ICHTHYOSIS **FOCUS**

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Published Six Times a Year by volunteers of F.I.P.S.T., P.D. Box 410453, San Francisco, CA 94141 (formerly The National Ichthyosis Foundation). Yelephone (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 the ichthyoses, a family of genetic skin disorders. Letters, suggestions and contributions are welcome. Valerie Lutters, Editor.

******** FROM THE EDITOR'S DESK ********

Well, I'd like to start off with a big thank you to all of you who responded to our first "It's May -- Renew Your Membership" campaign. About 100 of you responded, and quite a few not only renewed their regular memberships, they renewed their patron, contributing, or sponsoring memberships. We'd like to especially thank The Fraternal Order of Eagles of Austinwood, Ohio; The Milltown Lions Club of Milltown, New Jersey; Dr. Leonard Milstone, Reba H. Benson, Mrs. Charles Rogers, Jessie Deeley, and Walter Foxe for their particularly generous responses.

A special thanks too, to Julie Maeder of United Color, Inc., a printing company in Cliffside Park, N.J., which specializes in postcards. Mrs. Maeder offered to print some postcards for the foundation, and thanks to her, we now have the date thanks to send to s

up-to-date thank you cards to send to people who make a donation or send in their dues. Many of you have received thank

up-to-date thank you cards to send to people who make a donation or send in their dues. Many of you have received thank you cards recently. If the card was a lovely glossy one that used our new name, it came from Mrs. Maeder and her company.

Okay — that's the good news. The bad news is that although 100 responses is heartening, it's actually just a tiny percentage of our total membership of thousands. What about the rest of you? If you forgot or just didn't get around to responding in May, why not renew your membership now? We realize, of course, that some of you had renewed just prior to the membership drive, but as for the rest of you..... won't you pull your own weight? We realize dues are semi-voluntary because we want to be able to offer our services to all, regardless of ability to pay, but we also have a number of expenses and need the support of everyone. If every person on the mailing list paid the just minimum annual dues of \$15, we'd have an annual income of \$30,000! We could offer a lot of services with that much money, and we'd have it if each member paid just the minimum dues each year. How about you? member paid just the minimum dues each year. How about you?

I'd like to remind everyone to please use our new name and address: F.I.R.S.T., P.O. Box 410453, San Francisco, CA, 94141. Some of you are still sending mail to our old Belmont address; so far, it still gets forwarded, but that courtesy won't last forever, so please get into the habit of using the new address. And it's just as important to use our new name;

last forever, so please get into the habit of using the new address. And it's just as important to use our new name; we've still been getting a few checks made out to N.I.F., and this, too, can quickly become awkward.

And we'd like to be using your most accurate and up-to-date address, too, but we don't know what that is unless you tell us. If you change your address, let us know. If you stop getting Focus, let us know. If you refer someone to us, they sign up to become members, and then they don't start getting Focus...let us know. After nearly every issue of Focus gets mailed, we get a batch back with changes of address; we have to send them back again, at a slight cost, but at least we get the new address and can up-date the computer's mailing list, so we don't mind a bit. But we also get newsletters back with no information at all; just a "return to sender" stamp, or "no such address" or "not at this address." Messages like that make us sad, but there's nothing more we can do except to delete the name and address from the computer and hope the person in question gets in touch with us; we certainly can't get in touch with them — we don't have the right address! And every so often we get a letter saving. "I sent my name and address and a year's gues two years ago but I address! And every so often we get a letter saying, "I sent my name and address and a year's dues two years ago but I never heard another thing. Here's my money -- I'll try again. Hope to have better luck this time." Now that's really depressing! We don't want anyone to go for a year or two, or even much more than a month or two, without getting a response from us. So -- if your Focus stops coming, if a potential new member writes in and doesn't hear anything back -- follow up on it! We won't get upset, I promise. It may be that we're just a little behind, or it could mean that we read your handwriting wrong, or made some other error... Whatever, we want the opportunity to fix it -- right away! And one more thing -- if you send us a change of address, it would help a lot if you would include the label off your most recent Focus: it makes it easier for us to find the old address and then correct it.

> ***** AQUA GLYCOLIC LOTION STILL AVAILABLE -- FOR FREE! *****

Samples of Aqua Glycolic lotion from Herald Pharmacal, Richmond, VA, are still available, free of charge, through our Vice President, Ellen Rowe. Anyone who would like a sample may request one from Ellen, 6316 Secret Drive, Raleigh, N.C., 27612; (919) 848-3821; it will be shipped free of charge.

A number of our members, particularly those with Lamellar and CIE, find this lotion to be quite helpful, especially if used at least twice a day for several weeks. It helps with shedding, and then with keeping the skin from building up again. Henry Kamps, president of Herald, has also offered to sell the product wholesale to members of F.I.R.S.T. Aqua Siycolic can be purchased at \$4 for an 8 dz. bottle purchased in case lots of 12, or individually, through Ellen. Samples are 2 oz.

********* THINK CONFERENCE!! ********* ************************************

Every year it seems as though it's conference time before we know it, time to start thinking about the next conference when it seems as though the last one is still fresh in our memories. Well, that's doubly true this year, because we're planning on moving the conference up a few months, to October instead of December. Hopefully, that will make it more convenient for people by getting us a little further away from the holidays.

We hope to have the conference somewhere in the Northeast, possibly Connecticut. It's hard to imagine anyplace prettier than the Northeast in October, with its clear blue skies, crisp air, and gorgeous red, orange and yellow trees. Plans aren't quite complete yet, so we can't give you all the details, but we would like to let you know as soon as possible sp you can try to leave your calendar free for October. We'll give you all the details as soon as we possibly

possible so you can try to leave your calendar free for October. We'll give you all the details as soon as we possibly can, probably with a special mailing dedicated primarily to the up-coming conference. Meanwhile, think Fall!

And speaking of conferences, we're still getting nice comments about our last conference in New Orleans. Even people who were unable to attend have written to us after reading the report on Dr. Wilber Betts' presentation in the last issue of Focus. Dr. Betts' comments on the social and psychological aspects of ichthyosis sparked these responses:

"Your last article, Dr. Wilmer Betts', on accepting a disease was very helpful to us. We're trying to keep (our five-year-old's) life as normal as ever and working on his self-esteem every day. The article was excellent!"

And, from an adult with ichthyosis: "Dr. Betts' report to the Conference was right on target as to the importance of the parents' acceptance of their child's ichthyosis. (My ichthyosis) was perceived as a problem no different from another child's asthma, hearing loss or any other minor physical problem. I was taught early how to explain the basic facts of my skin condition to strangers while assuring them that it was not painful or physically debilitating....It is of utmost importance to reassure young people and their parents that they can, despite their condition, have happy, fulfilling lives with children and close family relationships."

Our thanks to Dr. Betts for sharing his insights at the conference, and our thanks, too, to those of you who took

Our thanks to Dr. Betts for sharing his insights at the conference, and our thanks, too, to those of you who took the time to write and tell us that you liked the article. A little positive feedback does us all a world of good!

Earlier this year the Board of Directors of F.I.R.S.T. voted to set up a small grant to support research into ichthyosis. Announcement of this grant was sent out to dermatologists, heads of dermatology departments at hospitals and universities, and to professional publications. We repeat here the announcement of that grant in hopes of reaching all people involved

with or interested in ichthyosis.

"The Foundation is pleased to announce its first Ichthyosis Research Grant in the amount of \$1,500. A Grant Award Committee, comprised of three members of the Board of Trustees and two members of the Medical Advisory Board of the Foundation will choose the Grant Recipient who will be announced December 1, 1987, in conjunction with the meetings of the

American Academy of Dermatology.

"Grant funds will be awarded to an individual or organization(s) for ongoing or future medical, psychological or social studies in subjects directly related to ichthyosis. Applications for the grant are available from F.I.R.S.T., P.O. Box 410453, San Francisco, CA, 94141, and must be received by this office no later than November 1, 1987. Details about requirements, procedures, and eligibility will be sent out with the applications. Inquiries or requests for applications may be made to that address, or call 415-591-1653."

We hope that anyone interested in doing research related to ichthyosis will apply for the grant. And we hope

you'll pass on the news of the grant to anyone you feel may be interested.

I like holidays. I especially like holidays that don't take themselves too seriously -- like Halloween, April Fool's Day, or St. Patrick's Day. Now there's a holiday with a sense of humor!
Although full of fun, though, St. Patrick's Day 1987 provided F.I.R.S.T. with some needed funds, or at least the opportunity to try to get some funds.

In Oklahoma, the ever-faithful Moose Lodge thought of F.I.R.S.T. during its annual St. Patrick's Day Dance. A member put up a poster with a big stone on it, along with a donation box. A message read, "Kiss the Blarney Stone and make a wish." We don't know how many moose actually kissed the stone, but they sent F.I.R.S.T. \$27 -- and that's no blarney!

Here in San Francisco a local radio station remembered that St. Patrick chased the snakes from Ireland and

Here in San Francisco a local radio station remembered that St. Patrick chased the snakes from Ireland and celebrated the day with a snake race. That's right, non-profit agencies throughout the Bay area were invited to race snakes, real live snakes, down a track, all to earn \$1000 in cash plus \$1000 of air time for the first place winner. It was B.Y.O. Snake if you had one, but if not, one was provided.

F.I.R.S.T. needed the money and the publicity, so we decided to enter. Besides, it seemed just so perfect — imagine, a scaly creature winning money to fight a scaling skin disease! We did win the first heat, but then got out—

slithered by a reptile named Homeless Harry during the finals!

Well, it made for an amusing morning, but nothing more! Will we try again next year? Probably not. We just couldn't help but feel that the snakes would have preferred to be anywhere but downtown San Francisco racing down wooden shutes, surrounded by shouting humans in green T-shirts. I guess when you have a scaling skin disease, you just can't help but feel a bit of empathy for other scaly creatures -- even when they're long and thin and slithery!

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Massachusetts Rep Cindy MacEachern has asked people in her area to get in touch with her. She's hoping that if there's enough interest, perhaps she can start a Massachusetts chapter, but she can't do it all by herself, so...... Meanwhile, all members are urged to get in touch with their local reps. Let them know you're there, let them know how they can help you or how you can help them. Reps can be a wonderful community resource, but only if you reach out, get in touch....

VIRGINIA WASHINGTON

CANADA

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As you may have noticed, we have added a number of names to our list of local representatives, and we'd like to thank all those new volunteers who have agreed to be resource persons in their neighborhoods. This is also an opportunity for us to thank all those faithful people who have so generously given of themselves over the years, quietly serving their local ichthyosis communities for so long. Meanwhile, I'd like to ask each of you to read and check your name in the above list and let me know, immediately, if there is any error, misspelling, or other problem with the entry as the list has been retyped from scratch. Thanks again to all of you, and once again, if anyone else would like to volunteer, please let us know. 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? Please contact Betty McMasters, 1838 So. Muskogee, Sapulpa, OK 74066 (Tel: 918-224-9099) for details.

Representatives who change their address are asked to let Betty and Focus know about the move as soon as possible.

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A New York member who has ichthyosis on the palms of her hands and the soles of her feet says she gets great results from Keralyt, a prescription product from Westwood Pharmaceutical in Buffalo, N.Y. She says the product is "fantastic," and excellent for softening the thick skin on her hands and feet.

This isn't a Hot Tip, exactly. It's more like a request for a Hot Tip. A New York member would like to know if any other members have found an insurance company that will cover expenses related to ichthyosis. Her son has EH and she says their present carrier for health coverage has "excluded anything to do with my son's condition." - So, if anyone has been fortunate enough to find an insurance company that will recognize the expenses involved with ichthyosis, perhaps they would sand the country of the country o send the name of that company in to Focus, along with any pertinent information about the company. I'm sure that finding such a carrier would be a boon to many members, not just the one in New York.

******** MONEY NEEDED TO HIRE ******** A PART-TIME DIRECTOR ******** ********

Many Focus readers probably wish they could read their newsletter without ever coming upon a request for money and frankly, we wish we didn't have to keep asking for it. Unfortunately, though, money is the grease that keeps our various wheels turning, and the bigger we get, the more wheels we have to grease.

Right now the foundation is growing, with lots of new projects in the works -- and that's good. What's more, one of those projects is a big publicity campaign, and once that's underway, we expect to grow even more -- and that's better still. But to keep things moving through all that growth we need direction, and the foundation's leadership feels that the time has come for some paid help.

At a meeting of the Board of Directors in June, the board members voted to hire a part-time managing director to

At a meeting of the Board of Directors in June, the board members voted to hire a part-time managing director to keep on top of foundation business and keep things running smoothly. The board feels that we are getting a little too big to depend entirely on volunteers. Naturally, we'll always need volunteers, as many good ones as possible, but from a leadership point of view, to coordinate things, to keep them all moving forward, we need someone in charge. The board, therefore, voted to look for a part-time director.

We anticipate that we will need \$500 a month for at least a year. Initially that money will have to come from the membership; hopefully, after a director has been working for us for a while, there will be enough results from fund-raising efforts to provide money from sources other than our membership. That is a big goal and one which, if achieved, will make it unnecessary for us to have to keep putting pleas for money in every issue of focus. But we have to start somewhere, and that somewhere is you, the membership. If you can possibly support the foundation, now is the time; if we can get enough money from you now to get us started with a good part-time director, maybe we won't have to ask for anything more than dues from you in the future. And what about those of you who haven't paid dues? If every member of the foundation paid his or her \$15 per year, we'd have 5 times the \$500 a month we need!

We need good leadership, and we need it now. And just as important, we need to know that you support the

We need good leadership, and we need it now. And just as important, we need to know that you support the

foundation's goal of good leadership.

We know that right now, summertime, is the very favorite time for many of our readers. The warm humid weather is much kinder to your skin than winter's harsh, dry cold, and many of you enjoy spending as much time as possible at the beach. The benefits of the seashore, however, are not without their downside, though, as this timely question from one of our members illustrates. Answering the Tell Me, Doctor, question for this issue is Gary L. Peck, M.D., Senior Investigator, Dermatology Branch, National Cancer Institute, NIH, Bethesda, MD. Dr. Peck is a member of our Medical Advisory Board.

- 9. I've noticed that my ichthyosis improves a lot in the summer when I spend a lot of time at the beach in the sun. But I've been reading a lot about exposure to the sun causing skin cancer, and I worry that having ichthyosis may make me more susceptible to this cancer. Also, I wonder if the early signs of skin cancer, such as change in color or texture, would be hard to detect on my kind of skin. Am I taking an extra large risk by being in the sun?"
- A. First, my answer assumes that you have Lamellar Ichthyosis which involves the face. Second, I believe your summer improvement may be the result of swimming at the beach and the increased humidity during the summer, rather than from sunlight exposure. You could test this yourself by using sunscreens and sitting under an umbrella the next time you go swimming at the beach. Thirdly, you raise a good question about the ability to detect sunlight-damaged skin in patients with Lamellar Ichthyosis. Certainly, if the skin is left untreated, the thick scales may cover a small skin cancer. Conversely, effective therapy of the ichthyosis will allow adequate examination of the skin for the presence of skin cancers. Finally, I know of no information that indicates that ichthyosis patients are more prone to the development of skin cancer. My assumption would be that the thick scales of untreated Lamellar Ichthyosis would, in fact, help block out sunlight and reduce the risk of sunlight-damage.

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 do request dues during May, "Renew Your Membership Month." 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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