



# European guidelines for ichthyosis therapy



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## Background

Ichthyoses are rare genetic skin diseases that profoundly affect the quality of life of the affected patients and are characterised by pronounced universal life-long scaling and often by marked skin inflammation, inability to sweat and heat intolerance, pruritus and by a proneness to infection and sometimes a failure to thrive. So far, no guidelines are available and therapeutic approaches for these diseases differ between various European countries. Also, because we are dealing with a rare disease, even that what can be

done for patients right now is mostly not accessible by the dermatologists or other medical doctors who are presented with these patients.

The aim of the project is therefore to create European guidelines in a concerted effort involving leading experts from European expert centres (especially experts from the European Reference Network for rare skin diseases) and from the European patient organisation for ichthyosis. The project will benefit patients suffering from ichthyosis, advance the management of ichthyosis in the community and improve patients' care and quality of life. The guidelines will also help clinicians in their clinical practice and further establish EADV as the leading organisation of dermatological care.

## A 3-step project

**Step 1** (achieved): preparation of the expert conference

The AGREE II instrument (a 23-item tool comprising 6 quality-related domains) was

used to develop this guideline. The clinical questions covered by the guidelines were listed and divided into five domains (topical therapy, systemic therapy, particularities of ichthyoses, complications, and psychosocial management). Literature searches limited to articles about humans, with no other restrictions, were performed using the PubMed database ([www.ncbi.nlm.nih.gov/pubmed](http://www.ncbi.nlm.nih.gov/pubmed)). Additional relevant references were added during the iterative process of guideline development. Levels of evidence were evaluated using the Scottish Intercollegiate Network guidelines. Due to the low number of clinical trials in AGREE II, a significant number of recommendations are based on the expert opinion of the expert group. A first draft of the guideline was circulated for comments to all participants prior to the conference that took place in April 2016.

**Step 2** (achieved): one-day expert conference held in Toulouse in April 2016.

A total of 36 experts attended (25 dermatologists, one paediatrician, one otorhinolaryngologist, one ophthalmologist, one clinical geneticist, one psychologist, one pharmacist, one dermato-epidemiologist, one nurse and three representatives from patient support groups).

**Step 3** (in process): writing the guidelines/ publication/dissemination. ●

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Expert conference in April 2016 in Toulouse

