

Lichen sclerosus

Under-estimated and under-diagnosed

Lichen Sclerosus (LS) is wrongly considered a rare disease affecting the skin of the genital organs of older women. Since its symptoms mirror those of vaginal and urinary infections, many sufferers don't initially receive correct treatment. Gynaecologists should consider LS if patients have recurring symptoms.

Lichen sclerosus (LS) is a chronic, non-infectious skin disease which usually affects the external genital organs of women; it can also affect other parts of the body. The disease is less prevalent in men. Even though most sufferers are older, LS can also affect children. "LS results from an auto-immune reaction mediated by T lymphocytes with an overstimulation of elastase which leads to perivasculitis", explains Prof. Andreas Günthert, Consultant in the Gynaecology Department of Lucerne Cantonal Hospital. He is committed to raising awareness of the disease in both sufferers and his colleagues because "the prevalence of the disease is probably under-estimated in menopausal women. LS is diagnosed in about one woman in thirty", he states. Hereditary transmission of LS is also higher than previously thought, and probably presents in 50% of cases.

Diagnosis and treatment

Female sufferers generally consult their doctor about pain, itching, and burning sensations in the genital region. During the medical examination, different skin changes may be noticed, including hyperkeratosis, rhagades (fissuring), erosions and excoriations. As a general rule, the result is a marked atrophy of the vulva. "Lichenification of the skin, that is whitish changes with a leathery look, is also typical", according to Prof. Günthert. It is not always necessary to do a biopsy to diagnose LS because usually the disease can be identified on sight. "However, if there is any doubt, a tissue sample could be useful", says the gynaecologist.

LS is treated with a topical immunosuppressant, in the form of an ointment with very potent

Keypoints

- *LS is a chronic, non-infectious skin disease of the vulva, set off by an auto-immune reaction provoked by T-lymphocytes.*
- *Women of all ages, men, and children of both sexes can be affected.*
- *The disease is often diagnosed and treated very late because it is often misdiagnosed as bacterial or fungal infections.*
- *It is treated with very potent corticosteroids which suppress the immune reaction. There is no cure.*

corticosteroids, such as clobetasol propionate or mometasone furoate. "If they are not tolerated, calcineurin inhibitors such as Pimecrolimus or Tacrolimus may be used", he says. There is no cure but treatment can slow or stop the progression of the disease. Immunosuppressants are used daily at the start of the treatment and if new symptoms present. Thereafter, maintenance treatment with longer intervals is recommended. If properly treated, skin atrophy will not occur. Daily application of fatty ointments is also advised.

Impressum



If the disease is not treated, or if it is treated too late, adhesions and scars may form, which could require surgical intervention. Basically, any gynaecologist can treat a patient with LS, says Prof. A. Günthert. "If someone is well trained, there is no need for specialists. A very good consultation and targeted information are necessary. As well as a good network with physiotherapists and sex therapists, because those affected often suffer from physical, psychological and sexual problems at the same time. In case of doubt, however, a consultation with a specialist is recommended".

Increase knowledge and awareness

LS is often diagnosed and treated very late. A lot of patients went through years of suffering before being properly diagnosed and getting correct treatment. One of the causes lies in the initial non-specific symptoms. "LS can be very difficult to diagnose in the initial stages because the characteristic changes are often absent and the symptoms can resemble a urinary tract infection or a vulvovaginal fungal

infection", stresses Prof. Günthert. In the first stages, biopsies are often not conclusive. "Moreover, this medical condition has been ignored for a long time, as has the vulva. Up to now, it (the vulva) was almost completely absent from training sessions, and it's only in recent years that it has become more important – and with it the images and medical conditions associated with it. With early diagnosis and correct long-term treatment, the consequences of LS may be almost completely halted. The risk of cancer does not appear to increase either; however, this is not the case in untreated LS". The Consultant in the Department of Gynaecology in the Lucerne Cantonal Hospital, who also contributed to the European S3 Lichen Sclerosus Guidelines, is actively committed to improving the situation.

Systematic training, refresher courses and further training are important for doctors. At the same time, patients should be better informed and educated so that they are not afraid to talk to their doctor about the subject. Lastly, public relations, such as participation in medical congresses, magazine articles, and television

documentaries, play an important role. Prof. Günthert advises all gynaecologists to think of LS when patients come to see them with recurrent vaginal thrush or yeast infections, nonbacterial cystitis or fissures on the skin of the vulva after sexual relations.

Dr. Corina Ringsell interviewed

Prof. Andreas Günthert

Consultant in the Gynaecology Department of Lucerne Cantonal Hospital

Note of the translator: Prof Günthert has left the Lucerne hospital as per November 2018 and can be contacted now at:
www.gyn-zentrum.ch

Quellen:

Interview mit Prof. Dr. med. Andreas Günthert, Chefarzt Frauenklinik, Kantonsspital Luzern, European Dermatology Forum: Guideline on Lichen sclerosus. 2014

Focal point, not only for patients with LS

A lot of people don't know what LS is. And a lot of sufferers don't realise that their symptoms are caused by a disease that cannot be cured but can be treated. The LS Association was founded in 2013 by people with LS – it is a focal point for both people with the disease, and those interested in it. Board member Bettina Fischer describes the role and aims of the Association, and explains why doctors appreciate her support.



©MedCommunications

Owner interviewee:
[Bettina Fischer](#)
Lichen Sclerosus Association
E-Mail:
vorstand@lichensclerosus.ch
www.lichensclerosus.ch
www.juckenundbrennen.ch
www.juckenundbrennen.at
www.juckenundbrennen.de

Many patients, but also certain doctors, have never heard of LS. Is the disease that rare? Who is most affected?

B. Fischer: The disease itself was first described about a hundred years ago but, despite this, a lot of doctors don't know it well. It's partly because the external genital organs, as opposed to breasts, are still a taboo subject. Many women don't know exactly what a vulva looks like, don't study it actively, and therefore don't notice any changes to it. Moreover, sufferers rarely speak openly about their symptoms. Lastly, until recently, the vulva and its diseases have been very neglected in medical training. LS is still considered a "rare disease" that mainly affects woman over the age of the menopause. This situation is unacceptable. It is estimated that one woman in 50 suffers from LS, including a lot of younger women. LS also affects men, and can occur in both sexes in childhood; it is thought that 1 in 900 children is.

What are the signs of LS in women?

B. Fischer: Signs of LS are recurrent itching and/or burning sensations in the genital region, skin fissures

during/after sexual intercourse, symptoms of urinary infections without bacteria, and whitish patches and redness on the skin of the vulva.

What are the signs in men?

B. Fischer: In men and boys, the foreskin is affected first, and shrinkage occurs. If LS is not treated, the disease can spread to the glans, where whitish patches can also be observed. The same symptoms as women are also felt: pain, burning sensation, sometimes itching, discomfort during sexual intercourse, and, at an advanced stage, shrinking of the urethra. However, full circumcision at the start of the disease can bring about full recovery.

What advice can you give to people suffering from the usual symptoms of LS? Where can they find qualified help?

B. Fischer: Our experience has shown that a lot of doctors have too little knowledge of the clinical presentation and the treatment of LS. Women should speak to their gynaecologist about their symptoms, if they suspect they have LS, and

ask if LS is a possibility. Dermatologists are often familiar with the disease. Another possibility is to consult a vulval specialist.

What can sufferers do, to supplement treatment?

B. Fischer: As well as a medical treatment according to a treatment plan with a very potent cortisone ointment, meticulous care of the genital region with fatty ointments and oils is necessary. They should be applied every time the person uses the toilet. It is important to keep the skin supple so that it doesn't tear, scar or harden. Excessive intimate hygiene should be avoided, because it irritates the skin even more. We also advise wearing loose clothing and cotton or silk underwear.

The LS Association was founded in 2013 by women suffering from LS. What were their reasons?

B. Fischer: The founders had all gone through medical marathons. For a long time, they hadn't had any help or been given any information, even though both existed at the time. Our first aim was to collect information and make it available to sufferers and to the doctors who

treat them. For example, on our website, you can find the current Guidelines for S3 treatment of LS, as well as a 2-page resumé of this for sufferers. As well as this information, sufferers need a chat forum. For example, sufferers open up more easily in a closed forum or in exchange groups with people also affected by the disease, when talking about very intimate questions or problems of sexuality, that are common in those affected by LS. Other sufferers can also give better advice than some doctors on how to manage the disease in daily life. Parents of children with LS, confronted by specific problems, are another group that cultivates an animated exchange.

What are the aims of the Association, and who can become a member?

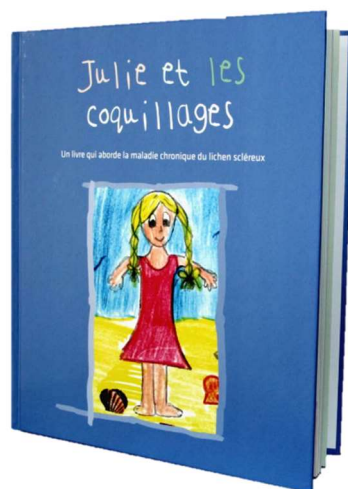
B. Fischer: Our main aim is to increase awareness in both doctors and the public. LS is not as rare as it was thought. Our membership application figures and corresponding studies are proof. Since the creation of the Association in 2013, more than 1,000 people have subscribed*. And since we're also present in the media, we have 1 or 2 new applicants every day. The support of experts such as Prof. Günthert at the Lucerne Cantonal Hospital gives greater weight to our agenda.

The large number of members enables scientific research and studies on LS to be undertaken. Many doctors recognise the value of our LS self-help groups, and send patients to us because they know that we understand the concerns and the problems of the sufferer, listen to them and give them advice and tips on daily life. Moreover, we encourage sufferers to correctly use the cortisone ointment, because a lot of people are afraid and hesitate to use it. Our work also lightens the load for doctors. LS sufferers, or parents of young LS sufferers, can become members of the Association, as well as anyone wanting to support

our work.

What work do you do?

B. Fischer: Since 2015, we have been present at medical congresses, where we can approach doctors directly. We are now also present in the media, with articles, reports and documentaries, for example in newspapers and on television. After each publication/appearance in the press, we receive an increased number of requests for information from affected women.



Many say that, after unfruitful treatment, they don't dare go back to their doctor because they have abandoned hope of ever getting help or, if they had been diagnosed, they didn't receive the correct treatment. We direct sufferers towards competent doctors or vulval specialists, offer discussions in different regional exchange groups or in protected chat groups, and organise workshops. We also give educational conferences, and urge women to observe their intimate areas with the help of a mirror. Self-examination really works, as is seen in the early detection of breast cancer. We also published an educational book, *Julie and the Seashells*, which gives information about the disease in a fun way for children, adults and doctors who want to give it to their patients. It can be ordered at our Association or in any bookshop.

In which countries is the LS Association active?

B. Fischer: We offer chat/help groups in Switzerland, Austria, Germany and Luxembourg. Individual members also come from France, Portugal, Israel and Canada*.

Are there differences in the countries in terms of knowledge of LS and the treatment of it by doctors?

B. Fischer: Yes, there are. In Switzerland, things are moving slowly. In Germany, we note that doctors don't have enough time for their patients – often, a "quick diagnosis" is fungal infection. In Austria, different tests and treatments without conclusive results are proposed. We have also observed that some doctors correctly diagnose LS, but don't treat it long term with potent cortisone, as per the Guidelines. I think it's important to inform and encourage patients to dare to address the doctor about the subject of the Guidelines.

What would you like to see in the future?

B. Fischer: That our work continues to bear fruit, and that the knowledge of doctors and LS sufferers continues to grow. A dream for the future would be the creation of special interdisciplinary centres of competence that would focus exclusively on LS sufferers and would bring together under the same roof the different specialists involved in the diagnosis and treatment of the disease. That would be a great help, not only for sufferers, but also for doctors.

Mrs Fischer, thank you for this interview.

The interview was conducted by Dr Corina Ringsell

**Note of the translator: the Association represents more than 2300 patients from over 18 countries as per September 2019)*