In the Spring of 2016, the Association undertook an informal survey to try to discover how many people are diagnosed with lichen sclerosis in the world.

Figures for the incidence of the condition were taken from various papers published by the medical profession. The numbers quoted were between 1% and 3%. 1% was chosen to be the base mark. Searches were made of reputable Global demographic websites and the 1% principle was applied to the overall world population at that time.

The figure arrived at was, 108 million diagnosed cases in the world.

Needless to say if 3% had been used, the figure triples.

Take into account that there may be equally as many 'undiagnosed' cases and that since Spring 2016, the figure of 108 million will have increased by hundreds of thousands.

Of course, the quoted outcome is not an academic study. However, those with the academic background and ability to prepare well researched statistics continually decline to do so.