

My name is Ellen Swanborn

I am the chairman of the

- Lichen Sclerosus foundation
- Red Vulva foundation

As a profession I am an illustrator and I mainly make medical illustrations and medical card games



Both the Lichen Sclerosus foundation and the Red Vulva foundation are all about vulvar skin conditions.

Talking about a skin condition is already difficult as it is, but talking about a vulva condition is a big taboo.



This causes the following problems:

- Loneliness
- Incomprehension
- Lack of knowledge
- Late diagnosis
- Late treatment

With all the consequences that entails, the **sooner** a vulvar condition is treated, the **less** chance of complications.



This has to change

- Women need to be aware of their vulva
- Women should be able to recognize that something is wrong with their vulva
- This requires knowledge and information

The Lichen Sclerosus Foundation provides this through:



A card game for children with Lichen Sclerosus

WHAT IS LICHEN SCLEROSUS (LS)



- Skin condition most often occurring on the genitals (private parts)
- ✗ NOT contagious
- ♣ Chronic inflammation with many symptoms
- Can appear on anyone at any age

Which medical specialists treat LS?



- Dermatologist
- ✗ Gynecologist
- ♣ Urologist
- Vulvar Clinic

Signs and symptoms of LS



- Itching
- ✗ The skin may turn white or pale
- ♣ Wounds and tight skin
- Sometimes painful when using the toilet

How to apply ointments?

WHEN LS IS ACTIVE



usually for about 4 weeks

- When LS is active: Thinly apply medicinal ointment to affected skin daily usually for about 4 weeks
- ✗ DAILY: Apply protective ointment at least twice a day.
- ♣ When symptoms subside: taper use of medicinal ointment to intermittent doses as prescribed
- How much to apply: half a fingertip on the affected area is plenty

What can you do yourself?



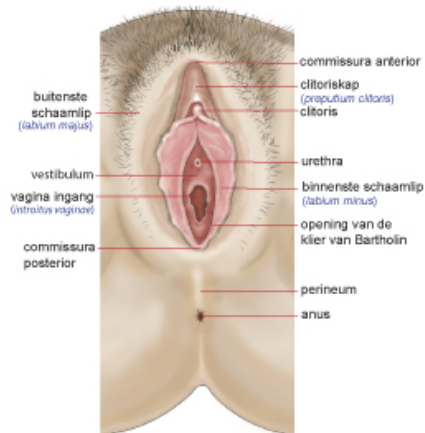
- Talk about LS to those close to you
- ✗ Wear comfortable clothing
- ♣ Avoid scratching as much as possible
- Only wash with lukewarm or cool water without soap

- With this game they learn what LS is, what the symptoms are, what to look out for, which doctor to go to and what does he/she do, how to treat and how to deal with it
- They can play it with friends or family to explain what is bothering them
- The game is widely used to give a presentation at school
- It promotes good coping with the condition and the treatment, and it promotes therapy compliance
- The game is also much requested by adults, because it explains very simply what a complicated disease like LS entails



A leaflet about self-examination of the vulva

Hoe kun je de vulva zelf onderzoeken?



Om de vulva zelf te onderzoeken ga je in een voor jou makkelijke houding staan of zitten. Met één hand spreidt je de schaamlippen iets uit elkaar en vervolgens kun je nu met een spiegel in de andere hand de vulva bekijken.
Het kan ook handig zijn om een foto te maken met je mobieltje. Doe wat je het prettigst vindt.

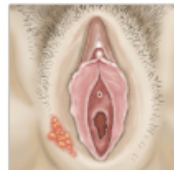


Doe dit zelfonderzoek 1 x in de 1 à 2 maanden.
Het belangrijkste doel is dat je verschil kunt opmerken! Zo kun je zelf in de gaten houden of er veranderingen zijn.

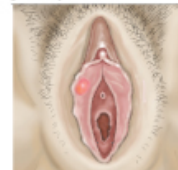
Als je één van bovenstaande afwijkingen ziet, schroom dan niet om naar de huisarts te gaan.

Mocht de huid anders aanvoelen dan je gewend bent en zijn er geen zichtbare veranderingen, ga ook dan naar de huisarts.

Waar moet u vervolgens op letten



Blaasjes



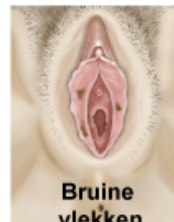
Blaren



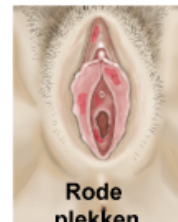
Wratjes



Pukkels



Bruine vlekken



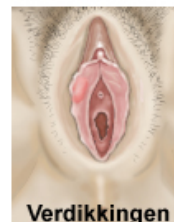
Rode plekken



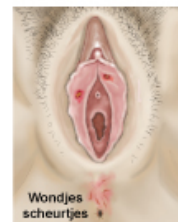
Witte verkleuring



Kleiner wordende kleine schaamlippen



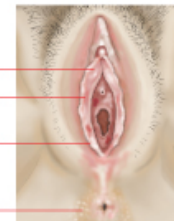
Verdikkingen



Wondjes scheurtjes

Voorbeelden hoe lichen sclerosus er uit kan zien

Kleiner wordende binnenste schaamlippen
Rode (geïrriteerde) plekken
Witte verkleuringen



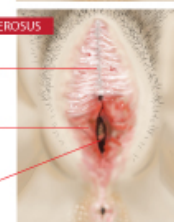
Gemoffeld aspect (lijkt op kippenvel)

UITGEBREIDE LICHEN SCLEROSUS

Begraven clitoris

Verstroken binnenste schaamlippen


Vernauwde (introitus) vagina-ingang



- The leaflet explains what the vulva consists of, this is very important for a visit to a doctor and most women do not know this
- The folder explains how the vulva can be examined by the woman herself
- The most common vulva abnormalities are shown, so that a woman recognizes whether something is wrong

If a woman does this self-examination regularly, she will be able to recognize abnormalities in time and go to a doctor in time





Vulva disorders are therefore taboo, among patients but sometimes also among doctors. It is sometimes also a gray area, does it belong to the dermatologist or the gynaecologist? Both are not always interested in this area. That is why the Lichen Sclerosus Foundation is committed to informing both, patients and doctors about vulvar disorders.

We distribute this information material to patients, but also to doctors, hospitals, pelvic physiotherapists, skin therapists and medical courses.

As a result, there is a change in awareness about the vulva in the Netherlands. This is our goal and we will certainly continue with it!

