Core Outcomes for Research in Lichen Sclerosus

Steering Group Member Biographies

Patient representative/s:

Suzanne von Seitzberg

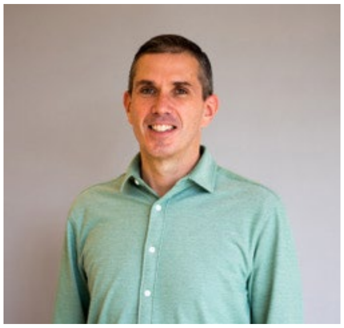
Suzanne is the founder and president of the Danish Lichen Sclerosus Association. The Danish Lichen Sclerosus Association was founded in 2010 and it is a patient association for all patients suffering from lichen sclerosus, genital lichen planus and plasma cell vulvitis/balanitis. They currently have 545 members, mainly women but also men, children and support members from all over Denmark. They cooperate with other associations in the world. 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 43 years old and was diagnosed with lichen sclerosus in 2008. Her work for the Lichen Sclerosus 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.

Jaclyn Lanthier

Jaclyn is the face behind The Lost Labia Chronicles, which includes a blog, a YouTube channel, as well as an eBook centering around vulvar Lichen Sclerosus. Jaclyn is passionate about disseminating evidence-based information and addressing mental and sexual health with Lichen Sclerosus. She is on the executive board of Lichen Sclerosus Support Network and spends a lot of time in the LS online communities helping to provide support to folks with LS. Jaclyn is 34 years old and was diagnosed at 31 (but symptomatic since she was 20) with vulvar Lichen Sclerosus. She works full-time as a data consultant and social media manager for an information services firm in Toronto, Canada. She did her Ph.D. in philosophy of neuroscience at Western University with a focus on the role of systematic review and meta-analyses for corroborating information about the mind-brain.

Author of The Lost Labia Chronicles @thelostlabiachronicles on Instagram and Facebook.
Secretary of the Board, Lichen Sclerosus Support Network. www.lssupport.net

Chris S.



Chris is relatively new to the world of lichen sclerosus, having been diagnosed in February 2022 at the age of 52 after experiencing symptoms for about nine months. His quest for information and guidance led him to the Lichen Sclerosus Support Network, which in turn led to his being referred to the CORALS project. Chris is not in the medical field; he has spent his career as a writer and creative director in the marketing industry, roles he now serves at an agency he co-founded in 2020. He writes both fiction and nonfiction in his spare time.

Clinical representatives:

Ione Bissonnette

Ione CNM, MSN, received her BS in Nursing degree from Columbia University in New York and her Masters in Midwifery degree from the University of Pennsylvania in Philadelphia. While practicing as a full-scope nurse midwife at Harvard Vanguard Medical Associates and Brigham and Women's Hospital in 1995, she met Dr Elizabeth G. Stewart, an OB GYN who later dedicated her career to caring for women with vulvovaginal disease. Dr Stewart is the author of The V Book: a doctor's guide to vulvovaginal health. Ione apprenticed with Dr Stewart and later worked in her Vulvovaginal Specialty Service at Harvard Vanguard for eleven years, seeing many genital lichen sclerosus patients.

In 2005, she became the first Advanced Practice Clinician (Nurse) Fellow of the ISSVD (International Society for the Study of Vulvovaginal Disease). She has lectured on vulvar lichen sclerosus (2005), vaginal microscopy, pH and KOH in vulvovaginal care (2006), vulvar dermatoses (2008), vestibulodynia (2009), vulvovaginal diagnosis and treatment, (2009), vaginal atrophy (2012), and bacterial vaginosis (2012). She and Dr Stewart have initiated teaching sessions at Beth Israel Deaconess Medical Center's Ob Gyn Residency Program (affiliated with Harvard Medical School) (2015-2016).

In the interest of furthering education about vulvovaginal disease, Ione and Dr Stewart created a comprehensive, internet-based learning program www.vulvovaginaldisorders.org that is free to all, but intended primarily for anyone who sees (or will see) women with these problems. Their residency modules were derived from the learning program.

Rosalind Simpson

Rosalind works as a consultant dermatologist in Nottingham, U.K. and Associate Professor at the University of Nottingham. She is lead for the CORALS project. 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 took time out of her training program to pursue a career in Academic Dermatology and completed a program of clinical research into vulvovaginal erosive lichen planus 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 was lead for the Lichen Sclerosus Priority Setting Partnership (completed in 2018). Rosalind became a Fellow of the

International Society for the Study of Vulvovaginal Disease ISSVD in 2011. She is Research Lead for 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 have previously practiced dermatology in academic centres in Oxford, UK and Amsterdam, NL. She has a special interest in vulval skin disease, pregnancy associated skin disease and blistering skin conditions. Gudula has a strong research interest and her work has contributed towards the production of more than 90 peer reviewed scientific articles, national/international clinical guidelines, and patients' information leaflets. Together with more than 20 co-authors she has edited a prize-winning book on vulval diseases. She works with the Cochrane skin group to deliver systematic reviews and sits on the oversight committees of clinical trials. Gudula is committed to excellence in clinical dermatology. She is a member of the Lichen Sclerosus PSP and the steering group to develop Core Outcome Sets (COS) for LS.

Gitte Vittrup

Gitte has been a registered nurse since 1988. She has mainly worked on the gynecological ward, surgery department and at the outpatient clinic. For 25 years Gitte has been working with the sexological aspects implementing this part in her job as a gynecological nurse. In 2008 she was trained as a sexological counsellor, authorized in NACS (Nordic Association of Clinical Sexology). As a sexual counsellor, Gitte primarily sees women with sexual dysfunction occurring because of chronic disease or after cancer treatment, medication or surgery. She always asks the women to invite their spouse to join the treatment/sexual counselling. Gitte has an interdisciplinary collaboration with general practitioners, consultants, physiotherapists and psychologists. In addition, Gitte teaches sexology and communication skills for health care professionals as well as teaching patient groups. In 2014 and 2018 she wrote a chapter about "Sexology" for a textbook for nursing students and a chapter about sexuality for a book named "F*** – I got cancer". In January 2018, Gitte initiated a randomized controlled trial, "Quality of Life and Sexuality in Women with Lichen Sclerosus". The results will be available in 2020. Gitte is vice chair in the Danish Society of Vulva Diseases (DSVL), and she hopes to become a Fellow of the International Society for the Study of Vulvovaginal Disease.

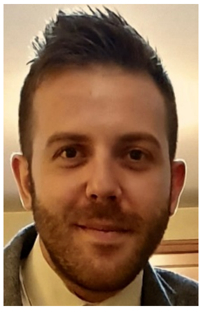
Amanda Selk

Amanda is an Associate Professor in the Department of Obstetrics and Gynaecology in Toronto, Canada. She is the clinical director of both the Colposcopy and Gynaecology Dermatology clinics at Women's College Hospital. She is currently the President-Elect of the North American branch of the International Society for the Study of Vulvovaginal Disease and is Chair of the Survey Committee for ISSVD. She is President of the Society of Canadian Colposcopists. She is on the Editorial Board of the Journal of Lower Genital Tract Disease. She has a MSc in health research methodology. She cares for many patients with lichen sclerosus and has been working on developing lichen sclerosus disease severity measurement tools.

David Foster

David is Professor Emeritus of Obstetrics and Gynecology at the University of Rochester School of Medicine and Dentistry in Rochester, New York. He has retired from clinical practice in general gynecology and pelvic surgery which focused on diseases of the vulvovaginal region and diagnosis and management of disorders of the lower urinary tract. David continues as Principal Investigator in NIH--funded research of the immuno-inflammatory basis and treatment of vulvodynia pain and is Editor-in-Chief of the *Journal of Lower Genital Tract Disease*.

Angelo Augenti



Angelo Augenti, MD gratuated in Medicine and Surgery at the University of Rome La Sapienza with a thesis on 'Regenerative Therapy in the Treatment of Male Genital Lichen Sclerosus'. Currently attends the Center of Andrological Surgery and Regenerative Medicine at the Health Center S. Caterina della Rosa in Rome, directed by Dr. Lauretti.

Stefano Lauretti

Stefano Lauretti, MD, PhD is the clinical director of the Andrological Surgery Service and Regenerative Medicine Program at “S. Caterina della Rosa Health Center”, in Rome. He is a consultant urologist and andrologist for the Italian Association of Lichen Sclerosus (LISCLEA), and member of the Italian Society of Andrology Executive Committee as a counselor. His main interests are male genital lichen sclerotrophicus, uro-sexual rehabilitation, and bioethics in sexual medicine. He organized the first International Workshop on Male Genital Lichen Sclerosus in Rome, in 2018. He is currently involved in research on the expression of glutathione transferase in patients affected by phimosis secondary to lichen

Martin Promm

Martin works as a Consultant at the Department of Pediatric Urology in Regensburg, Germany. He studied at the University of Leipzig and the Technical University of Munich. After specialization in Urology, he subspecialized in Pediatric Urology and became Fellow of the European Academy of Paediatric Urology (FEAPU). Besides clinical and research work in congenital urogenital disorders (esp. bladder exstrophy-epispadias-complex) he is focusing in genital Lichen sclerosus in children. He has a research interest in the etiology, the long-term outcome and especially in therapy options in chronic course of this entity.

Researchers:

Kim Thomas

Kim is Co-Director of the Centre of Evidence Based Dermatology and Professor of Applied Dermatology Research. Her main research interests focus on conducting large, pragmatic randomised controlled trials to provide a better evidence-base for the prevention and treatment of skin disease.

In addition to the COS GLS initiative, she is an Executive Group member for the Harmonizing Outcome Measures for Eczema (HOME) initiative (www.homeforeczema.org), and is lead for the HOME Long-term Control Working Group. She also provides methodological support to other core outcome groups through the Cochrane Skin Core Outcomes Set Initiative (www.cs-cousin.org) and has helped to develop and validate a number of new outcome measurement instruments.

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 10 years.

Jan Kottner

Jan obtained his master in Nursing Science and Education in 2007 after having worked as registered nurse in several hospital settings. Validation and reliability of pressure ulcer risk diagnoses and pressure ulcer classification, application of statistical process control methods in healthcare and epidemiology of care problems were topics of his PhD thesis and his postdoctoral qualification. In 2011, he became the Scientific Director of the Clinical Research Center for Hair and Skin Science at the Department of Dermatology and Allergy at the Charité-Universitätsmedizin Berlin. Today, key research interests of Jan Kottner are skin and tissue integrity and preventive skin care with a special focus on skin physiology, skin barrier restoration and maintenance as well as efficacy of skin care interventions and pressure ulcer prevention. He has also special interests in evidence-based practice including systematic reviews, clinical trial design and conduct, and outcome development and validation. Since 2015, he works within Cochrane Skin-COUSIN and is involved in core outcome sets development in dermatology.