



Bullet Points for Media

- Ichthyosis (pronounced ick-thee-oh-sis) is a family of rare, genetic skin diseases characterized by dry, cracked, scaling skin that may be thickened or very thin
- At least 300 babies are born each year with a **moderate to severe** form of ichthyosis.
- There is currently no cure for ichthyosis. Dedicated researchers continue to develop effective ways to manage the disorder.
- The thickness of the skin and scale of those affected does not allow their sweat to reach the surface of their skin and cool them effectively. In warm weather, those affected are at risk for overheating, heat exhaustion, and heat stroke.
- The Foundation for Ichthyosis & Related Skin Types, Inc.[®] (FIRST) is the only national non-profit foundation located in the United States dedicated to assisting families affected by ichthyosis.
- FIRST provides information on its website www.firstskinfoundation.org, printed publications, and a quarterly newsletter, *Ichthyosis Focus*. FIRST hosts a biennial national family conference, and regional meetings which provide families the opportunity to create connections with each other and consult with leading medical experts.
- FIRST's Research Grant Program has funded 15 worthy projects totaling nearly \$1.7 million since 2006.