



## **FOR IMMEDIATE RELEASE**

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## **NEW STUDY ESTIMATES INCIDENCE OF RARE GENETIC SKIN DISORDER BETWEEN 200-400 EACH YEAR**

*Until Now, Severe Ichthyosis Cases Not Formally Recorded; Shines New Light on Rare Disease*

**COLMAR, PA (November 29, 2012)** - A new study, published in the September 2012 issue of *Archives of Dermatology*, suggests the incidences of moderate to severe ichthyosis - a family of genetic skin disorders characterized by dry, cracked, scaling skin that may be either thickened or very thin - is between 200 and 400 new cases each year.

The study, which was conducted by Dr. Leonard Milstone, of Yale University and Chair of the Medical and Scientific Advisory Board for the **Foundation for Ichthyosis & Related Skin Types, Inc.**® (FIRST), shines light on the incidence of moderate to severe cases of ichthyosis. Prior to this study, most statistics on the incidence of rarer, more severe forms of ichthyosis have been approximations.

Dr. Milstone, along with Kay Miller, Merle Haberman, and Jayna Dickens of Thomson-Reuters, found that the incidence of moderate to severe ichthyosis is 5-10 per 100,000 people in the United States. The study, which lasted over a 10 year period, captured the number of babies less than 1 year old who were discharged from the hospital or who appeared on an insurance claim with the diagnosis of ichthyosis. They found that the calculated incidence of ichthyosis was rather consistent each year over the period 2001 to 2010. The study also suggests that baby boys had a higher incidence of ichthyosis than girls, with the difference increasing over time.

The actual incidence of ichthyosis may be even higher, however. The newly published rates do not reflect the much larger number of newborn babies affected with milder forms of ichthyosis such as ichthyosis vulgaris and X-linked ichthyosis.

“Ichthyosis is can range from mild to quite severe,” said Jean Pickford, Executive Director of FIRST. “Although there is no known cure for this disease, dedicated research such as this gives us more information and helps us not only get closer to a cure, but to better manage the disorder.”

(more)



Although incidences of moderate to severe ichthyosis is between 200 – 400 each year, more than 16,000 babies are born with some form of ichthyosis annually, according to FIRST. This disease affects people of all ages, races and gender. The disease usually presents at birth, or within the first year, and continues to affect the patient throughout their lifetime. The most common form, ichthyosis vulgaris, affects approximately one out of 250 people. The symptoms are very mild, and therefore may go untreated or undiagnosed.

***About the Foundation for Ichthyosis & Related Skin Types, Inc.®***

The Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST) is the only nonprofit foundation in the United States dedicated to families affected by the rare skin disorder ichthyosis. FIRST provides information via printed publications, on our website, [www.firstskinfoundation.org](http://www.firstskinfoundation.org), and a quarterly newsletter, Ichthyosis Focus, sent to its 2,000 members. For more information, call toll-free at 1-800-545-3286 or visit [www.firstskinfoundation.org](http://www.firstskinfoundation.org).

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