



The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

Send all correspondence to:
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VOLUME 1, NUMBER 6

FEBRUARY-MARCH 1981

FROM A MEDICAL POINT OF VIEW

In the next few newsletters, we will be carrying a series of contributions by Dr. Joseph McGuire, Professor of Dermatology, Yale University School of Medicine, New Haven, Connecticut. Dr. McGuire is actively engaged in psoriasis and ichthyosis research, is a member of our Medical Advisory Board, and cares for several of our members.

SIGNIFICANCE OF APPEARANCE AT BIRTH

An issue that needs to be resolved is the relationship between the appearance of the skin at birth and the type of ichthyosis that is present late in life. The medical literature is confused and confusing on this point. The importance of this information is to be able to give a parent a reasonable prediction of what to expect in later years.

Collodion babies have a shellacked appearance; the skin is taut, dark, split and the eyelids and lips are forced open by the tightness of the skin. There are contractures around the fingers. The membrane is lost between 2 and 4 weeks of age. The question is, what happens to these children in later life? Because of the rarity of the disorder, a single physician can have only a limited experience with infants with collodion membrane. For example, some newborns with epidermolytic hyperkeratosis have raw, red, eroded areas on their skin where the epidermis has been rubbed off. These infants are occasionally mistaken for collodion babies and confusion results. Other infants with epidermolytic hyperkeratosis have blisters at birth. If you or your child

has a firmly diagnosed form of ichthyosis, what was the appearance of the skin at birth? Was the skin red, tight, shiny or cracked? At what age was the first manifestation of scaling?

HOW ICHTHYOSIS IS INHERITED

The diagnosis of the various forms of ichthyosis depends to some degree on the inheritance pattern as well as the clinical appearance. For example, of the four major ichthyoses, two are inherited as a dominant trait (ichthyosis vulgaris and epidermolytic hyperkeratosis) one is sex-linked (x-linked ichthyosis) and one is recessive (lamellar ichthyosis). The two ichthyoses most difficult to differentiate clinically are ichthyosis vulgaris and x-linked ichthyosis. They have different forms of inheritance. A dominantly inherited disorder such as ichthyosis vulgaris or epidermolytic hyperkeratosis is, in theory, transmitted to half the offspring of an affected person. If a mother or father has a dominant disorder, half of the children should be affected whether they are male or female. Sometimes, however, dominantly inherited disorders appear unexpectedly without a preceding family history. This unpredicted appearance of a dominant disorder is thought to be due to a spontaneous mutation or alteration of the genetic material in the father's sperm or mother's egg. Some mutations appear more frequently than others and are thought to represent instability at a

particular location of a chromosome. Once the mutation occurs in a chromosome and is expressed as a disorder, it is passed on to subsequent generations of that individual as a dominant trait. If the *parents* of the child with spontaneous disease have more children - the incidence of the disorder in their subsequent children should be no greater than that of the general population unless there is some basis for chromosomal instability. In other words, appearance of ichthyosis in a child as a result of a spontaneous mutation of a gene does not mean that his brothers and sisters are likely to have the disease.

Two Day Educational Workshop

The National Ichthyosis Foundation is planning a two day workshop which will include both educational and practical segments. The dates are Saturday, December 5, and Sunday, December 6, 1981. Exact details will appear in a later issue. Please reserve these dates now. We look forward to seeing you in San Francisco.

MEDICAL ADVISORY BOARD

The Medical Advisory Board will hold its next meeting on April 27 at 5 P.M. The location for the meeting will be announced later.

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.

A STAR SHINES FOR N.I.F.

We have a new Board Member! Most of us recognize him from his weekly television series. You've got it! . . . He's Gary Ewing of Knots Landing, generally seen Thursday nights on CBS.

Recently, he was the star of a made-for-T.V. movie called "Terror Among Us."

If you haven't guessed by now, it's none other than that tall good-looking blonde, Ted Shackelford.

Born and raised in Tulsa, Oklahoma, Ted is the son of Dr. and Mrs. Paul O. Shackelford. Dr. Shackelford is a member of the N.I.F. Medical Advisory Board.

Coincidentally, Ted spent six weeks in Vallejo living at Mare Island Naval Shipyard and attending school in Vallejo while his father was in Guam.

Ted spent a number of years on the road performing in dinner theaters; and in 1976, played Raymond Gordon in the daytime soap opera, *Another World*.



One year later, Ted arrived in California and began appearing on various television shows.

In 1978, he co-starred with Raymond Burr (also born and raised in Vallejo) in *The Jordan Chance*. Since 1979, we have seen him on Knots Landing.

Ted, we are proud to have you on our Board of Directors. Thank you for caring about us. We wish you luck in your career.

Reflections

The following reflection was submitted by one of our New York officers. She says that when she is feeling down, it helps to bring peace of mind.

"Why Me, God?"

One night I dreamed I was walking along the beach with the Lord.

Scenes from my life flashed across the sky.

In each I noticed footprints in the sand.

Sometimes there were two sets of footprints; at other times there was only one.

During the low periods of my life I could see only one set of footprints,

So I said, "You promised me Lord, that you would walk with me always. Why, when I have needed you the most, have you not been there for me?"

The Lord replied, "The times when you have seen only one set of footprints, my child, is when I carried you."

CHAPTER NEWS

CAROLINA CHAPTER

We are proud to announce that a new chapter has formed in the east. The states to be covered at this time will be North Carolina, South Carolina, Tennessee, Georgia, Alabama, and Florida. Regional Representative for the area is Mrs. Karen Stone, 26 Springwood Dr., Asheville, North Carolina 28805. Her phone number is (704) 298-6499. Please feel free to contact her at any time. She will be looking forward to meeting you.

OHIO CHAPTER

The next meeting of the Ohio Chapter will be on April 5 at the offices of Dr. Frank Yoder, 29 West College Avenue, Westerville, Ohio. For time and directions, write or phone 614-890-7708. Family and friends are also welcome.

CONNECTICUT CHAPTER

There is yet another new chapter forming. And it's in Connecticut. This Chapter will cover Connecti-

cut, Massachusetts, New Hampshire, Maine, Rhode Island, and Vermont. The Regional Representative is Mrs. Alise Kummer, 69 Church St., Seymour, Connecticut 06483. Her phone number is (203) 888-0037. She will be available to you whenever you need her.

COLORADO REPRESENTATIVE

We now have a Regional Representative for the states of Colorado, Utah, and Wyoming. Her name is Mrs. Teri Thompson, 349 Silver Springs Court, Colorado Springs, Colorado 80919. Her phone number is (303) 598-8020.

VIRGINIA/MARYLAND CHAPTER

Mrs. Donna Tormey has announced that she is interested in starting a chapter in her area. Anyone interested please contact her at 116 N. Harrison Rd., Sterling, Virginia 22170. Her phone number is (703) 430-0585. She is looking forward to hearing from you.

NEW YORK CHAPTER

"A Feeling of Togetherness, Shared by All" . . .

One of the most exciting, emotional days has just been experienced by the members of our New York Chapter. Our first official meeting took place on January 17, 1981, at 2:30 p.m.

Little by little, families walked through the door and into our meeting room. There was happiness on their faces as they were introduced to each other. Even the children that attended had their own little party.

After about an hour and a half of sharing our feelings with one another, we walked upstairs to set up our formal meeting. The love and happiness was felt by all. Seeing everyone joined together as a big "family" is something that was dreamed of for such a long time, and now that dream has come true . . . for all of us.

We had our meeting and each of us shared our feelings and told how we got involved with the Founda-

Continued

New York *continued from page 2*

tion. We felt a great warmth inside us knowing we aren't alone and we never will be again! Yes, that is what we are all about.

We elected officers for the Chapter and set the date for our next meeting in May. We even discussed opening chapters in Pennsylvania and Connecticut. Most of all we shared feelings that were bottled up inside for so long. We truly enjoyed ourselves!

How thankful we are that this meeting took place. Each one of you out there are very special, and we are so grateful that we are growing so fast.

A special note to our President, Barbara Landwehr . . . Barbara, you are one in a million. Without

you this meeting never would have taken place and the National Ichthyosis Foundation would still be just a dream. God Bless You!

And God Bless all of you for just being you.
Respectfully submitted,
Mrs. Marisa Mandia
Mrs. Donna DeAngelis



New York Chapter Officers. L.R: Claudia Kennington, Vice President; Marisa Mandia, Secretary/Treasurer; Donna DeAngelis, President.

HAPPY BIRTHDAY...

We missed a birthday last month. So an extra big special Happy Birthday to Miss Dawna Harris who is now 11 years old.

Happy Birthdays for the month of February go out to:

- Angela Rogers — 11 years old
- Scott Prichard — 18 years old
- Valerie Charles — 13 years old
- Linda Droste — over 21 years old
- Katy Jo McMasters — 2 years old

We are also extending Happy Birthdays for the month of March:

- Robert Massey — 9 years old
- Josie Hamilton — over 21 years old

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.

Please Check:

- Parent _____
- Friend _____
- Physician _____
- Teacher _____
- Relative _____
- Patient _____
- Agency _____
- Professional _____
- Other _____

(Please Specify)

CHECK ONE

New member

Renewal

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 _____

MAIL TO:
THE NATIONAL ICHTHYOSIS
FOUNDATION
151 Toyon Drive
Vallejo, California 94590

Correspondence Corner

Many of you have requested correspondence with others facing the same problems. If you would like to send your name and address and a short paragraph about the type of person you are looking to write to, you can send it to CORRESPONDENCE CORNER, c/o Ichthyosis Focus, 151 Toyon Drive, Vallejo, California 94590.

Karen Stone
26 Springwood Dr.
Asheville, North Carolina 28805
— Would like to hear from others with E.H.

Mrs. Gloria Hamor
P.O. Box 8804
Savannah, Georgia 31412
— Would appreciate address of any family with children with E.H.

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Parting Thoughts. . .

Our Foundation is really growing! And as the Foundation grows, so grows our friendship and our feelings toward one another.

What started out as just a small seed, has blossomed into a great big tree. And as each of our "branches" grow, our roots get stronger. But we must continuously water and nourish our tree so that it will always stay strong. Won't you help us "shower" our tree with water? Can you find it in your heart to send in just a small donation? It would be so much appreciated. Help make our "branches" spread out to all people everywhere. We need you.

Until next time, keep a smile on your face and never forget what we're all about. God Bless You All!

Marisa Mandia

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Important Notice

The National Ichthyosis Foundation is a charitable organization. All the money collected by it will be used for charitable purposes, such as education, counselling, and ichthyosis research. The organization's major expenses are the mailing of its newsletter and the printing of educational material. 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 are deemed tax-deductible under California Law and we expect will also be deductible under Federal Law.

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We join our hearts and our hands together as one family

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