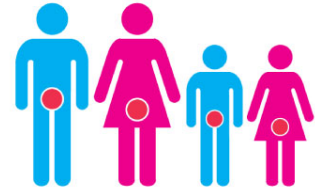


The Association for

**Lichen Sclerosus & Vulval Health**



## UK LICHEN SCLEROSUS CONFERENCE

This Association has been in existence since 1994. It was the first in the world and inspired many other countries to form their own National organisations.

It has only been able to arrange ONE conference. This was funded by the kindness of the students at Exeter University as part of their Rag Week.

So why has there been no conference since?

- FUNDING
- LACK OF INTEREST FROM THOSE DIAGNOSED WITH LICHEN SCLEROSUS
- THE IMPACT OF FREE BUT OFTEN UNVALIDATED AND INCORRECT INFORMATION ON SOCIAL MEDIA

In the past our Founder has tried to encourage more real world participation. The value of face to face meetings with others has been negated by the internet. Our Founder has offered membership (that could have funded an annual conference) She has been told, 'I do not want to pay for information that I can get free on the internet.'

Generally, it would appear that Britain is very different from other European countries who seem more able to attract support and committed interest for their National organisations.

ALSVH is based in Brighton on the South East Coast. A face to face meeting group has been offered here and published on the website with absolutely no interest at all.

If you are reading this, if you have a view or an opinion please email using the contact email address.