IMPACT REPORT 2024

Lichen Sclerosus Support Network

OUR MISSION

We are a not-for-profit organization whose mission is to empower people with Vulvar Lichen Sclerosus by providing evidence-based education and support.

OUR VISION

Our vision is a world where those affected by Lichen Sclerosus are informed, educated, and diagnosed early.

WHAT IS VLS

Vulvar lichen sclerosus (VLS) is more than just a skin condition; it's a life-altering experience. The persistent itching, burning, and pain can make even the simplest tasks feel impossible.
Sadly, millions of women suffer in silence with VLS. It is often misdiagnosed and misunderstood. This lack of awareness has real consequences, leading to delayed treatment and a diminished quality of life. At LSSN, we're determined to change this narrative.

NOT So Fun FACT

It can Take 5-15 Years on Average to Get a Diagnosis

TOGETHER WE CREATE PEACE OF MIND, CONFIDENCE, AND SUPPORT.

A MESSAGE FROM THE DIRECTOR

2024: A Year of Growth and Community!

It's been an amazing year of growth and community! In 2024, LSSN more than doubled the number of people we reached. We expanded our programs to include more educational events, launched our Circle of Support for corporate partners, and created the Circle of Hope monthly giving program.

But what matters most is the impact we've had on individuals living with LS. We've provided a safe space for people to connect, learn, and find support. We've empowered them with knowledge and given them hope.

Thank you for being a part of the LSSN family. Together, we're making a difference.

Kathy Ruiz-Carter, Executive Director

VOICES FROM OUR COMMUNITY

Finding LSSN after living with LS for 20+ years was absolutely transformative for me. ... Knowledge is power! I was able to use LSSN's library of resources to learn at my own pace and expand my knowledge of this chronic condition. **Since joining LSSN, I have discovered and tried new treatments that have helped tremendously and greatly improved my quality of life.** Most importantly, being part of LSSN allowed me to hear stories from others impacted by this disease **and to find self-acceptance.** Thank you to the LSSN!

MANON
PROGRAM
PARTICIPANT/DONOR

IRIS
PROGRAM
PARTICIPANT/DONOR

The LSSN has helped bring me out of darkness and feelings of despair by providing education and camaraderie. Thank you.

OUR PROGRAMS

VIRTUAL SUMMITS

SUPPORT GROUPS

LIVE EDUCATION EVENTS

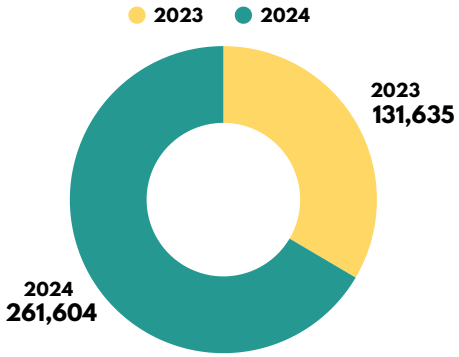
PROVIDER DIRECTORY

EDUCATIONAL RESOURCES

PROVIDER EDUCATION PROGRAM COMING 2025

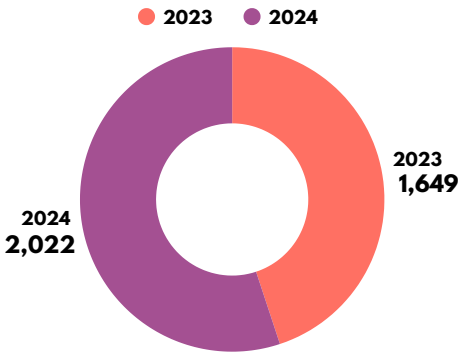
GROWTH BY THE NUMBERS

WEBSITE VISITORS



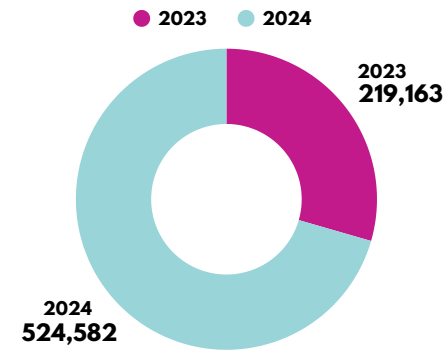
Up 99%

LIVE ATTENDEES



Up 23%

RESOURCES ACCESSED

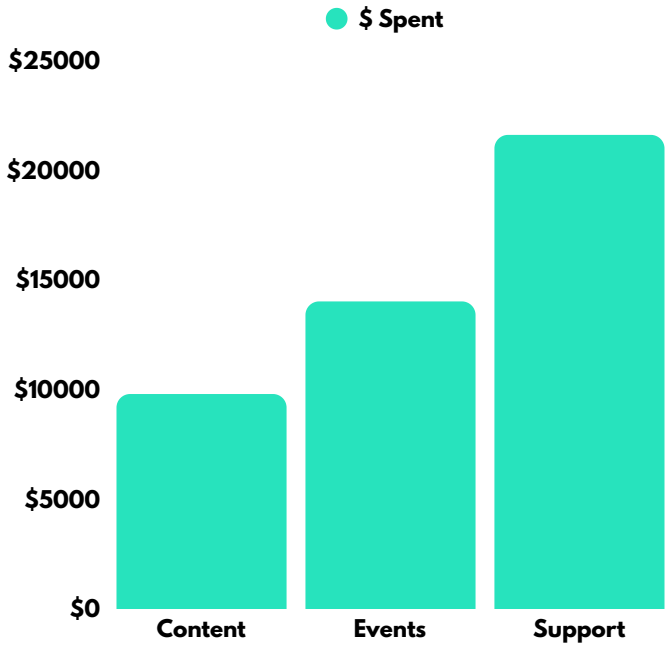


Up 139%

THANKS TO OUR AMAZING DONORS AND PARTNERS, WE WERE ABLE TO RAISE A RECORD **$116,288.11** LAST YEAR!

AND WE PUT YOUR MONEY TO WORK, SPENDING **$45,373.06** ON EDUCATING AND SUPPORTING OUR COMMUNITY!

YOUR SUPPORT IN ACTION



A DEEPER LOOK

LICHEN SCLEROSUS PODCAST:

21,723 DOWNLOADS

EMAIL SUBSCRIBERS

4,674 SUBSCRIBERS

UP 32% FROM 2023

AVG OPEN RATE 47.91%

SUMMITS ATTENDANCE:

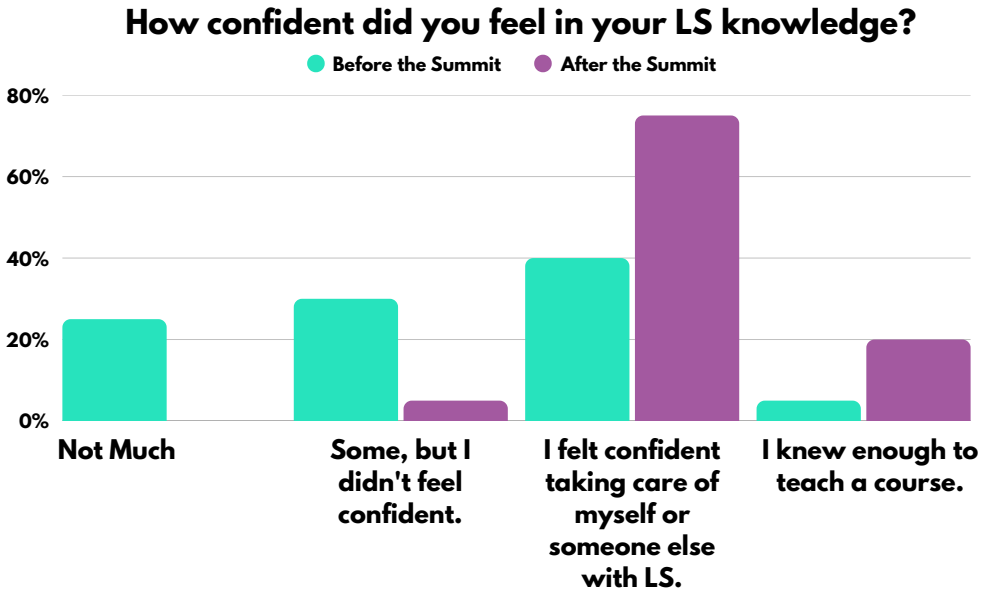
943 REGISTRANTS

YOUTUBE CHANNEL:

113,739 VIEWS

UP 93% FROM 2023

THE SUMMIT EMPOWERED 90% OF ATTENDEES TO FEEL CONFIDENT MANAGING THEIR LS.



At LSSN, we're committed to empowering individuals with vulvar lichen sclerosus through education, support, and community.

Our programs, like the **LSSN Summit**, provide a platform for learning and connection, breaking down the barriers of misinformation and isolation that often surround VLS.

The Summit empowers attendees to take control of their health.

"THE LSSN SUMMIT HAS BEEN AN EMPOWERING EXPERIENCE IN A SAFE AND SUPPORTIVE ENVIRONMENT. IT HAS GIVEN ME THE TOOLS I NEED TO ADVOCATE FOR MYSELF WHEN SEEKING HELP FROM DOCTORS."
- 2024 SUMMIT ATTENDEE

“THIS WAS MY FIRST SUMMIT, BUT DEFINITELY NOT MY LAST. I LEARNED MORE ABOUT MY LS THAN I HAVE IN THE LAST FOUR YEARS OF HAVING LS FROM MY DOCTOR."
- 2024 SUMMIT ATTENDEE

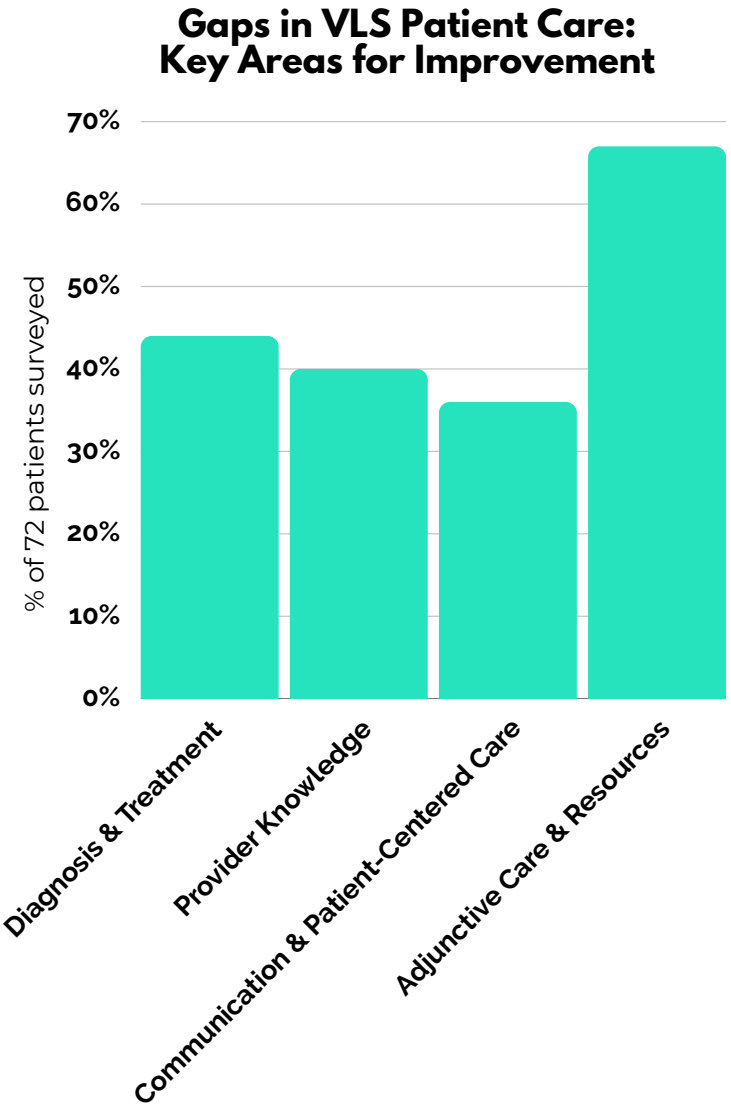
INTRODUCING THE PROVIDER CONTINUOUS EDUCATION PROGRAM

At LSSN, we recognize that empowering individuals with VLS goes hand-in-hand with empowering healthcare providers. That's why we're thrilled to announce the launch of our **Provider Continuous Education Program (PCEP)**, a groundbreaking initiative designed to bridge the knowledge gap and transform the way VLS is diagnosed, treated, and managed.

WHY THE NEED FOR PCEP

The **PCEP** addresses a critical need in the VLS landscape. Studies have shown that VLS is frequently **misdiagnosed** or diagnosed with significant delays, leading to years of **unnecessary suffering** for patients. Patient surveys also indicate high levels of dissatisfaction with current VLS care, highlighting the urgent need for better provider training and education.

The PCEP is designed to equip healthcare providers with the **knowledge, skills, and confidence** to address these challenges and provide patient-centered, evidence-based care.



ADDRESSING THE NEED

The PCEP directly addresses critical gaps in provider knowledge and practice identified through a comprehensive needs assessment and patient feedback

- **Challenges in diagnosis and differential diagnosis**: Difficulty recognizing VLS and distinguishing it from other conditions.
- **Limited understanding of long-term management**: Challenges in appraising the risks and consequences of VLS and ensuring appropriate long-term management.
- I**nadequate knowledge of treatment options**: Insufficient knowledge about alternative treatment options and adjunctive therapies.
- **Lack of trauma-informed care**: Inadequate practice/training in understanding and addressing the psychological and social impact of LS on patients.

THE COMPREHENSIVE CURRICULUM

Presented through online modules, case studies, and video demonstration

Included topics:

- Accurate diagnosis and differential diagnosis
- Evidence-based treatment options
- Long-term management strategies
- Trauma-informed communication and care
- Patient education and resources
- Updates on current research and emerging therapies

GOALS AND EXPECTED OUTCOMES

The PCEP aims to:

- Reduce misdiagnosis rates and delays in diagnosis
- Improve treatment outcomes and patient quality of life
- Enhance provider confidence and competence
- Expand the LSSN Provider Directory
- Promote trauma-informed care

WHAT LEADING MEDICAL PROFESSIONAL SAY

"The PCEP is a much-needed resource for healthcare providers who treat VLS. By providing comprehensive training and support, this program will significantly improve the lives of countless patients." - **Dr. Jill Krapf, Leading Vulvar Specialist and Researcher**

"This program fills a huge void in the medical education community. The focus on trauma-informed care is extremely important." - **Dr. Melissa Mauskar, Leading Vulvar Dermatologist and Researcher**

DESIGNED FOR

- Dermatologists
- Gynecologists
- Primary Care Physicians
- Nurse Practitioners
- Physician Assistants
- Other healthcare professionals treating vulvar conditions

"The PCEP has the potential to transform the lives of people with VLS by empowering healthcare providers with the knowledge and skills they need to provide the best possible care," says ***PCEP Patient Town Hall participant Barbara.*** *"I'm so grateful to LSSN for making this program a reality."*

Enrollment in the **PCEP** will be available through the LSSN website upon program launch. Join our waitlist for notifications and updates by scanning the QR code below.

lssupportnetwork.org/pcep

OUR MEDICAL ADVISORY BOARD

As an organization founded on our determination to empower people with VLS through evidence-based education, we needed a way to make sure the information we shared was scientifically accurate and up-to-date.

That's why we worked hard and hand-picked experts in various medical fields that impact people with vulvar LS for our medical advisory board.

As part of the LSSN Medical Advisory Board, members are unpaid medical professionals who ensure that the information, education, and support provided by the organization is evidence-based and accurate.

They review, edit, and provide input on key resources, as well as keep the board informed of new developments pertaining to lichen sclerosus in their respective fields.

They support the organization by donating their time at sponsored events and championing LSSN at functions to help further the mission.

JILL KRAPF, MD, MDSCP (SHE/HER)
OB-GYN VULVAR SPECIALIST
TAMPA, FLORIDA

COREY BABB, DO, FACOOG, IF, MSCP (HE/HIS/HIM)
GYN VULVAR SPECIALIST
TULSA, OKLAHOMA

CAROLIN KLEIN, PHD, RPSYCH (SHE/HER)
PSYCHOLOGIST & SEX THERAPIST
VANCOUVER, BC

ASHLIE CREWE, PT, DPT, WCS, PRPC (SHE/HER)
PELVIC PHYSICAL THERAPIST
HARRISBURG, PA

ERIN FOSTER, MD, PHD (SHE/HER)
DERM VULVAR SPECIALIST
PORTLAND, OREGON

GET INVOLVED

MAKE A ONE TIME DONATION

JOIN OUR SPONSORSHIP CIRCLE
GET MORE DETAILS

JOIN OUR CIRCLE OF HOPE WITH A RECURRING MONTHLY GIFT

Connect with us:

- **lssupportnetwork.org**
- **instagram.com/lichensclerosussupportnetwork**
- **facebook.com/lichensclerosussupportnetwork**
- **linkedin.com/in/lssn/**
- **kathy.ruiz-carter@lssupportnetwork.org**

Lichen Sclerosus Support Network

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