

EMERGENCY CONTACTS

Name: Phone:

Name: Phone:

MEDICAL CONTACTS

Name (GP/pediatrician): Phone:

Name (specialist): Phone:

Rare disease reference center: Phone:

<http://www.maladiesrares-necker.aphp.fr/magec/>



European
Reference
Networks



RARE DISEASE EMERGENCY CARD

ICHTYOSIS

Family name: First name:

Date of birth:

CAUTION: my skin is fragile and painful



ICHTHYOSIS



Hereditary ichthyosis is a rare chronic skin disease of genetic origin. It results in the thickening of the skin, with scales. It can be erythematous, accompanied by detachments. Depending on the gene involved, specific extra-skin lesions can occur (eyes, CNS, liver ...).

In every case, the skin is dry and permeable, sometimes: fragile, fissured, painful, infected. It does not sweat or only a little, with an intolerance to heat.

GESTURES AND ACTS TO AVOID IN SOME CASES:

Highly adhesive dressings

Topical caustic products

Placing the patient near a heat source

RECOMMENDED GESTURES AND CAUTION:

- › Thorough skin disinfection before any invasive action
- › Beware of the possibility of rapid dehydration
- › Listen +++ to the patient, he knows himself perfectly
- › Emergency procedures (eg intubation) are possible
- › Be careful with eye care if there is an anaesthesia

See also DISEASE-SPECIFIC EMERGENCY CHARTS