Glossary:

- **Immune system** is the body’s way to recognize and fight:
  - germs that cause disease
  - harmful substances
  - abnormal changes in your body such as cancer

- **Autoimmune disease** is a disorder that is caused by your immune system attacking part of your own body

- **Vulva** is the part of the body that includes all the external female genital parts from where pubic hair grows (mons pubis) to the opening that stool comes out of (anus). In between are the large outer lips (labia majora), small inner lips (labia minora), clitoris, the opening that urine comes out of (urethra), and the opening to the vagina (vestibule).

- **Chronic** means lasting a long time.

- **Inflammation** is the body’s response to injury, infection, or disease. Heat, swelling, and pain are signs of inflammation.

**What is Lichen Sclerosus?**

Lichen sclerosus (LS) is an **autoimmune disease** of the **vulva** (see figure 1). It starts when the **immune system** mistakes healthy tissue as foreign and attacks it. We do not know what causes this change. Women with LS often have a personal or family history of another autoimmune disease such as thyroid disease. LS is not contagious and cannot be passed to a sexual partner. LS occurs most commonly in women who have gone through menopause, but may occur at any age.
What are the symptoms?

LS most commonly causes itching, discomfort, or pain. Sexual activity is often very painful. It may affect a small area or involve the entire vulva, from the hood of the clitoris to around the anus. The affected skin often has a white color and a thin, shiny, crinkled appearance. It is fragile and may tear easily. Scratching or rubbing can cause small cracks in the skin (fissures) that are very painful. A fissure near the anus can cause pain during bowel movements. LS does not involve the skin inside the vagina.

Untreated LS can cause:

- Scarring and changes in the appearance of the vulva
- The labia minora to stick to the inside of the labia majora and shrink
- The opening to the vagina to get smaller
- The hood over the clitoris to become scarred so that it does not move
A small portion of patients have LS on other parts of their bodies or are affected by multiple skin conditions at once.

**How is it diagnosed?**

Often, a diagnosis is made based on the way your vulva looks to the health care provider performing your exam. However, a biopsy must be done to make a definite diagnosis. A **biopsy** involves removing a small piece of skin for laboratory diagnosis. A biopsy is also necessary when there are concerns for dVIN or vulvar cancer. You will get an injection of numbing medicine before the skin is removed.

**How is it treated?**

LS is a chronic disease that cannot be cured but can be effectively treated. Treatment of LS has two goals:
1. Stop itching and other symptoms.
2. Stop the chronic inflammation that leads to scarring and increases the risk of dVIN and cancer.

Additional information about treatment is provided below.

**Symptom relief**

While you are waiting for the treatment to take effect, symptoms can be reduced by:

- **Using comfort measures.** Read about comfort measures in the vulvar irritation and itching section of the Vulvar Diseases booklet or view the “Comfort Measures to Decrease Vulvar Irritation, Itching, and Pain” handout at: [http://michmed.org/O5v80](http://michmed.org/O5v80).
- **Getting yeast or bacterial infections treated.** We will check for these and prescribe treatment if needed.
• **Taking an oral medicine at bedtime** to prevent itching so that you do not scratch yourself while asleep if prescribe.

• **Using vaginal lubricants.** You can use a lubricant to increase comfort during sexual activity. For more information, see the “Vaginal Lubricants” section of the Vulvar Diseases” booklet or view the “Vaginal Lubricants” handout at: [http://michmed.org/lApJ3](http://michmed.org/lApJ3)

• **Using vaginal estrogen.** After menopause, vaginal tissue can become thin, dry, and easily irritated. If we think this is part of what is causing your symptoms, we may prescribe vaginal estrogen. There are different kinds of vaginal estrogen products including creams, suppository tablets, and a long-acting silicone ring. We will help you choose one to start with. Research has shown that using vaginal estrogen does not increase the risk of getting breast or uterine cancer in women with no personal history of these cancers.

**Topical steroid treatment**

Topical steroids are medicines that are applied topically (to the skin), like a cream or ointment. They reduce inflammation and itching. These come in many brands and strengths. We usually start treatment with a strong steroid ointment called clobetasol. To use, squeeze a small, pea-sized amount on your finger and gently apply to the affected skin. We will show you what part of the vulva you should treat. The usual schedule after you are first diagnosed is:

1. Apply every day in the morning and at bedtime for 1 month
2. Apply every day at bedtime only for 2 months.

It is very important to continue treatment on this schedule after itching stops. The symptoms you feel will stop before the inflammation is well-treated.

After your symptoms have stopped and we have seen through an exam that your vulvar skin has responded to treatment, we will give you a schedule for
ongoing treatment. This may be daily use of a weaker topical steroid or a different schedule for using clobetasol ointment.

**Other treatments**

If treatment with a topical steroid is not effective, there are other options that are usually not used as the first treatment. These include:

- Topical medicines that target a specific part of the immune system
- Steroid shots
- Oral steroids (taken by mouth)

**Surgery**

Sometimes surgery is needed to open scar tissue. Scar tissue may make it difficult to urinate or have any sex that includes putting something in the vagina. If you need surgery we will discuss the surgical plan and how to prevent scar tissue from reforming after surgery.

**Can LS cause cancer?**

**Chronic inflammation** from LS can cause abnormal skin changes that can turn into cancer if not treated. The medical name for this is differentiated Vulvar Intraepithelial Neoplasia (dVIN). Overall, 0.3 out of a 100 women will develop vulvar cancer during their lifetime. For women with LS, the likelihood is over 10 times higher, about 4 women out of 100. Treatment that prevents inflammation lowers the risk of getting dVIN and cancer (see figure 2).

**Figure 2:** Chart comparing cancer risk in women with and without LS.
**Follow-up**

We will see you as needed until treatment is effective. After that, you should get an examination of your vulva done every 6-9 months. The purpose of the exam is to:

- Confirm that treatment is still effective
- Look for changes that should get biopsied to check for dVIN or cancer

This can be done by your gynecologist or primary care provider if it is something they feel comfortable doing. If not, we will help you find a Michigan Medicine provider to see.
When should I call the call center?
We want you to do regular self exams. Call or use the patient portal to send us a message if:

- You see something new
- Your symptoms come back
- You get new vulvar symptoms

What is the contact information?
Call: (734) 763-6295

Resources
- International Society for the Study of Vulvovaginal Disease Patient Education
  https://www.issvd.org/patient-education/
- The Association for Lichen Sclerosus & Vulval Health
  The association’s aim is to offer responsible and medically sourced information and support for people with lichen sclerosus.
  http://lichensclerosus.org/