



ICHTHYOSIS FOCUS

VOL. 7, NO. 1

SPRING 1988

Published Six Times a Year by The Foundation for Ichthyosis and Related Skin Types, Inc., (F.I.R.S.T.), 3640 Grand Avenue, Suite 2, Oakland, CA 94610 (formerly The National Ichthyosis Foundation). Telephone (415) 763-9839. F.I.R.S.T. is a non-profit California corporation for the benefit and education of its members and the public regarding medical, psychological and social aspects of the ichthyoses, a family of primarily genetic skin disorders. Letters, suggestions and contributions are welcome. Charles Eichhorn, Editor; Valerie Lutters, Contributing Editor.

FROM THE EDITOR

Wishing On A Star

Our struggle for recognition and understanding of a rare disease like ichthyosis is often discouraging. Although progress is sure, it is also slow, and on an individual basis it often seems we are about to be overcome by the effort of everyday living.

The following story appeared in THE ORPHAN DISEASE UPDATE, the newsletter of the National Organization for Rare Disorders, and reminds us of the magnitude -- and importance -- of the task we all face.

As the old man walked the beach at dawn, he noticed a young man ahead of him picking up starfish and flinging them into the sea. Finally catching up with the youth, he asked him why he was doing this. The answer was that the stranded starfish would die if left until the morning sun. "But the beach goes on for miles and there are millions of starfish," countered the old man. "How can your efforts make any difference?" The young man looked at the starfish in his hand and then tossed it to safety in the waves. "It makes a difference to this one," he said.

F.I.R.S.T. is trying to change the way everyone thinks of ichthyosis, but we, too, have to do it one step at a time. We are just a few people, stretched thin across the whole world. We have only a small office and a handful of volunteers, working on a tiny budget. We are "throwing starfish" as fast as we can, but need your help to accomplish more. We need volunteers and financial help to beat the morning sun.

-- Charles Eichhorn, Editor

1988 NEW HAVEN REGIONAL CONFERENCE SET

F.I.R.S.T. will sponsor a Regional Conference on May 14 in New Haven, Connecticut, at the Yale University Medical School. The program will include medical presentations by Medical Advisory Board members on diagnosis and treatment of the various ichthyoses, including a discussion of the most recent information on research advances, topical treatments, and the use of retinoids. A school administrator who is the parent of a child with ichthyosis will be on hand to discuss recent problems in schools where children with ichthyosis may be confused with victims of AIDS. Then a psychiatrist will address the emotional and psychological aspects of living with ichthyosis from the perspective of the patient and the parent.

This Conference will also feature a special effort to allow attendees to have lots of opportunities to meet and get to know other conference attendees. The program will include a special upbeat Evening Edition social event.

Remember, May 14 is the date to save! Watch your mailbox for a special registration flyer to be mailed soon! We'll have registration information as well as suggestions for accommodations.

NEW NIAMS SKIN DISEASE RESEARCH CENTERS

In the face of a serious budget decline for the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS), the recently created Institute's Director, Lawrence Shulman, M.D., went ahead with plans to create two new skin disease research centers this year. We all thank Dr. Shulman for his strong support of skin disease research. NIAMS, a division of the National Institutes of Health, is the largest skin disease research facility in the U.S. and coordinates research nationwide.

FROM THE PRESIDENT'S CHAIR

Ellen Rowe, of Raleigh, North Carolina, took office January 1, 1988, as the new President of F.I.R.S.T. The Board of Directors meets often in a national conference telephone call to save on travel costs. At the December meeting of the Board Of Directors, the following officers were appointed in addition to Mrs. Rowe: Sarah Massey of Fountain Inn, SC, Secretary; Kathy Rogers of Austin TX, Treasurer. The Board approved an agreement with Charles Eichhorn to provide office services as Executive Director for 1988.

Dear F.I.R.S.T. Members: Thanks for your enthusiasm! More than 250 people have written to me, and I have enjoyed receiving all of your heart warming and friendly letters. I only wish I had enough hours in the day to answer each and every one of personally.

We are looking forward to another year of growth for F.I.R.S.T., and want to encourage everyone to continue to support us in our efforts to spread the word about ichthyosis. Talk about your condition. Let people know what you have. Tell your friends and neighbors about F.I.R.S.T. Ask them to send us a small donation to help keep us going. It is time for us to stop being embarrassed about our skin, and instead, come out in the open and tell it like it is.

Yes, I have ichthyosis, and sometimes I find it difficult to talk about it, but the more I talk, the more I realize that most people care, most people understand; and when I reach out, there is always somebody who will be there for me. So try talking about your skin, first with loved ones, then try a few strangers. Let's work together to bring ichthyosis out in the open.

-- Ellen Rowe

NEW OFFICES FOR F.I.R.S.T.!

Again, F.I.R.S.T. has changed its address and telephone number. Charles Eichhorn, Board member and newly appointed Executive Director of F.I.R.S.T., has offered to let the foundation use space in his law offices in Oakland, CA, just across the Bay from San Francisco. A new telephone line has been installed and all of the foundation's records and supplies are centralized in the new office. Mail is being forwarded (usually) from the old address, but jot this one down, effective immediately:

3640 Grand Avenue, Suite 2, Oakland, CA 94610

The new telephone number is **415-763-9839**. Charles or a volunteer is often available during the day to answer your call. When no one is available, an answering machine will take over, and the staff will call you back promptly.

THE TAXMAN COMETH

A donation to F.I.R.S.T. is deductible under state and federal tax law, both for income tax purposes, as well as for estate tax purposes. We recently heard from a member who has changed her will so that F.I.R.S.T. will receive a generous bequest on her death. This will also reduce her estate taxes! A simple clause in your will can make a tremendous difference to the ichthyosis community we serve. And, of course, you can make a contribution at any time! The Foundation needs continuing financial support in order to maintain its programs, like this newsletter and our annual ichthyosis research grants. All donations, both large and small, are needed and appreciated; all are tax deductible as allowed by law.

SOME HEARTFELT THANK YOU'S

A very special thank you to James and Elise Phillips and to Lynne Showers for their generous donations to F.I.R.S.T.

Special thanks to Scott Gillis, Gary Oswald, Elaine Mack and Chris Eimiller for their generous commitment to dermatological education, exemplified by the printing of our new brochures by Westwood Pharmaceuticals.

We also want to thank the Tulsa Oklahoma Chapter for their special donation to help us distribute the new informational brochures on ichthyosis. The Tulsa Chapter is the strong right arm of F.I.R.S.T. and we give them our sincere thanks for their continued support.

Thanks to a great crew of volunteers, too! Ellen Rowe, our new President, followed up on the work of Susan DeHaan, past President, and managed to get the new brochures into print. Of course, if Valerie Lutters, our day-to-day administrative assistant hadn't written and typeset them for us, the project would never have gotten off the ground. Thanks, Valerie, for the brochure work as well as all the correspondence we're still trying to get filed! Mary Williams, M.D., Chairperson of the Medical Advisory Board oversaw the technical review of the material and made sure we told the truth, the whole truth and nothing but the truth, so help us. Thanks, Dr. Williams. Chris Renaldi and Mike Dattel of the Academy of Art College have provided us with our new logo and the start of a great public relations campaign. We appreciate their skill and generosity.

Do you donate to the United Way at work? Ask if you can designate F.I.R.S.T. as the specific recipient of all or part of your contributions! Many members have chosen this easy way to help us and themselves! But you have to ASK! In many cases, we receive the Donor contribution, but never hear who it was from . . . "We don't know you, but we love you!"

Every time a newsletter comes out, our tireless (almost) volunteer crew gets together for a long day of stapling, folding, labeling and sorting. Thanks to Valerie Lutters, Susan Shields, and Diane Teilh for always being there when needed.

TELL ME, DOCTOR

Dr. Paul Honig, Director of Pediatric Dermatology, The Children's Hospital of Philadelphia, answers this issue's question:

QUESTION: I've heard about mites, very tiny insects, that live in dead skin. Since people with ichthyosis have a buildup of dead skin, wouldn't they be more likely to be troubled by these mites?

ANSWER: Mites exist in many parts of our environment. The mite most people know about is the one that causes scabies. You must come into contact with an individual infested with this kind of mite to become infested yourself. Allergists have noted that some patients are affected by dust mites, and pediatric dermatologists sometimes think various mites are the cause of one or another disorder in pediatric dermatology. The most common disorder caused by mites is scabies. Although there is no definitive research investigating a link between mites and ichthyosis, there appears to be no reason for concern.

[Editor's note: Dust mites, tiny spider-like insects, are common in various parts of the country. They live on dead skin and hair. They do not seem to be a problem themselves, but some people are highly allergic to the "dust" or feces of the dust mite. An ichthyosis household has lots of dead skin lying around to feed dust mites. If you are in area where they are common, and if you or someone in your household is allergic to dust mite "dust", avoid rugs, draperies, open bookcases, etc., to minimize the collection of skin (and mite) dust. Clean your vacuum bag out every time you use it, and consult an allergy specialist!]

DERMATOLOGY FOUNDATION RESEARCH GRANT

The Dermatology Foundation recently awarded \$25,000 to Dr. Ruby Ghadially to support her work in ichthyosis research at the VA Center in San Francisco. Dr. Ghadially is working with Dr. Peter Elias and Dr. Mary Williams in developing phenotypic markers in cultured ichthyotic keratinocytes, that is, to develop a library of normal and ichthyotic skin cultures to be examined and compared to determine the basic defect causing the abnormally thick stratum corneum.

ORPHAN DISEASE COMMISSION HEARINGS

Kathy Rogers, F.I.R.S.T. Board member and Treasurer, recently testified before the National Commission on Orphan Disease in Dallas, Texas. She expressed to the Commission F.I.R.S.T.'s determined commitment to support research on orphan diseases as a path to understanding more common diseases as well as rare disorders, and asked for the dissemination of information about rare diseases to researchers and the public to foster this development. The Commission's report is due by Fall 1988.

WINTER 1987 AAD MEETING

The AAD held its Winter meeting in San Antonio, Texas, the first week of December 1987. Kathy Rogers, Charles Eichhorn and Ellen Rowe met there to participate in the Exhibit Hall activities and to meet with other members of the Coalition of Patient Advocates for Skin Disease Research.

The F.I.R.S.T. Exhibit, newly designed by Valerie Lutters, was a big hit and really stood out among the displays from almost a dozen other skin disease volunteer groups.

Two scientific exhibits in particular caught our attention: One included information about AIDS victims with ichthyosis-like symptoms of scaling. The other described how Lac-Hydrin, an alpha hydroxy acid-based skin lotion for ichthyosis and other forms of severe dry skin, not only removes scale effectively, but manages to keep scale from regrowing, thereby requiring a lower maintenance dosage in many cases.

HOT TIPS

HOT TIPS are information we receive from readers and other sources and are not recommendations by F.I.R.S.T. Always consult your dermatologist before trying anything you read about in HOT TIPS.

Old News: Suddenly RETIN A cream and gel (from Johnson and Johnson), a skin care product introduced over ten years ago, is in the news. Tests have shown that it lessens or removes wrinkles for many people. Part of its mechanism is the removal of cells from the upper layer of the skin. Some patients have used it successfully for their ichthyosis, but caution about its use in the sun: it makes the skin very sensitive to sunlight. Ask your dermatologist if it might help you.

Retinoids update: The biggest difference between Accutane and Tigason (etretinate), products of Hoffman LaRoche, is that Tigason remains in the body longer. This is of particular concern to women of child-bearing age, since both products have been shown to cause serious birth defects in pregnant women using them. The products are designed to combat severe acne in short term use, and should be used in ichthyosis treatment only under a doctor's careful supervision.

Tried and true: In a hurry to remove a lot of dead skin? Here's a popular way to remove it fast, then keep it off. Spray a mixture of half water and half propylene glycol (a harmless clear penetrant available cheaply from a pharmacy or chemical supply house - about \$15/gallon) on the affected skin, then cover up with a watertight plastic exercise or sweat suit. Wait 6-8 hours and shower. (This also works on the scalp, kept under a plastic shower cap.) Use a rough face cloth or loofah sponge to wipe off the old dead skin. Don't overdue it or you'll be sore all over and could open the way for infection. Dry off then use a good moisturizing lotion to seal and lubricate the surface of the new skin. A moisturizing product with lactic or glycolic acid will help keep new scale from building up, if used at least once a day.

Help for X-Linked Patients: 5% Glycolic acid in a water-soluble base (so its not too greasy), applied one or two times a day gives one FOCUS reader great satisfaction. "My scales are almost non-visible", he writes.

MAIL ORDER PHARMACIES

We would like to a list of prescription services that specialize in mail order. Can you help us by letting us know of your experience, good or bad, with a mail order pharmacy? Please drop us a line so that we can put together this article for the next newsletter. Just a short note will do. Thanks!

"FIRST" F.I.R.S.T. ICHTHYOSIS RESEARCH GRANT AWARD

On December 15, 1987, F.I.R.S.T. named Peter Elias, M.D. the first recipient of the F.I.R.S.T. ICHTHYOSIS RESEARCH GRANT. The \$2,500 research stipend was awarded to Dr. Elias after the Proposal Review Committee considered four ichthyosis research proposals for their short and long term effects, number of ichthyosis patients served by the research, and originality of the subject matter. Dr. Elias will apply the funds to the collaborative work already underway with Drs. Mary Williams and Ruby Ghadially studying the structural abnormalities of various ichthyoses in hopes of finding the cause of the excessive stratum corneum buildup characteristic of the ichthyoses.

F.I.R.S.T. ICHTHYOSIS INFORMATIONAL BROCHURES

For years, there has been no printed up to date information about ichthyosis available to the general public. A long time dream of all Foundation members came true when twenty-five boxes of brochures all about ichthyosis, its diagnosis, treatment, genetic characteristics and F.I.R.S.T. started arriving a few weeks ago. 10,000 each of three brochures on ichthyosis have been printed and are ready for distribution. The brochures, ICHTHYOSIS - AN OVERVIEW, ICHTHYOSIS - THE GENETICS OF ITS INHERITANCE, and THE FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, were written and typeset by staff administrative assistant and FOCUS contributing editor Valerie Lutters. Dr. Mary Williams of the Medical Advisory Board reviewed the material for accuracy and we were ready to go to print. Our problem was the cost of producing and mailing the brochures.

Meanwhile, the hard-working Tulsa Chapter of F.I.R.S.T. donated \$1,000 to be set aside for the brochure project. The money will be used to finance the distribution of the brochures to medical centers, schools, health professionals and national media.

The best news of 1987 came from Ellen Rowe when she reported that her efforts to find a company to help us print the brochures were successful. Westwood Pharmaceutical Company, a leading company in dermatological skin products and the manufacturer of Lac-Hydrin lotion for ichthyosis, has kindly produced a first class printing run of 10,000 of each brochure.

The brochures are ideal for explaining ichthyosis to family, teachers, school officials and health personnel, employers, health clubs, local newspapers, etc. They are white with blue printing and carry the F.I.R.S.T. logo on the cover. They range in length from 6-22 pages.

Brochures are available to Foundation members and the public at no charge. A shipping and handling charge of \$1.00 covers mailing for a set of all three. Shipping charges for larger quantities are available on request.

F.I.R.S.T. REPRESENTATIVES NEEDED NATIONWIDE

We need representatives in the following areas to complete our national network. Representatives are a telephone lifeline for families and patients with ichthyosis, and help us distribute information about ichthyosis and F.I.R.S.T. Drop us a line or telephone the office to discuss the responsibilities and advantages of joining our team of "starfish throwers."

MAINE	OREGON	MONTANA	WYOMING	NEVADA	UTAH	SOUTH DAKOTA
VERMONT	ARKANSAS	MICHIGAN	WISCONSIN	NEW HAMPSHIRE	ALABAMA	WEST VIRGINIA

National Ichthyosis Fndt./F.I.R.S.T.
3640 Grand Avenue, Suite 2
Oakland, CA 94610
Address Correction Requested

Non-profit Org.
U.S. Postage
PAID
San Francisco, CA
Permit No. 10956

DATED MATERIAL

F.I.R.S.T. -- The Foundation for Ichthyosis and Related Skin Types, Inc.
(formerly the National Ichthyosis Foundation)
3640 Grand Avenue, Suite 2
Oakland, CA 94610
(415) 763-9839

F.I.R.S.T., the Foundation for Ichthyosis and Related Skin Types, Inc., (formerly the National Ichthyosis Foundation, Inc.), is a charitable organization, incorporated in 1981 under the non-profit corporations laws of California. Its tax exempt status has been confirmed by the California Franchise Tax Board and the Internal Revenue Service. All contributions are fully tax deductible as allowed under California and federal tax law.

The opinions expressed in this newsletter are those of the Editor, and not necessarily those of the Board of Directors, Officers, Medical Advisory Board, or membership. F.I.R.S.T. does not endorse any particular product or treatment for ichthyosis. All medically related news and information is intended to inform and educate, and is not to be taken as a recommendation for use in any particular case. Readers are urged strongly to confer with their own physicians and proceed with treatment only on a doctor's specific recommendation.