

## *Infant Care* *Epidermolytic Ichthyosis*

Infants with a bullous (blistering) form of ichthyosis, called epidermolytic ichthyosis (EI), are born with red, blistering, and denuded skin (patches where the outer layer of skin has peeled away to reveal red, raw skin). There may also be patches of thickened skin (hyperkeratosis) on some areas of the body.

Babies born with EI have some special care needs and will need to be taken to the neonatal intensive care unit right away. The blisters and denuded areas of skin leave the infant open to infection; the baby should be watched closely for localized and systemic (whole body) infection and be kept in protective isolation. The nature of the infant's skin makes it difficult for them to hold moisture in their skin, which puts them at risk of other complications such as dehydration, electrolyte imbalance, and body temperature instability. The shedding and repair of the skin in babies with ichthyosis requires a lot of calories. Infants with ichthyosis may need extra feedings or a feeding tube to help them get the calories they need.

Infants with EI have very fragile skin and must be handled gently.

- The smallest trauma may cause more blistering.
- The medical tape used to secure IV lines and monitors may tear the skin and should be used with caution.
- When EI babies have wounds that need to be bandaged, a non-stick bandage pad can be held in place by soft cotton wrapping or stretch gauze.
- Babies with EI often cannot wear disposable diapers because they are too rough on the skin.
- All-cotton diapers tend to be less irritating.
- Thickly greasing the diaper area with petroleum jelly helps to prevent urine or feces from contacting the baby's skin.
- If the baby has extremely fragile skin, they may not be able to wear clothing at all without blistering or peeling.
- Wrapping the baby in oversized cotton receiving blankets can be another option.



Because ichthyosis is a rare and sometimes complex disease, specialists may be brought in to examine and treat your baby.

- The easiest way to keep track of who is caring for your baby and how, is to get a notebook that you can carry comfortably.
- Make a note of each of the medical people you meet; note their names, departments, how to reach them, and which one is in charge of your baby's care.
- Using your notebook to keep track of tests, medications, your baby's progress, and doctors' and nurses' observations will help you feel in control of the well being of your child.
- Helping in your child's daily care, bathing, feeding, diapering, and applying lotions, will help you to feel confident in caring for him or her once they are home from the hospital.

FIRST can connect you to other parents of children with ichthyosis through our Support Network. An experienced parent can support you through the first few weeks or months at home, as you get to know your baby and his or her needs. The FIRST publication, "*Release the Butterfly, A Handbook for Parents and Caregivers of Children with Ichthyosis*," will also help guide you through the first few months. FIRST also offers a series of resource fact sheets on issues related to ichthyosis that your child might experience. Available topics are: *Ear Wax & Scale, Itching, Overheating, Retinoids, and Scalp Scale*

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