

The National Ichthyosis Foundation

NEWSLETTER

Send all correspondence to;

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INTERESTING INFORMATION...

The ichthyoses are a group of disorders characterized by excessive scaling. They are currently classified: 1) by their clinical characteristics; i.e., the age of onset, the type of scaling, where the scaling occurs on the body, the presence or absence of other medical problems, etc.; 2) by their histologic appearance; i.e., the pattern seen on microscopic examination of a skin biopsy; and 3) by their mode of inheritance; i.e., how they are transmitted from generation to generation. One would like to be able to classify them also by their cause, but the underlying reason for the abnormal scaling is only known for one of the ichthyoses, x-linked ichthyosis, and this was only recently discovered. Hopefully as research in this field continues and as the causes of ichthyosis are better defined, improved methods of treatment will be developed based on an understanding of the underlying abnormality.

The Newsletter has been asked several questions about one form of ichthyosis, Epidermolytic Hyperkeratosis, which I will try to answer.

Question: What does Epidermolytic Hyperkeratosis mean?

Answer: Epidermolytic Hyperkeratosis (E.H.) is a rare form of ichthyosis. The words are descriptive of the pattern seen when the skin is examined under the microscope. This pattern is very distinctive and therefore the diagnosis of this form of ichthyosis can be made by skin biopsy of the fetus.

Question: Are there as many boys with E.H. as girls?

Answer: Yes, boys are affected with E.H. as often as girls. E.H. is inherited as an autosomal dominant trait. "Autosomal" indicated that males and females are equally likely to be affected. "Dominant" indicates that it takes only one dose of the abnormal gene for the condition to be present. In other words, people with E.H. have a gene for normal skin and a gene for E.H. The effect of the gene for E.H. overrides the effect of the normal gene, and ichthyosis results. In some families there may be variability in the severity of the ichthyosis, for example, more widespread involvement in some family members. The reason for such variability is not known but it occurs in many genetic disorders.

Submitted by:

Dr. Mary L. Williams

GOOD NEWS..

We haven't even finished the incorporation process and we already have our first auxillary chapter forming in the Midwest, in Ohio. Their first meeting is scheduled for December 7th at 1:30p.m. The location is the office of Dr. Frank Yoder, 29 West College Ave., Westerville, Ohio, 43081. Dr. Yoder has warmly extended an invitation to all interested people to attend. A big "thank you" to you, Dr. Yoder. Let's all give him your support!

SOMETHING TO THINK ABOUT...

Marisa Mandia, Eastern Representative of the National Ichthyosis Foundation, has started a PEN PAL FAMILY for those of us who wish to share directly with someone like us. If you would like to participate, just send her a letter and ask her to forward your name, age, diagnosis, and sex, to someone that relatively matches you. She is looking forward to hearing from you.

MAIL TO:

Marisa Mandia
687 E. 5th St. 2nd Floor
Brooklyn, New York 11218
(212) 854-7084

A BIG "THANK YOU"...

We extend our most gracious "thank you" to the Hoffman-LaRoche Company, the Research Division, for their generous donation to help us get our foundation started. And a special "thank you" to Dr. Dorothy B. Windhorst for making it possible.

LET'S NAME OUR BABY...

We had some responses with ideas for a name for our Newsletter. We would still like some more ideas before we make a decision. Please keep it very positive and upbeat. Remember it's your Newsletter too!

OUR BEGINNING CONTINUED...

Much has happened since our last Newsletter. Having received an appreciable response from our first letter has prompted Drs. Williams and Elias to contact Derm Centers nationwide.

We have designed our logo and are in the process of getting it approved. Our logo was suggested by Marisa Mandia of Brooklyn, New York. Thanks Marisa for your contribution!

The National Ichthyosis Foundation has successfully peaked public curiosity. On October 6th ABC (KGO-Channel 7-San Francisco) interviewed Barbara Landwehr, Rita Karassik, Pam Brown, and Deatra Landwehr, regarding our goals and dreams for our foundation. We expect it to be aired early in the week of October 13th. We are very enthusiastic about having had this opportunity to reach out letting people know that we exist. We encourage you to contact your local ABC affiliate requesting coverage. Your affiliate can acquire a copy of the film from KGO-Channel 7-San Francisco, California.

We have established an account at the American Savings and Loan, 901 Tennessee Street, Vallejo, California, 94590, and are excited about having received our first donation. If anyone wishes to donate, you can send it directly to the bank under the name THE NATIONAL ICHTHYOSIS FOUNDATION.

TO BE CONTINUED....

If you are interested in being added to our permanent mailing list, please fill in the form below and send to Barbara Landwehr, 151 Toyon Dr. Vallejo, Calif. 94590.

Name _____	Birthdate _____
Address _____	Phone () _____
Diagnosis _____	

COMMENTS: Why you are interested in our Foundation. If you don't have Ichthyosis who do you know that does? If you have it, tell us something about yourself and your family. Feel free to attach a separate sheet.

NEXT MEETING...

Our next meeting will be held on November 2, 1980, at 2:30 p.m. The location will be
The Dermatology Foundation House
1301 4th Avenue
San Francisco, Calif.
(on the corner of 4th Ave. and Irving)
Please come. We look forward to meeting all of you.

DEAR DEATRA...

Hello, my name is Deatra. I'm fifteen years old. I was born with Lamellar Ichthyosis. I will be writing a regular column, so if you have any questions PLEASE feel free to write to me.

It's very rough having Ichthyosis. People can be very mean sometimes; but others can be very kind and understanding and concerned.

Sometimes I feel as though everybody is against me, and I feel like crying; but, if I go off into a corner and cry, then nobody will want me around.

I used to feel that I hated my skin, but I found out later that I hated my whole self. You can't just hate one part of you without hating your whole person.

When people like or don't like me, it's not because of my skin. Instead, it's because of me as a person. I am a person--an individual! My skin is only the outer part of me-- a small part of the whole me.

PARTING THOUGHTS...

Our dream is really coming true everyone! So many good ideas and so many wonderful people helping us, is bringing us closer to our goal. Our future can only be a bright one. Please, keep your chin up and a smile on your face always; we've got so much to be grateful for.

Here's a thought that helps me to live each day for my child, who suffers from Ichthyosis too...

I will do more than belong,
I will participate.

I will do more than care,
I will help.

I will do more than believe,
I will practice.

I will do more than be fair,
I will be kind.

I will do more than forgive,
I will forget.

I will do more than dream,
I will work.

I will do more than teach,
I will inspire.

I will do more than earn,
I will enrich.

I will do more than give,
I will serve.

I will do more than live,
I will grow

I will do more than be friendly,
I will be a friend.

If we can always remember the things written in this verse, then we will all add to the special spirit of love and caring that we all wish to share with one-another as part of this Foundation.

Until nexttime,
Remember...the old saying...
"When the going gets tough,
the tough get going!"

NEVER GIVE UP THE FIGHT!!!