

## Infant Care (Collodion Baby)



Children with some forms of ichthyosis (lamellar, CIE, Netherton syndrome, and harlequin ichthyosis) are born covered in a collodion (co-load-ee-un) membrane: a tight, shiny shell of skin that resembles plastic wrap. The collodion is a sheet of skin cells that failed to shed while the baby was growing in the uterus.

The tightness of this membrane may distort the baby's facial features and may restrict his or her movements. The membrane will crack and peel off over the course of several weeks. While the membrane sheds, your baby will probably need to be

cared for in the neonatal unit. He or she should be placed in a high humidity chamber. A high humidity environment will allow gradual sloughing off of the membrane. The membrane will come off on its own and should not be peeled off. Frequent applications of mild petroleum-based moisturizers may help the infant feel more comfortable while the membrane is peeling off.

The cracking and peeling of the membrane, increases the risk of infection from bacteria and viruses. The nature of the baby's skin also makes it hard for him or her to hold moisture in their skin, putting them at risk for complications such as dehydration, electrolyte imbalance, and body temperature instability. The infant will need to be closely watched for these complications. The shedding and rebuilding of the skin in babies with ichthyosis requires a large amount of calories. Infants with ichthyosis may require extra feedings or a feeding tube to help them get the calories they need.

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 easily. 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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