



The National Ichthyosis Foundation

ICHTHYOSIS FOCUS

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FALL 1986

Published Six Times a Year by volunteers of The National Ichthyosis Foundation, P.O. Box 252, Belmont, CA 94002. Telephone (415) 591-1653. NIF is a non-profit California corporation, for the benefit and education of its members and the public regarding medical, psychological and social aspects of ichthyosis, a genetic skin disorder. Letters, suggestions and contributions are welcome. Valerie Lutters, Editor.

***** IT'S CONFERENCE TIME AGAIN *****

It's time to make plans to attend the National Ichthyosis Foundation Annual Conference, coming up Saturday, December 6. This year's conference will be held in picturesque New Orleans, Louisiana.

The conference will be a full day's event. In the morning, following registration from 8:30 to 9, members of our Medical Advisory Board will bring attendees up to date on the latest medical knowledge about ichthyosis, touching on an explanation of what ichthyosis is, what the most up-to-date treatments are, and what's new in research. After a short coffee break, the doctors will set up a panel, moderated by Dr. Mary Williams, chairman of the M.A.B., to discuss issues and answer questions of particular concern to conference attendees. Although questions will be taken from the floor during the panel discussion, it would be particularly helpful if N.I.F. members could send in some questions ahead of time. A space for your questions is provided on the registration form. Take a minute and think about issues you would like to see addressed; after all, this is your conference.

We'll break for lunch from about 12 to 1:30 pm, and then the afternoon session will feature discussions relating to how ichthyosis affects our social and emotional life and the lives of our children. North Carolina Representative Ellen Rowe, coordinator of the afternoon program, will introduce her father, Dr. Wilmer C. Betts, a psychiatrist in private practice in Raleigh, N.C., and president of the Board of Directors of the Wake County Mental Health Clinic. Dr. Betts is the father of four children, three of whom have Lamellar Ichthyosis. After a brief introductory talk by Dr. Betts, conference participants will break up into small groups. If possible these groups will be divided by categories such as: parents of children with ichthyosis, adults with ichthyosis, teenagers -- whatever the make-up of the attendees would indicate. The groups will find common issues which they would like to see addressed. Then participants will re-form into the larger group, and Dr. Betts will address those issues found to be of interest during the small group discussions. There will also be a question and answer period.

N.I.F. President Susan De Haan will present a brief State of the Foundation talk, filling attendees in on what's been happening with the Foundation over the past year and what N.I.F.'s goals are for 1987. The activities will conclude around 5 pm.

The conference location is the Napoleon Room of the Days Inn, 1630 Canal Street, New Orleans, LA., 70112, 1-504-586-0110. Registration fee is \$30 for an individual and \$50 for a family. The fee includes a luncheon of entree, vegetable, potatoes and beverage to be served in the Terrace Gallery of the same hotel. The Foundation has also reserved a block of sleeping rooms at the Days Inn, and conference attendees who register early will be able to reserve one of those rooms at a reduced rate of \$41 per night single occupancy, \$45 for double occupancy; children under 18 may stay with their parents at no additional charge.

It would be wise to make reservations early; the hotel suggests trying to reserve by November 5 to assure a reduced rate. Making those travel plans early could mean a substantial savings on plane fare, too. If, for some reason, you just can't make arrangements early, please don't think that means you can't attend the conference; it just means you may not be able to do it in the most economical way. The Foundation urges anyone planning to attend to make plans early, though, because it helps conference coordinators make arrangements if they know well in advance how many people to expect.

Make reservations to attend the conference directly through the Foundation by filling in the registration form elsewhere in this issue and returning it, with your check made out to the National Ichthyosis Foundation, to: National Ichthyosis Foundation, Box 252, Belmont, CA., 94002. Make room arrangements directly with the Days Inn and be sure to tell the reservations clerk that you are part of the Ichthyosis Foundation Conference.

Days Inn is said to be near the colorful French Quarter, so if you're able, you may want to spend a little extra time in New Orleans after the conference, walking around, sightseeing, listening to jazz and dining on Creole delicacies. If you're going to be traveling with children, you may be pleased to know that there are also some handy fast food places nearby. Child care will be available during the actual conference; sitters will do their best to keep the children entertained, but parents should bring plenty of their child's favorite books, games, etc. The Foundation hopes to offer child care free of charge, but it may become necessary to charge a fee, so please be advised that you may have to pay for this service.

This will be the Foundation's Fourth Annual Conference. Each conference so far has been bigger and more successful than the previous one, so we are hoping that this will be the biggest yet. All members are encouraged to come, and local reps are especially urged to attend. At the conclusion of each of the previous conferences, attendees were enthusiastic about all they had learned, touched by the new friendships they had made, and eager to take a more active part in Foundation activities. So -- circle that date, Saturday, December 6, 1986, on your calendar, hurry over to your local travel agent, and plan to meet your fellow members of the ichthyosis community.

 ***** TELL ME, DOCTOR *****

Beginning with this issue, the Tell Me, Doctor column is experimenting with a new format. We submitted one question to several experts, and are printing all the answers together so that readers can see and compare more than one opinion or observation. We hope that this approach will be useful, both in establishing those points on which there appears to be general agreement, and in illustrating the range of informed opinion on those points where there is less agreement. We approached not only members of our own Medical Advisory Board but also other experts in the particular areas covered by a given question.

QUESTION

I have the EH form of ichthyosis. I also have two children whom I breast fed when they were babies. To my surprise, I found that while I was breast feeding, my ichthyosis improved so much it nearly disappeared. Then, when attending one of the Foundation's annual conferences, I heard a number of other people, men and women, and people with other forms of ichthyosis as well as EH, say their skin improved considerably once they reached puberty. An older woman said she improved at puberty, and then found her skin condition going downhill once again when she completed menopause. All this suggests to me that there must be some sort of connection between ichthyosis and hormones, but I've never heard the issue discussed. Is there any concrete evidence linking hormones and ichthyosis? My observations seem too extensive to be just coincidence.

RESPONSES

Lowell A. Goldsmith, M.D., Chief, Dermatology Unit, University of Rochester Medical Center, Rochester, N.Y., and outgoing chairman of our Medical Advisory Board:

. . . In my personal experience I have not found changes at puberty or at menopause with EH. I have had some people who have had viral infections with some extended period of clearing after that infection. Until we find the cause of EH and its exact molecular basis, it will be difficult to understand these observations. As more research protocols are conducted in conjunction with the Ichthyosis Foundation, knowing how common any of these findings are will be extremely important. Also to be remembered in interpreting any of these phenomena, that although we talk about EH as a single disease, there is no doubt heterogeneity within that disease as there is in ichthyosis in general. There is no evidence that hormonal therapy of any kind to patients has a therapeutic value in ichthyosis.

Howard P. Baden, M.D., Professor of Dermatology, Harvard Medical School, Department of Dermatology; Massachusetts General Hospital, Boston, MA.

I really don't know of any relationship of EH to hormones. I suspect that the improvement is more related to increased experience in handling the problem and the decreased tendency to blistering with increasing age.

Gerald D. Weinstein, M.D., Professor of Dermatology and Acting Dean, University of California, Irvine, Irvine, CA

. . . I have seen a number of patients with epidermolytic hyperkeratosis over the past twenty years and have not been aware, from discussions with these patients, of any specific relationship between hormones and their disease. While the four major forms of ichthyosis, i.e. ichthyosis vulgaris, sex-linked ichthyosis, lamellar ichthyosis, and epidermolytic hyperkeratosis, all have genetic patterns of inheritance, I am not aware of any studies that suggest that there is an associated hormonal influence on the course of these diseases. It would be very attractive for both scientific and clinical reasons if such a relationship existed, but I am not aware that these associations have been made in other than isolated instances.

Anne W. Lucky, M.D., Associate Professor of Dermatology and Pediatrics, University of Cincinnati College of Medicine, Cincinnati, Ohio

. . . These observations certainly are suggestive that there may be hormonal influences on ichthyosis; exactly what hormones would be fascinating to discover. Prolactin, a pituitary hormone, is one of those that is elevated during the initiation of breast feeding, but is not necessarily elevated once lactation has been established. During pregnancy there are elevations of a number of estrogens and progestins. At puberty not only are there increases in estrogen and progesterone in girls, but in both girls and boys there are elevations of androgenic hormones such as testosterone. In addition, there are innumerable other metabolic and hormonal changes which occur at puberty.

I feel that the observations noted by the patient should prompt physicians taking care of other patients with ichthyosis to carefully follow their clinical course during times of hormonal change. In this way we may perhaps be better able to define what hormonal influences, if any, affect ichthyosis and perhaps even therapeutically influence ichthyosis with hormonal treatment. However, I should caution at this stage that because of the many adverse side effects of excess hormones of any sort that no one should try hormonal therapy until we understand this phenomenon better.

What about you? Did you notice any significant changes in your skin at any particular period in your life? Write and tell us. Let us know your age, your sex, the type of ichthyosis you have, and what, if anything, changed at that time. Or, if you noticed no change, tell us that, too.

 ***** HOT TIPS *****

A member from the midwest is enthusiastic about Mennen's "Balm Barr." She uses it on her four-year-old daughter who has ichthyosis and encourages others to try it, too.

Another midwest family is extremely pleased with Lac-Hydrin from Westwood and would like to share some tips on how to get the most use out of a tube or bottle. They put tips on the bottle (the long tips from hair coloring kits work especially well) and then squirt it onto their son's scalp. They find that using this type of tip wastes less of the Lac-Hydrin because it is easier to direct it right onto the scalp, wasting less of it on the hair. And they recommend heating it by soaking the bottle in hot water for a while (a microwave might do the trick, too) until it reaches approximately body temperature so that it will flow more easily. If you can get Lac-Hydrin only in tubes, just transfer it to a bottle with a tip by cutting the tube in half and scooping and scraping it out with a popsicle stick or tongue depressor. Even if they're not transferring it from a tube to a bottle, they find that cutting the tube open allows them to get a lot of ointment that would otherwise go to waste.

Last spring we mentioned that Henry Kaaps, president of Herald Pharamcal, had donated a number of 2-oz. samples of Aqua Glycolic lotion to the foundation for our members to try out. A number of you have written in asking for the samples, but we still have quite a few left, so if anyone would like to try a sample, just send us your name, address, and \$1 to cover postage and handling. Our North Carolina rep tells us that Aqua Glycolic shampoo is on the market now, too.

 ***** N.I.F. MEDICAL ADVISORY BOARD *****
 ***** Mary L. Williams, M.D., Chairman *****

- | | |
|----------------------------|---|
| Howard P. Baden, M.D. | Warren Bldg., 5th Floor, Mass General Hospital, Boston, Mass., 02114, (617) 726-3993 |
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| Frank W. Yoder, M.D. | 29 West College, Westerville, OH 43081, (614) 890-7708 |

Dr. Mary Williams was installed as the new chairman of the Medical Advisory Board at the board's meeting in May in Washington, D.C. She follows Dr. Lowell Goldsmith, a Professor of Dermatology and Chief of the Dermatology Unit at the University of Rochester Medical Center, Rochester, N.Y. Dr. Goldsmith had been M.A.B. chairman since the Foundation's incorporation in 1981. Foundation President Susan De Haan presented Dr. Goldsmith with a plaque which expressed the Foundation's appreciation for his years of help, encouragement, and expertise.

Dr. Williams is an associate professor in the Departments of Dermatology and Pediatrics and attends in the Pediatric Dermatology and Keratinization Clinics at the University of California, San Francisco, Medical Center. Her research, conducted in conjunction with her husband, Dr. Peter M. Elias, at the Veterans Administration Medical Center in San Francisco, is in the area of lipid (i.e., fat) metabolism in epidermis (outer skin layers). Dr. Williams has been active in the National Ichthyosis Foundation since its inception.

There are also some new doctors on the Medical Advisory Board. They will be highlighted in a future issue.

 ***** CURRENT REPRESENTATIVES AND CHAPTERS *****

- ALASKA: Lynette Finstad, 1606 Marika Road, #4, Fairbanks, AK 99701 (907) 456-6842
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- VIRGINIA: Mrs. Janet Weary, 110 Magnolia Drive, Charlottesville, VA 22901
- WASHINGTON: Richard Kelley, 12305 SE 73rd Place, Renton, WA 98056
- BR. COLUMBIA: Valerie Munroe, 2492 West 45th Ave., Vancouver, B.C. V6M 2J8 Canada (Chapter)

We need informal representatives and support persons in every state and major city. How about you? Would you spend a few hours each month sharing information and "being there" for someone in distress? We particularly need help in the following areas where there is no one for new parents to turn to: Maryland / Kansas-Nebraska / Vermont-Maine / North and South Dakota-Wyoming-Montana / West Virginia-Kentucky-Tennessee-Alabama / Arizona / Arkansas. Please contact Betty McMasters, 1838 So. Muskogee, Sapulpa, OK 74066 (Tel: 918-224-9099) for details.

Representatives who move from their area are asked to let Betty know about the move as soon as possible. Also, please notify Focus directly of your move so we can remove your name from the published list as quickly as possible.

 ***** N.I.F. TESTIFIES IN WASHINGTON *****

N.I.F. president Susan De Haan, Sarah Massey, a member of our Board of Directors, and Sarah's son, 13-year-old Robert Massey who has EH, spent several days in May testifying before Congressional subcommittees in Washington, D.C. They all report that the experience was rewarding and enlightening.

As representatives of the National Ichthyosis Foundation, they urged Congressional support for adequate funding for the new Arthritis, Musculo-Skeletal and Skin Diseases Institute in the National Institutes of Health. Mrs. De Haan says committee chairmen Senator Lowell Weicker and Representative William Natcher were interested in ichthyosis and receptive and encouraging about funding for skin disease research.

While in Washington, Mrs. De Haan attended a meeting of a coalition of skin foundations, including D.E.B.R.A., the National Psoriasis Foundation, and others. This coalition met with Dr. Peyton Weary who, in addition to being a member of N.I.F.'s Medical Advisory Board, is also a Congressional liaison for the American Academy of Dermatology. The coalition's main purpose is to unite the various foundations so that they can coordinate and organize their efforts towards the mutual goal of skin research and public awareness. The group plans to meet again in December.

YES, I'M COMING TO THE CONFERENCE
8:30 am to 5:30 pm, Saturday, December 6, 1986, at
Days Inn, 1630 Canal Street, New Orleans, LA, 70112

NAME(S): _____

STREET ADDRESS OR P.O. BOX: _____

CITY: _____, ST: _____, ZIPCODE: _____

TELEPHONE NUMBER: (please include area code): (_____) _____

NUMBER OF ADULTS ATTENDING: _____ NUMBER OF CHILDREN ATTENDING: _____

AGES OF CHILDREN ATTENDING: _____

I AM _____ AM NOT _____ PLANNING TO USE YOUR CHILD CARE/BABYSITTERS (Please check one).

AMOUNT ENCLOSED: _____ (\$30/individual, \$50/family)

HERE ARE SOME TOPICS OR QUESTIONS I'D LIKE TO SEE ADDRESSED AT THE CONFERENCE: _____

(You may attach an additional sheet if necessary, but remember, questions should be fairly brief.)

***** NEW COLUMN COMING *****

We're planning a new column for upcoming issues. The format of the column will be similar to that of "Tell Me, Doctor," but the topics will be social and psychological rather than medical. Initially the column will be written by our president, Susan Nye De Haan, a social worker and counselor with years of experience counseling children and adults. It was through her work with a child with ichthyosis that she became interested in the effects of this disfiguring disease on individuals and their families, and ultimately became involved with the Foundation itself.

The new column will deal with all sorts of emotional aspects of ichthyosis. It could address the ways adults with ichthyosis interact with their world and how they might, perhaps, improve that interaction. It could advise parents about how to best deal with raising the child inside the skin so that that child will be better equipped to function in a happy, healthy manner when he or she reaches adulthood. It could address the best ways to handle stress on parents and other family members when they are suddenly faced with a child with ichthyosis.

The new column will deal with whatever issues trouble you, the readers, because we are hoping that you will send in your questions for Susan or other professionals to answer. What non-medical aspects of ichthyosis would you like to see addressed in this column? Send in your questions or suggestions. We're hoping for a lively, thought-provoking new column.

***** CORRESPONDENCE *****
***** CORNER *****

Carol Licalzi has twin boys, four years old. One of the boys has Lamellar Ichthyosis, and Mrs. Licalzi would like to correspond with other people who have ichthyosis or who have children with ichthyosis. You can write to her at 97 Poplar Street, Garden City, N.Y., 11530.

Austin Saith, 7 Grace Street, Albany, N.Y., 12205, would like to correspond with other adults in the East who also have X-linked Ichthyosis as he does.

Rachel Winsor was recently diagnosed as having Lamellar Ichthyosis, and now that she knows exactly what she has she's eager to correspond and/or chat with others who have the same thing. Rachel is 17 years old and would like to hear from others around the same age or older. You can reach her at 6928 Lombardy, Crystal, MN, 55428.

Just a Reminder -- Ichthyosis Focus is sent out six times a year to members of the National Ichthyosis Foundation. The annual membership fee is \$15 for regular membership, \$25 for contributing member, \$50 for sustaining member. A contribution of \$75 per year designates a sponsor, and \$100 per year a patron. At this time the Foundation does not send out annual bills, but at a recent Board of Directors meeting it was suggested that we might begin designating one month per year as "Renew Your Membership Month." An annual membership drive could make it easier for individuals to remember to pay their annual dues, and for our hardworking bookkeeping staff to keep track of everyone. Meanwhile, if you can't afford to contribute at this time, you need not worry that the newsletter will stop coming to your home; it won't. As yet, no one has been turned away from any of the services of the Ichthyosis Foundation based on fees and finances. We ask you to contribute an annual membership fee, but if you just can't right now, we understand, and trust you to help us as much as you can as soon as you can. And, of course, you can make a contribution at any time! The Foundation needs continued financial support in order to maintain its programs. All donations, both large and small, are needed and appreciated; all are tax deductible. And you can designate the National Ichthyosis Foundation to be the recipient of your United Way contribution through its Designated Charity Program. Ask for the special form to direct your contribution to a specific organization, whether you will be donating directly or through payroll deduction.

The National Ichthyosis Foundation
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We join our hearts and our
hands together as one family

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P.O. BOX 252
BELMONT, CALIFORNIA 94002
(415) 591-1653

1986 OFFICERS:

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Jeannette Jensen	Secretary/Treasurer
Betty McMasters	1st Vice-President
Dick and Carol DeLoughary	2nd Vice-Presidents

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