LICHEN SCLEROSUS CHILDREN'S CHARTER

For the purpose of this Charter the Association for Lichen Sclerosus and Vulval Health is abbreviated to ALSVH. Lichen Sclerosus is abbreviated to LS.

The images are real girls. They are now mature adult women. They grew up in innocence in a world with insufficient education about LS. They have donated their images to raise awareness because they say, ‘We do not want children to grow up and face life with disfigured genitals and symptoms and complications that take away their rights to enjoy sexual pleasure. We believe there must be education to ensure that children are not harmed by ignorance. We wish them to live their lives as normal women, something we have been denied. “We believe a woman deserves an Indian Summer, not a Winter of discontent.”

ALSVH is concerned that nowhere in any charter or legislation for the protection and best interests of children, are there any specific rights, regulations or safeguards with regard to a female child who grows up with genital disfiguration as a result of failures in medical education and training.

The World Health Organisation (WHO) and the United Nations (UNICEF) references are mute on this subject. Therefore, children diagnosed with lichen sclerosus must be considered to be a ‘marginalised group. (See right-to-education.org) Article 24 of the United Nations Convention on the Rights of the Child states “Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.”

ALSVH believes every nation must pursue full implementation of rights to ensure healthy functioning at the highest level for children diagnosed with lichen sclerosus. In particular, they shall take appropriate measures to ensure the inclusion of the needs of children with genital skin disease (this must be gender inclusive) and to ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care, the development of preventive health care including guidance and information for parents


Practice Gaps “Down There” Failures in Education, Physical Examination, Recognition, Diagnosis, Therapy, Follow-Up care.

‘children are not spared. Because it (LS) is usually asymptomatic, patients are seen with advanced disease, having flattened labia minora, narrowed introitus, a scarred-down clitoris, and sexual dysfunction. This can occur as early as age 20 years, and therapy at this advanced stage is problematic.’

https://jamanetwork.com/journals/jamadermatology/article-abstract/1724030?redirect=true

ALSVH recognises the issues for boys. Many undergo circumcision. There are not enough long term studies to show the efficacy of circumcision into adulthood. More education is needed.