

July 22, 2014 (revised)

TO WHOM IT MAY CONCERN:

I am a physician, and I have Lichen Sclerosis.

I was first diagnosed with Lichen Sclerosis in March 2007, after about 6 months of itching. The next few months I searched for what medication combination was best for me, as I watched my vulvar architecture disappear, and my symptoms get worse. I searched on the internet, and found a clinical trial related to Lichen Sclerosis that I could participate in, and I found several list serves/on line groups in which to participate.

The Yahoo list serve through Yahoo Groups, is open to anyone with LS or with a loved one with LS at: <http://groups.yahoo.com/group/LichenSclerosis/>. This is quite different than many other internet groups I have seen and participated in, whether topic or disease specific. In this group, there is true support and understanding, with open sharing. Similar information is available at [www.lichensclerosus.net](http://www.lichensclerosus.net) for open access.

The owner, Dee Troll, has also gathered the largest repository of information related to Lichen Sclerosis that probably exists anywhere; she has collected this information over 12 years. And the women (and a few men) have, through trial and error, found a protocol that works for many who have not previously been helped by "typical" treatments. I, too, am one of those people, who after various attempts, found that the combination, first suggested in this group, of clobetasol, topical estradiol, and topical testosterone has allowed me to have primarily symptom-free days.

This includes clobetasol, usually as an ointment, usually 0.05%; topical estradiol, usually compounded, usually 0.01%; and topical testosterone, usually 2%, also compounded. The amounts used topically of each are tiny, and the ratio used varies from person to person, usually starting with clobetasol (a tiny pea size) daily, estradiol 3 times a week, and testosterone 2 times a week.

The clobetasol is quickly tapered as symptoms improve, but is often continued once or twice a week forever to keep symptoms in remission. The amount of estradiol and testosterone may increase or decrease depending on an individual's needs.

The basic idea behind this, which has not been tested scientifically, is that the clobetasol decreases the active symptoms of LS, the itching and inflammation, and prevents progression, the estradiol "feeds" the estrogen starved vulvar cells in a way that can't happen with oral or systemic estrogen, and the testosterone strengthens the previously damaged skin, possibly also increasing the estrogen receptors in the vulvar tissue.

This combination seems to work whether someone is in their child-bearing years, peri- or post-menopausal, and even includes young girls and men. The amounts of estradiol and testosterone used topically are usually too small to increase systemic blood levels or give systemic side effects.

Many have found that when LS is active, the tissues are very sensitive to essentially everything, so that the "inactive" ingredients in creams and other estrogen preparations are also irritating. Many find that even KY jelly aggravates the symptoms. Often coconut oil, emu oil, or olive oil can be used as soothing lubricants. Many members need to have their estradiol and testosterone compounded in mild, non-irritating bases.

The document compiled by Dee Troll, called "Meds and Suggestions" which your patient may also give you, explains all this in more detail, as well as other options to try.

I have chosen to write this, and to allow LS group members to give to their physicians, for several reasons. First, to have a physician who is well known and well respected in her areas, note that this particular group is of high quality, non-inflammatory, and medically sound. And second, to encourage physicians to let their patients try this protocol, and prescribe the tools of compounded topical estradiol and testosterone for their patients.

I am quite willing to have physicians and other practitioners contact me for further discussion, at [drsved@aol.com](mailto:drsved@aol.com)

Sincerely,

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