

ALSVH is the first patient advocacy in the world and has been running since 1994. Over the course of the years it has seen many changes in lichen sclerosus and been involved in published papers and helping with making medical policies to help EVERYONE who has lichen sclerosus. Our Governing document states that we must include men in any work we do and it would be a breach of that document to support such a biased project. It is therefore, with sadness that it has become necessary for ALSVH to boycott and condemn a particularly discriminative project that will not equally honour the needs of men and small boys. It has been discovered that a group of medics and academics will meet on 18th July, in London to start a James Lind PSP. You can read about it on the [James Lind website](#). Two of the aims of a PSP are transparency of process and balanced inclusion of patient, carer and clinician interests and perspectives. On enquiry, we have been shown no evidence of a balance of male and female patient representatives. The aim is to spend many thousands of pounds to make a list of priorities for research into lichen sclerosus. Our Founder has had to fight in very aggressive correspondence to ask for men to be included in the steering group. She has had her character vilified by those whose main interest lies only in female lichen sclerosus. Only one person will represent men, a doctor, against a backdrop of a possible delegation of 20 others who are mainly concerned, or who are working with vulva lichen sclerosus. Patient representatives are all female. Lichen sclerosus is, perhaps, the only skin disease in the world to have been gender separated. If you look at eczema, psoriasis etc, you will find that gender and age equality exist. It was felt important that visitors to this site be aware of the very considerable power of those who sit around a table and make decisions for your lives and can exclude thousands who also suffer on the basis of their gender. Never, ever think that politics do not matter. They are the process that governs what treatment you receive, what information you are offered and whether you are important enough to be included in academic research or not. Those taking part have sufficient knowledge from years of seeing patients, to be able to come up with a list in a more cost effective way. Transparency and balance could have been achieved by the facilitators agreeing to include men at the very beginning of negotiations with this non-profit, instead, they declined to enter into negotiation and at the expense of men and small boys, which does not appear to be in accordance with the promises of the James Lind statements. However, there is professional kudos attached to undertaking a project of this nature for anyone ambitious enough to add it to their CV.