



Core Outcomes for Research in Lichen Sclerosus

Symptoms Domain

Working group progress:

Objectives:

- To identify reported and measured symptoms in persons with lichen sclerosis
- To obtain international agreement on which symptoms should be included in a core outcome set (COS) in trials evaluating lichen sclerosis

Progress to Date:

- An international Steering Committee of 11 people was formed (Canada, America, Argentina, Germany, UK, India) which contains experts in lichen sclerosis and methodology
- An electronic modified DELPHI process was conducted among Steering Committee members to identify/prioritize symptoms
- The first meeting of Steering Committee was held June 2023 to discuss results
- An international survey of 863 respondents affected by lichen sclerosis narrowed and prioritized symptoms. This was performed to get the patients' perspective
- The second meeting of Steering Committee was held in September 2023 to discuss results.
- A scoping review of 95 published trials revealed a common list of symptoms studied. All three arenas of information were compared & contrasted (Delphi results, international survey, and scoping review)
- The third meeting of the Steering Committee was held January 2024 to discuss results (three arenas of data were crossed for similarity and priority). Loose discussion of the common symptoms to be included in COS
- Abstract preparation (for ISSVD) due March 1, 2024



Prof Catherine Leclair,
MD
Clinical representative

Dr Catherine Leclair is currently a professor of OBGYN at Oregon Health & Science University in Portland, Oregon, USA. She is the Director for the Program in Vulvar Health, a specialty clinic serving the west coast of the United States. This program sees over 600 new and 1200 return patients annually and has research, clinical and educational goals. Additionally, the program includes 4 gynaecologists, 1 dermatologist, and on-site/off-site pelvic floor physical therapists and sexual health therapists. Dr. Leclair's career focus is in vulvovaginal health, with the goal to improve the physical and psychosexual health of women. With 25 years of experience, dozens of publications and present/past leadership positions, she serves as an expert in vulvovaginal diseases, especially for women and practitioners in the Pacific Northwest.



Dr Erin Foster, MD, PhD
Clinical representative

Dr Erin Foster is a medical dermatologist with a special interest in complex skin disorders such as autoimmune blistering diseases, oral and vulvar dermatology. Dr Foster also sees patients for cosmetic dermatology and treats general dermatologic conditions such as acne and skin cancer checks. Her research focuses on shared decision making with patients and the immunological basis of skin disease. As a clinician -researcher, she is keenly equipped to participate in CORALS.



Jaclyn Lanthier
Patient representative

Jaclyn is the face behind *The Lost Labia Chronicles*, which includes a blog, YouTube channel, and 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 much time in the LS online communities helping provide support to folks with LS. Jaclyn is 34 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



Dr Amanda Selk, MSc, MD,
FRCSC
Clinical representative

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 past President of the North American branch of the International Society for the Study of Vulvovaginal Disease and is Co-Chair of the Social Media Committee ISSVD. She is past President of the Society of Canadian Colposcopists. She is on the Editorial Board of the Journal of Lower Genital Tract Disease and their social media editor. She has a MSc in health research methodology and a MHA. She cares for many patients with lichen sclerosus and has done research on developing lichen sclerosus disease severity measurement tools.



Alpana Mohta, MD
Clinical representative

Dr Alpana is consultant dermatologist from India who is a strong advocate for women's dermatological and reproductive health in the western Rajasthan. She is an active member of the Indian Women's Dermatologic Association, from whom she received the prestigious L'oreal Leadership grant. She has received numerous coveted scholarships including the prestigious Imrich Sarkany Non-European Memorial Scholarship by the European Academy of Dermatology and Venereology (EADV), the British Association of Dermatologists travel grant scholarship, the American Academy of Dermatology scholarship and the Dubai Derma scholarship. She has a keen interest in research which is evident by her 80+ research publications with special interest in venereology, dermatopathology, dermato-oncology, and dermoscopy.



Aruna Venkatesan, MD
Clinical representative

Dr. Aruna Venkatesan is Chief of Dermatology, Clinical Professor of Dermatology and Director of the Genital Dermatology Clinic at Santa Clara Valley Medical Center, a teaching affiliate of Stanford Hospital & Clinics. She is active in clinical teaching and education with professional interests including genital skin disease, resident education, primary care provider education, and the use of telemedicine to improve patient care access for vulnerable populations. She has trained with noted vulvovaginal disease experts Dr. Joanna Badger and Dr. Libby Edwards. Dr. Venkatesan is a Fellow of the ISSVD and President for the North American Chapter of the ISSVD.



Dr Rosalind Simpson
Clinical representative

Rosalind works as a consultant dermatologist in Nottingham, U.K. and Associate Professor at the University of Nottingham. She is overall 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). She now leads the SHELLS (Establishing Effective Diagnostic Criteria for Lichen Sclerosus) and PEARLS (Proactive Against Reactive Treatment for Lichen Sclerosus) studies. 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.



Veronica Suzuki, MD
Clinical representative

Dr Suzuki is a practicing gynaecologist in Argentina, South America. She has a special interest in vulvovaginal disease for which she sought extra training/mentorship in America with vulvar pioneers Drs Hope Haefner and Libby Edwards in 2004. She served as a Teaching Assistant in the Division of Gynecology at Hospital de Clínicas “José de San Martín” in the University of Buenos Aires from 2007 to 2021. She has a number of publications in the arena of vulvovaginal disease and co-authored several books on this subject. In 2008 she became a member of the ISSVD and then in 2009 became a Fellow. She serves on the Editorial Board of the Journal of Lower Genital Tract Disease and remains actively engaged with the ISSVD and has served on the Website Committee and the Executive Council.

Amy Li, MD,
Clinical representative

Dr Li is a Foundation Year 2 doctor in Leicester, East Midlands, UK, having received her medical degree in 2021 at University of Newcastle. She is pursuing a Master’s in Public Health at University of Nottingham. She has a special interest in Dermatology and has previously served as President of New Castle University Dermatology Society.



Prof Kim Thomas
Researcher

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
Researcher

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 Centre 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.
