



# ICHTHYOSIS FOCUS

First F.I.R.S.T. edition

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Published Six Times a Year by volunteers of F.I.R.S.T., P.O. Box 410453, San Francisco, CA 94103 (formerly The National Ichthyosis Foundation). Telephone (415) 591-1653. 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 ichthyosis, a genetic skin disorder. Letters, suggestions and contributions are welcome. Valerie Lutters, Editor.

## HAPPY NEW YEAR

The "Happy New Year" in this issue of Focus is more than just a generic, midwinter pleasantry. It's more like a declaration, a statement of purpose, a birth announcement of sorts, for with the new year we have a new face, a new name, new plans. And all of it is aimed at providing more and better services to the full ichthyosis community.

F.I.R.S.T. of all -- effective January 1, 1987, the National Ichthyosis Foundation became F.I.R.S.T., the Foundation for Ichthyosis and Related Skin Types. The Board of Directors voted unanimously in October, 1986, to adopt this new name to reflect the foundation's goal of representing a broader range of ichthyotic disorders.

As most of our members know by now, ichthyosis is not a single disease but a collection of at least 24 known diseases. The five best-known of those disorders are: Ichthyosis Vulgaris, Lamellar Ichthyosis, Congenital Ichthyosiform Erythroderma (CIE), Recessive X-linked Ichthyosis and Epidermolytic Hyperkeratosis (EH, sometimes called Bullous Ichthyosis). A few of the less-known ichthyotic disorders are Sjogren-Larsson Syndrome, Child Syndrome, Refsum Disease, KID Syndrome, Peeling Skin Syndrome, Epidermal Nevus Syndrome, and Darier Disease, to name a few.

The goals and organizational structure of the foundation will remain the same, but hopefully a larger number of people will benefit. The expansion was recommended by the Medical Advisory Board which is comprised of a number of leading scientific researchers from all across the country who are involved an expanding knowledge of skin and skin disorders. These doctors see people with a variety of ichthyotic disorders, including those mentioned above. They noticed that these people had no foundation or support group of their own, and called this situation to our attention. Members of our Board of Directors remembered how isolated they felt when they thought they were all alone with ichthyosis and how much they welcomed the services of the Ichthyosis Foundation when they learned it existed. They sympathized with the plight of people who had yet to find a place they could turn to and welcomed the chance to extend our hand to them. And so the foundation is now reaching out even further, and its new name reflects that expansion.

For the sake of continuity and a smooth transition, the names "F.I.R.S.T." and "National Ichthyosis Foundation" will be used almost interchangeably throughout this newsletter and, briefly, in some other areas as well. In general, any activities conducted while we used the old name will be reported under that name; present and future activities will be discussed under the name F.I.R.S.T.

Our address has been changed to:

F. I. R. S. T.  
P.O. 410453  
San Francisco, CA 94103

We hope you will direct all correspondence to our new name and address from now on. Our telephone number and logo will also change, but the old ones will still be in effect for a while.

As for that new year. . . it should be a big one. This is the year our brochures will become available. This is the year we plan to institute a campaign of public awareness about ichthyosis; it will be under the guidance of Ellen Rowe, our North Carolina representative and new PR/publicity coordinator, with Charles Eichhorn, past co-president, who is overseeing a potential campaign of public service advertising. In 1986 we voted to set aside some money for research, and we hope to award that money, as a research grant, sometime in 1987. We intend to be more involved legislatively in 1987; last year N.I.F.'s president, Susan De Haan, testified before Congress to request a good appropriation for the new National Institute for Arthritis, Musculo-Skeletal and Skin Diseases. We, along with a coalition of other support groups, were successful in getting a good appropriation in a tight fiscal year, Mrs. De Haan reports, and we hope to continue providing testimony to Congress in the future. Beginning in 1987, May will be Renew-Your-Membership Month. We plan to be more assertive in fund raising this year. And we are arranging to have a part-time volunteer become a full-time temporary employee to keep some of these things moving along. It looks as though 1986 was a sort of gestation year, a deceptively quiet year during which a lot of preparatory work was going on in anticipation of 1987, a year when we hope to see the fruits of some of that previous year's labor.

What all this means for our members is: more of the same but better, in terms of the services of the foundation -- support, education, research. But it also means more and better efforts from the membership, too. We hope that more and more of you will take an active part in helping your foundation achieve its goals. We have big hopes for 1987 and we hope that each and every one of you will decide to put F.I.R.S.T. things first, in 1987 and in the years to come.

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 \*\*\* FOURTH ANNUAL CONFERENCE \*\*\*  
 \*\*\* THE BEST CONFERENCE YET! \*\*\*  
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The first weekend in December has always been a big one for the National Ichthyosis Foundation, and in 1986 it was bigger than ever. The foundation hosted its Fourth Annual Conference December 6, 1986, in New Orleans, LA, and a record number of people attended the day-long event. Approximately 50 men, women and children gathered to hear about the latest medical findings related to ichthyosis, to learn more about its social and psychological repercussions, and simply to meet with each other and make new friends.

A slight variation this year was an emphasis on participation by all who attended. This wasn't the conference to just sit back and take it all in; this was a conference with group discussions and lots of questions from the audience.

The morning session was primarily medical in nature. Mary Williams, M.D., gave a brief overview of ichthyosis. Dr. Williams is Associate Professor of Dermatology and Pediatrics at the University of California at San Francisco and chairman of F.I.R.S.T.'s Medical Advisory Board. She then introduced the panel of dermatologists who would answer questions from the audience; they were: Nicholas Lowe, M.D., UCLA, Los Angeles, CA; Eugene Van Scott, M.D., Temple University, Philadelphia, PA; Peter Elias, M.D., Veterans Administration Medical Center, San Francisco, CA; and Joseph McGuire, M.D., Yale University Medical School, New Haven, CT. All are members of F.I.R.S.T.'s Medical Advisory Board.

Noting that there are "at least 24 separate diseases under the umbrella of ichthyotic diseases," Dr. Williams described the major characteristics of ichthyotic skin. She said that in most cases the skin either fails to shed normally (retentive hyperkeratosis) or is produced too quickly (hyperproliferation). She said most ichthyoses are genetic and described some of the major types, dividing them according to their genetic patterns.

**Epidermolytic Hyperkeratosis (EH).** This is a disorder is caused by a dominant gene; it can also come about spontaneously through mutation. It is a hyperproliferative disorder characterized by some redness and a tendency to blister. It can be localized or appear over the entire body. At birth, she said, the child with EH often has raw patches on his body and/or many blisters. It can be diagnosed prenatally through fetoscopy (taking a skin biopsy from the fetus).

**Ichthyosis Vulgaris,** another ichthyotic disorder caused by a dominant gene, is the most common type of ichthyosis. Only a portion of the body may be involved, and the scale is usually fine and white.

**X-linked Ichthyosis.** This type of ichthyosis appears only in males and is carried by females. There are scales, but no redness. It is caused by the lack of a particular enzyme, said Dr. Williams, and since the cause is known, it can be diagnosed quite specifically through a skin biopsy or a blood test. Prenatally it can be diagnosed through amniocentesis which is a simpler process than fetoscopy.

**Classical Lamellar Ichthyosis and Congenital Ichthyosiform Erythroderma (CIE):** These variations of ichthyosis are caused by recessive genes, meaning that to display the disease, a person must have two genes for the disorder, one from each parent. With CIE there are usually fine white scales with redness underneath. In Classical Lamellar, the scales are large and dark; most people seem to display about the same degree of severity.

After Dr. Williams's introductory remarks, the panel of doctors answered the following questions from the floor:

**Q. What are the pros and cons of systemic treatments (drugs taken internally) such as synthetic Vitamin A (Tigeson, Accutane, etc)?**

Dr. Lowe began by noting that Accutane has been available in this country for several years for treating acne, and, in special research programs, for ichthyosis. Etretinate, called Tigeson, has just been approved by the FDA for use in this country. He said these drugs can work well for certain types of ichthyosis, notably EH and Lamellar Ichthyosis, but added that they are also very toxic.

Among the side effects from these drugs are hyperostosis (overgrowth of bones usually at the spine or joints), dry lips and mouth, thinning hair, and headaches. Both drugs cause birth defects if they are in the mother's system when she is pregnant. Accutane, therefore, is somewhat preferable because it is excreted from the body more rapidly; the drawback is that stronger doses are needed to get results. Tigeson is effective in lower doses, but stays in the body longer. For that reason, said Dr. Lowe, he prefers Tigeson for males and Accutane for women, for those patients who have decided that they do, indeed, want systemic treatment.

He also recommends that the patient, male or female, take the lowest possible effective dose, and have frequent blood, liver, and other tests to check for side effects. Some patients are willing to risk the side effects, he said, because some of the severe forms of ichthyosis can improve "dramatically" with this treatment.

Dr. McGuire echoed that thought, saying doctors and patients have a bit of a "love-hate relationship" with these drugs because the improvements can be "fantastic" and the side effects "terrible." He added that most of the side effects of the drugs go away once the drug is discontinued, except for the bone problems which seem to be permanent. "If you take it long enough, you will see bone changes," he said. He noted that 13 of the 15 patients he knew who had taken the drug for 24 months or more showed some bone changes. "Not all of them are severe, though some are," he said, "but they are there." He said he was not sure if using pulse therapy (going on and off the drug rather than taking it continuously) would alleviate this problem.

Dr. Lowe added that more research is being done into newer forms of the drug which might be less toxic, but answers would be "a long time coming."

When asked if topical treatments (putting a substance on the skin, rather than ingesting it) with Vitamin A could be toxic, the doctors agree that they would not be, simply because it would take such a large amount of the substance to get a toxic dose into the body through the skin. Dr. Van Scott said there could be skin toxicity in the form of irritation, but this would not be dangerous, only uncomfortable, and would signal the person to stop using the treatment long before toxic amounts were absorbed. Dr. Lowe, however, said there could be enough side effects to keep him from recommending such a treatment for babies, and added that for a patient of any age he prefers using external Vitamin A treatments on spots, rather than over the entire body.

\*Accutane and Tigeson are trademarks of Hoffmann-La Roche Inc., Nutley, N.J.

**Q. What about topical treatments that do not involve Vitamin A? What are the pros and cons of these treatments and what seems to work the best?**

Dr. Van Scott explained that the two requirements for skin comfort with ichthyosis are keeping the skin thin and keeping it moist. Any of several alpha hydroxy acids will help reduce scale, he said, and substances like glycerine or propylene glycol help retain water. He mentioned Lac-Hydrin, by Westwood Pharmaceuticals, Buffalo, NY, as effective but requiring a prescription, and Aqua-Glycolic lotion, which is non-prescription and can be obtained from Herald Pharmacol, Richmond, VA. He said he also prescribes a sort of "generic" lotion made from 6-7 ounces of lactic acid mixed with a pint of propylene glycol and added to one gallon of water. This can be applied to the skin with a spritzer bottle or a wash cloth. It's possible to get both ingredients without a prescription, though some pharmacies may ask for one.

Dr. Lowe endorsed what Dr. Van Scott said, and added that occluding the skin with a sauna suit can help but warned that this practice may exacerbate infections and blistering in an individual already prone to those problems.

**Q. Just what does cause blistering, and what's the best way to deal with it?**

Noting that blistering is most frequent in the EH form of ichthyosis, Dr. Lowe said it could be caused by the separations between the cells of the skin, resulting in one type of blistering or ulceration. A different type of infection is also possible if bacteria get into those areas of separation. For preventing the latter type of blistering/infection, Drs. Lowe and Van Scott recommended washing with astringent soap or antibacterial cleansing agent such as Hibiclens to keep the bacteria count low. For long term or recurring infections, they recommended antibiotics, but emphasized that this is not something to do continually, but only occasionally according to need. Dr. McGuire added that "you can win the infection game with Lamellar Ichthyosis, but with EH it's a constant battle."

Parents were concerned both about exposing their own vulnerable child to infections from other sources, and about possibly giving a child's ichthyosis-related infection to another person. In answer to those questions, the doctors said that other people were not at risk of infection from someone with ichthyosis who was having a problem with blisters caused by everyday bacteria that had invaded the skin through cracks and fissures. A staph infection, however, could be passed between two people if they touched each other.

**Q. What can be done about the odor sometimes present in ichthyotic skin?**

Bacteria, again, are at fault, said Dr. McGuire, but he differentiated between the more "foreign" or "bad" bacteria that can cause infections, and the bacteria that cause odor, which are the very same bacteria normally found on perfectly healthy skin. The odor is caused because ichthyotic skin, being thick, provides too good a "home" for these bacteria; they become too numerous, thus causing odor. He added that this embarrassing problem is more common with EH.

He suggested adding a chlorine bleach like Clorox to bath water because it will help kill the bacteria. About 2 teaspoons per gallon of water seemed best, he said, as anything much stronger would sting. He said Hibiclens or Betadine could also be added to the bath, but were more expensive. "This is not a one-shot deal," Dr. McGuire added; it needs to be done frequently, continuously. The Catch-22 is that people with ichthyosis bathe not only to get clean, but also to hydrate the skin, and bleach, etc, are very drying, "so you need to compensate for that," he said.

When asked if systemic treatments could help eliminate odor, Dr. Lowe said that anything that helps reduce scale will help reduce odor, since scale is where the bacteria grow. Dr. McGuire confirmed that observation, saying that skin odor, or the lack of it, is often an excellent barometer of how well a treatment is actually working; if the odor is lessening, then the scale is probably lessening, too.

**Q. What can be done to reduce or get rid of scaling on the scalp?**

You treat scales on the scalp the same way you treat scales anywhere else on the body, said Dr. Van Scott, suggesting occlusion at night, putting on an alpha hydroxy cream, and shampooing in the morning. Or, put lactic acid in the shampoo, he said. He added that a person with ichthyosis may suffer from thinning hair because the scales impact the otherwise normal hair follicles. Dr. McGuire said many people with Lamellar Ichthyosis lose their hair early and it may be because of this problem of obstructing the follicles, or there could be something constitutional that goes hand in hand with ichthyosis. Dr. Lowe said that using a little dishwashing liquid on the scalp helps, too, because it cuts grease and oil.

**Q. When is eye surgery, to correct ectropion, a good idea?**

Seen primarily with Lamellar Ichthyosis, ectropion is the turning outwards of the eyelids due to the tautness of the surrounding skin. Dr. McGuire explained that the aim in controlling this problem is to keep the eye itself from drying out which can damage the cornea. The eye can get dry because the tears are not always being wiped across the whole eye surface, especially during sleep when children with this condition are frequently observed to "sleep with their eyes open." He said that some approaches to try before turning to surgery are: putting drops in the eyes; taping the eyes shut or blindfolding the child before he goes to sleep to keep the eyes in a shut position. If you are still approaching corneal damage, then you need surgery, he said.

**Q. Can ichthyosis be treated nutritionally, with a special diet or vitamins?**

Dr. Elias said that at the present time, there does not seem to be any indication that ichthyosis can be improved through diet, but he added that in the future there may be findings that diet can help. He noted that people sometimes take Vitamin A in an effort to treat their ichthyosis, but he warned against this practice since Vitamin A can be toxic and, if taken for long, can damage the liver. "The big problem with that," he said, "is that you don't get any symptoms, or even any warning in test results, until the damage is already done; and that damage is irreversible."

Dr. McGuire concurred, saying that to see any results in the skin from Vitamin A, a person would have to take enough of it to reach the toxic stage.

Susan De Haan, N.I.F. president, thanked the doctors for their time and expertise, and reminded the conference attendees that if they have additional questions on these, or any other topics, they can write to the members of the Medical Advisory Board. They can either respond themselves or recommend you to a dermatologist in your area. You can also send questions in to this newsletter for the "Tell Me, Doctor" column.

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The afternoon session focused on the social and psychological aspects of ichthyosis. It featured a discussion by Dr. Wilmer Betts who is not only a psychiatrist currently practicing in Raleigh, N.C., but the father of three children with ichthyosis as well. We will report, in depth, what we learned during the afternoon session in the next issue of Focus.

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 \*\*\*\* Mary L. Williams, M.D., Chairman \*\*\*\*  
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New this year to F.I.R.S.T.'s Medical Advisory Board are: Drs. Freedberg, Hansen, Holbrook, Spraker, and Sybert who have graciously accepted our invitation to join the M.A.B. and share their knowledge and expertise. The foundation welcomes these esteemed researchers and practitioners to the M.A.B. and thanks them for joining us. And, to those doctors who have so faithfully served on the board over the years, now is as good a time as any to thank you, too, for all your help and advice, and the generous sharing of your already-crowded time.

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 \*\*\*\*\* HOT TIPS \*\*\*\*\*  
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People with ichthyosis might want to glance at page 36 of the April '86 issue of American Health. Sent to us by a member in Pennsylvania, the article discusses a compound called Glyceridacid 100. According to the article, a chemist working with the product found his hands were getting quite soft and smooth; he had it looked into by a university professor and now some cosmetics companies are looking at it, too. There's nothing on the market as yet, but it just might be something to watch for.

Pretty Feet and Hands, a product from Norcliff Thayer, Tarrytown, NY, is something that a Southern member uses on more than just her feet and hands. She puts it on elbows and other thick places, massages it gently, and finds that the dead skin then "comes off in sheets." She follows with a good skin cream.

Some tips from the Southwest: 10% salicylic acid in petroleum jelly; Eucerin (Beiersdorf, Norwalk, CT) and propylene glycol, mixed 50-50, and used after a daily bath; soaking in the tub with Aveeno Bath from Rydelle Labs, Racine, WI, to relieve itch; Dermovan-base and Velvachol-base cream (from Owen Labs, San Antonio, TX), but you'll have to ask the druggist for them as they are usually behind the counter; Jade all-purpose oil and Jade hair and bath shampoo by Jade Products of Tulsa, OK.

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 \*\*\*\*\* CORRESPONDENCE \*\*\*\*\*  
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Jennifer Heersink, 1203 East Park, #11, Hastings, NE, 68901, is 23 years old, married, and has Lamellar Ichthyosis. She would like to hear from anyone who is interested in corresponding and comparing notes about living with ichthyosis. She would particularly like to hear from other women with Lamellar who have borne children and who might be able to give her information about how ichthyosis did, or did not, affect pregnancy and/or delivery.

Sue Plotner of Vacaville, CA, has ichthyosis on her hands and feet; her 11-year old son does, too. Sue would like to talk or correspond with others who have this type of ichthyosis and with parents of children with any type of ichthyosis. You can write to her at 365 Fir Street, Vacaville, CA 95688, or call 707-446-1428.

When you go away to college, you can't leave ichthyosis at home. How did you, or your son or daughter, deal with the care of ichthyosis when living in a college dormitory? If you have any suggestions, or want to warn about any particular pitfalls, drop a line to Else Phillips, 31311 Fairview Drive, Bay Village, Ohio, 44140, 216-871-5636. A family member is heading for college in the fall and would appreciate any ideas or suggestions.

Those of you with particularly rare forms of ichthyosis may be able to perform a special service that no one else could possibly do. Because, as rare as your type of ichthyosis might be, there is probably at least one other person out there with the same thing, and feeling mighty isolated by it. If you have Ichthyosis Hystrix in particular, why not drop a line to Mona B. Heinz, 3320 Balomede, Lancaster, TX, 75134, 214-228-4604. Mona has Hystrix, and would love to hear from another person with the same type of ichthyosis. And if anyone else has any other type of especially rare variation of ichthyosis, why not send your name in to Focus; we can act as a clearinghouse and put all you folks who thought you were "the only one" in touch with each other.

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 \*\*\*\*\* OKLAHOMA CHAPTER CONDUCTS \*\*\*\*\*  
 \*\*\*\*\* DAMP BUT SUCCESSFUL FUND-RAISER \*\*\*\*\*  
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Two days of off and on rain couldn't dampen the spirits of the Greater Tulsa (Oklahoma) Chapter when volunteers conducted a garage sale to raise funds for the Ichthyosis Foundation. The fund-raiser, which took place during the stormy weekend of September 26 and 27, 1986, was a tremendous success, bringing in over \$900.

Betty McMasters, chapter president, felt the event was helpful not only in raising money for the foundation but also in gaining publicity. That publicity, she feels, can lead to more public awareness of ichthyosis and possibly to reaching more people who have the disease. Betty hopes that through events like the fundraiser, "maybe more will come out of the shells they are in and reach out for help and support." She also hopes that other chapters, or would-be chapters, can look to the Tulsa group and see that they can, indeed, "get something special going" between families and individuals who can relate to each other's needs and lean on each other for support.

Betty would like to particularly thank Kenneth, Marge, Rick and Diane Boyd for their hard work and support, not just during the garage sale but "through all the years I've known you. We all know we have many more years ahead of us, but with God's helping hand we will survive and overcome this problem we face day in and day out. God bless you all and Happy New Year."

The efforts of the Greater Tulsa Chapter were acknowledged at the annual conference when President Susan De Haan presented Marge Boyd and Diane Boyd with a certificate of appreciation to take back to Oklahoma and share with the rest of the chapter.

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 \*\*\*\*\* AQUA GLYCOLIC LOTION \*\*\*\*\*  
 \*\*\*\*\* NOW YOU CAN TRY IT FOR FREE! \*\*\*\*\*  
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Ellen Rowe, F.I.R.S.T.'s North Carolina representative and our new publicity coordinator, met with Henry Kamps, president of Herald Pharmacal, Richmond, VA, shortly after the annual conference. She spent an afternoon touring the Herald plant and discussing treatments for ichthyosis. Herald makes several products which a number of ichthyosis patients have found particularly helpful. A key ingredient seems to be glycolic acid, which penetrates the skin because it is such a small molecule, Mr. Kamps told Ellen. Ellen says that although she hasn't delved into the chemistry of it all, she does know that Herald's Aqua Glycolic Lotion works well for her and many others with DLE and Lamellar Ichthyosis.

She says it's important to use the lotion at least twice a day for at least 2-3 weeks before you expect to see results. Then, she says, the initial shedding can be quite dramatic. After that the lotion continues to keep the outer layer of skin thin enough to prevent scales and flakes from building up. Some people like to add about 2 ounces of pure glycerine to 8 ounces of the lotion to increase moisture retention.

The first few applications may sting, she reports, but that sensation quickly disappears for most people. And she finds it's more comfortable to use than preparations containing lactic acid.

Anyone who would like to try Aqua Glycolic Lotion can write to Ellen Rowe, 6316 Secret Drive, Raleigh, N.C., 27612 (919) 848-3821 and request a sample to be shipped free of charge. The foundation had been offering samples at a charge of \$1 to cover postage and handling; now you can get a sample for free through Ellen. Mr. Kamps has also offered to sell his products at wholesale prices to members of F.I.R.S.T. Aqua Glycolic at \$4 a bottle can be purchased by the case (12 bottles) or individually, through Ellen.

Just a Reminder -- Ichthyosis Focus is sent out six times a year to members of F.I.R.S.T. The annual membership fee, due in May, is \$15 for a regular member, \$25 for a contributing member, \$50 for a 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 we will request dues during May, "Renew Your Membership Month." An annual membership drive could make it easier for individuals to remember to pay their 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 F.I.R.S.T. 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 as allowed by law. And you can designate F.I.R.S.T. (formerly 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.

National Ichthyosis Foundation

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