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The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

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VOLUME I, NUMBER 5

JANUARY 1981

FROM A MEDICAL POINT OF VIEW...

Our guest columnist this month is Ervin Epstein, Jr., M.D., Assistant Clinical Professor of Dermatology at the University of California Medical Center, San Francisco, California. We thank him for sharing his expertise on X-linked ichthyosis.

Question: What is X-linked ichthyosis?

Answer: X-linked ichthyosis is the second most common type of inherited scaly skin, affecting 1 in 6000 males. It affects only males, is usually not present at birth but starts during infancy, and generally lasts throughout life.

Question: Why is it called "X-linked?"

Answer: Unlike other common forms of ichthyosis, the gene that causes the scaling is carried on the X-chromosome. Since women have two X-chromosomes and men only one X-chromosome, women are far less likely to have the disease because the presence of one normal gene is enough to prevent the skin from becoming scaly. The characteristic pattern of inheritance is for patients to have clinically normal children. The daughters, however, may be "carriers" of the disease, and their sons may have scaly skin.

Question: How is the X-linked type of ichthyosis diagnosed?

Answer: X-linked ichthyosis may be differentiated from other types by the darker color of the scales, especially on the sides of the neck, by the history of scaly skin in uncles and grandfathers in the mother's family, and by new chemical tests. Three years ago it was discovered that patients with X-linked ichthyosis lack one specific enzyme that is important in metabolizing some types of steroids. This enzyme now can be measured in scales, blood, or skin cells, and these tissues from patients with X-linked ichthyosis lack the enzyme.

Question: Is there any treatment specific for X-linked ichthyosis?

Answer: We do not know any such treatment now. However, the finding of a missing enzyme has sparked research into this disease in a dozen laboratories around the world and we are hopeful that this new effort will teach us why the skin is scaly and then how to treat the scaling much more effectively.

IMPORTANT NOTICE...

The National Ichthyosis Foundation is a charitable organization, and 100 percent of the money collected by it will be used for charitable purposes, such as education, counselling, and research regarding ichthyosis. The organization's major expense at this time is the mailing of its newsletter and the printing of educational material. The organization's address is 151 Toyon Drive, Vallejo, California 94590. The Articles of Incorporation as a non-profit organization have been approved by the California Secretary of State and its Tax Exempt Status has been approved by the California State Franchise Tax Board. An application for determination of the organization's tax exempt status under Federal Law will be filed with the Internal Revenue Service. All contributions to the organization will be deemed to be tax-deductible under California Law and we expect they will also be deductible under Federal Law.

HAPPY BIRTHDAY..

Birthday wishes for the month of January are extended to:
Marwana Keishk age 10

Printing costs for this issue of Ichthyosis Focus have been defrayed by a grant from the educational division of Hermal Pharmaceutical Laboratories, Oak Hill, N.Y. 12460

TEEN TOPICS...

Hi! Well here I am again, with some more of my "teen topics."

Many people have complimented me on my thick hair when, in fact, it is very thin. This is why it was decided that the topic for this month will be "Hair Care."

Some people have very thick hair and others, well, they have very thin hair. My hair can look thick or thin depending on the way my hair is curled. I mainly get my hair to look thick by washing my hair clean and hanging my head upside down while blow-drying it so my hair won't be matted to my scalp. (Hair tends to look thinner when matted to the scalp.) When my hair is totally dry I flip it under all the way around.

I can use any kind of shampoo but to keep the scales off my scalp I use "Head and Shoulders" and a cream rinse to keep my hair from splitting and breaking.

I have a very high hairline so that's why I curl my hair under and leave it down. When I pull my hair back it shows how thin my hair really is. I do get tired of the same hair style, washing, drying, and curling my hair day in and day out, that sometimes I just don't want to do my hair at all! But if that's what makes my hair look nice, then that's what I have to do.

So remember the things I told you and also remember that one hair style won't look good on everybody.

REMEMBER THIS...

IT'S NOT THE QUESTIONS THAT HURT. IT'S THE IGNORANCE!!!

MIDWEST REGIONAL CHAPTER...

The Midwest Chapter of the National Ichthyosis Foundation had its first meeting in Westerville, Ohio on December 7, 1980. Over 40 patients and relatives attended and it was quite beneficial to everyone there. Many of the patients had never known or had the opportunity to talk with anyone else afflicted with a similar condition. There was a lengthy discussion on social interaction of patients with ichthyosis and also their parents and how they each respond and react to the public. It was very nice in that we had patients from various age groups, ranging from age 3 to age 42.

Several of the patients, who are now married, productive citizens with children of their own, told of their hardships and the ways that they were able to carry on despite their disability. Several of the participants own words summarized many of the thoughts of others in a positive fashion, on how they have coped with their problems in the past.

One set of parents thought they were all alone with this type of affliction, which they really found to be a "blessing in disguise." Another patient, who is an adult now, stated, no one knew what he had, and it was quite frustrating for him. He had been treated with topical medications without much help for several years. He felt that having ichthyosis makes one mature earlier than other people their age, because of the difficult social interaction they have during their school years and life. He felt that the most important thing is support from family, friends, and loved ones. One of the parents stated, "It is difficult not to be overprotective of her children, but they don't want to entirely ignore the problem, so they try to give us as much support as possible."

One group participant summarized, "Everyone has limitations of some kind, but everyone must make the most of the opportunities that exist. Parents obviously cannot make everything okay, but they can develop a sense of inner well being in each child and support him in this fashion."

After the group discussion, there was a discussion about the Retinoids and the treatment of Ichthyosis. The theme was "How can we get patients with Lamellar Ichthyosis and also other forms, treated earlier than FDA approval?" This is obviously a difficult question to answer and no true answers are available at this time.

We will have our next meeting on Sunday, April 5, 1981, at 1:30 p.m., at the office of Dr. Frank Yoder, 29 West College Avenue, Westerville, Ohio 43081. For more information please feel free to contact Dr. Yoder at (614) 890-7708.

NEW YORK REGIONAL CHAPTER

The National Ichthyosis Foundation welcomes you to our first East Coast Meeting in this area. We will be setting up our New York Chapter at this time.

There will be others who have Ichthyosis present at our meeting, and we'd like you to come and meet us all too!

A "pot-luck" dessert bar will be planned. Please bring along a favorite "goodie" of yours. Punch and cookies will also be provided.

It will be held at the Church of Jesus Christ of Latter-Day Saints, 1218 Glenwood Road, Brooklyn, New York 11218. For directions, please call Marisa Mandia at (212) 854-7084.

Families and friends are welcome...see you soon!

MEDICAL ADVISORY BOARD

We would like to take this opportunity to welcome all the doctors who have so graciously agreed to sit on our Medical Advisory Board. As soon as our list is completely confirmed we will make a formal announcement in the newsletter.

PARTING THOUGHTS...

Looks like a whole new year is upon us. Let's pray that it will be filled with lots of good news for us, and our families.

We can only keep on believing that this year will bring us many new

beginnings...in research and in all the future plans we have for our foundation.

You **all** are always on our minds, and at the start of this new year, we wish to send you our love, and best wishes for all the blessings you so richly deserve.

"Keep On--Keeping On!!!"

HAPPY NEW YEAR!!

1981 MEMBERSHIP FORM

- Here is \$10 to cover my 1981 newsletter subscription.
- Enclosed is my additional contribution to further the goals of the Foundation.
- I wish to continue to receive future mailings but am unable to contribute at this time.
- Please delete my name from your mailing list.

CHECK ONE

New member

Renewal

Please Check:

Parent _____

Friend _____

Physician _____

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Professional _____

Name (Please print clearly) _____

Address _____

City _____ State _____ Zip _____

Phone () _____ Birthdate _____

Diagnosis _____

(If Applicable)

I give my permission to NIF to release my name and address to other members.

Signature _____

Date _____

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