

29 March 2019

Dear Doctor

Your patient has a rare genetic skin disease called ichthyosis. Recent guidance from NHS England <https://www.england.nhs.uk/wp-content/uploads/2018/03/otc-guidance-for-ccgs.pdf> has advised that emollients should not be prescribed for mild, dry skin conditions. As Chairperson of the Medical Advisory Board of the Ichthyosis Support Group, I would like to stress that ichthyosis, even the milder forms, are not mild, dry skin conditions. The ichthyoses are life-long conditions which have a major effect on quality of life and ichthyosis patients need regular emollients. In the recent European Guidelines on Care for Congenital Ichthyosis published in the British Journal of Dermatology, it was agreed that bathing, soap substitutes and moisturisers are all an important part of the care of patients with ichthyosis and we would be grateful if you could continue to prescribe these.

Additionally the recently published CLOTHES trial concluded that using silk garments for the management of eczema is unlikely to be cost-effective for the NHS. Again, we would like to emphasise that ichthyosis is a life-long severe condition and some patients do find silk garments helpful. The CLOTHES trial was about eczema **not ichthyosis** and GPs should not stop prescribing silk garments for ichthyosis patients that find these helpful.

Yours sincerely

Professor Edel O'Toole

Chairperson, Medical Advisory Board, Ichthyosis Support Group

Professor of Molecular Dermatology and Consultant Dermatologist  
Barts and the London School of Medicine and Dentistry  
and Royal London Hospital, Barts Health NHS Trust