultant Dermatologist with specific clinical and research interests in male genital lichen sclerosus, its causation (by urine), its treatment and its association with penis cancer. He does two male genital dermatology clinics a week seeing about 100 patients with lichen sclerosus each month. He works very closely with specialised Urologists at CWH and UCLH so that patients receive multi-disciplinary attention. Chris is a member of the British Association of Dermatologists committee working on the updating of the lichen sclerosus guideline. He is past President of the British Association of Dermatologists (2012-14).

### **Ruth Murphy**



Ruth is a Consultant Dermatologist with clinical experience of lichen sclerosus in women and children. She is President Elect of the British Association of Dermatologists and current President of the British Association of Paediatric Dermatology. She is a fellow of the International Society for the Study of Vulval disease (ISSVD) and on the Executive committee of the British Society for the Study of Vulval disease (BSSVD). Ruth is based at the Royal Hallamshire Hospital, Sheffield.

### **Paul Anderson**



Paul is a Consultant Urologist specialising in male genito-urethral reconstructive surgery (GURS). As such lichen sclerosus and its surgical management represents approximately a third of his overall workload. He frequently lectures on the topic and was regularly seen on Channel 4's Embarrassing bodies raising the profile of conditions such as lichen sclerosus. He is based in Dudley and also at the Royal Centre for Defence Medicine in Birmingham where he carries out GURS on injured servicemen.

### **Researchers:**

#### **Kim Thomas**



Kim is Co-Director of the Centre of Evidence Based Dermatology and Professor of Applied Dermatology Research. She has long been a supporter of patient and public involvement in research and has helped to run several skin-related Priority Setting Partnerships over the last 5 years. Her main research interests are in eczema, vitiligo, cellulitis and rare skin conditions.



## Emma Smith



Emma is a junior doctor who has recently completed her foundation training. She has previously worked with the University of Nottingham on a review into cellulitis trial outcomes, using feedback from the cellulitis Priority Setting Partnership as part of the project. She will be working on the Lichen Sclerosus Priority Setting Partnership as a research assistant. Her work will predominantly involve designing the taxonomy for the survey and categorising the first round survey responses.

## The Partnership and the priority setting process will be supported and guided by:

### Maryrose Tarpey



Maryrose is the JLA adviser for the Lichen Sclerosus Priority Setting Partnership. She has extensive experience of involving patients and practitioners in research as well as in project management and facilitation. Before becoming a JLA Adviser, Maryrose worked for [INVOLVE](#) (an organisation funded by the National Institute for Health Research supporting public involvement in health and social care research) for over ten years. She has had links with the JLA since it was first set up in 2004.

## Project co-ordinator:

### Maggie McPhee



Maggie is research co-ordinator for the UK Dermatology Clinical Trials Network. Her role involves co-ordinating submissions of research ideas to the network and supporting subsequent pilot/ feasibility work. Maggie has been involved in several priority setting partnerships in dermatology; including eczema, cellulitis and hidradenitis suppurativa. She also coordinated the Cystic Fibrosis Priority Setting Partnership in 2016 with the University of Nottingham Child Health team.