



# ICHTHYOSIS FOCUS

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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

### **No Pain, No Gain**

F.I.R.S.T. is the only national not-for-profit organization that focuses on ichthyosis. Its goals are to raise funds to promote and support research, to provide moral support to distressed patients and families, and to educate the lay public and professional community about the ichthyoses. In my address at the recent F.I.R.S.T. Conference in New Haven, I listed 39 separate projects for F.I.R.S.T. that virtually every attendee agreed were worthwhile and exciting. Yet two factors prevent these projects from becoming successes: people and money.

F.I.R.S.T.'s day-to-day work is carried on by two part-time staff members guided by a small voluntary Board of Directors spread out all over the country. F.I.R.S.T. is not a large, well-staffed group of professional administrators, but real people, living with ichthyosis, just like most of our members. We receive no federal or state government funds whatsoever. We must rely solely on the donations and dues from our membership and friends.

When I joined a health club to work on my pot belly and poor stamina, the instructor told me it would take a lot of work: "No pain, No gain!" he said. In just a few months I gave up on the health club. The gain of losing a few inches wasn't worth the pain of hours of repetitious weight lifting.

But I won't give up on F.I.R.S.T., and I hope you won't either. The gain is certainly worth the effort. Most ichthyoses are genetic in origin, which means the same disease will be appearing in babies a thousand years from now, in every generation, until someone is willing to take the pain to get the gain. Your donation of money and time to F.I.R.S.T. can make a difference in your own life, but more importantly, in the lives of millions of children yet to be born.

If you have already paid your membership dues or made a donation this year, THANK YOU! Please send in the enclosed envelope to let us know if you'd like to volunteer your time or skills to our cause.

If you missed the May Membership Renewal Month, please use the enclosed envelope to bring your membership up to date. Can't afford a donation at this time? WE UNDERSTAND!! Just return the envelope with a note to let us know you'd like to stay on our mailing list.

To tell you the truth, I don't even notice the pain when I see the gains F.I.R.S.T. can make!

Charles Eichhorn  
Editor

**BOOKS IN PRINT**

**AFTER THE TEARS** is a book about raising a child with a disability. It is for parents of children with disabilities and the professionals who serve them. *After the Tears* contains the personal stories of parents who have found ways to deal successfully with the shock, anger, grief, guilt and despair that can be part of life with a disabled child. Available from: TASH (The Association for Persons with Severe Handicaps), 7010 Roosevelt Way NE, Seattle, WA 98115. Tel. (206) 523-8446. The price is \$7.00, which includes postage and handling.

You can order a free copy of the fact sheet, *FINANCIAL AID FOR DISABLED STUDENTS*, from HEATH Resource Center, One DuPont Circle, Suite 670, Washington, DC 20036-1193 (Tel. 1-800-544-3284). The publication describes post high school education financial aid systems and how to apply. Other resources such as Social Security and vocational rehabilitation are also discussed. Free.

**UNITED WAY DONATIONS**

We certainly appreciate it when members support our work with their donations. Some members send cash or checks, others offer to help on a Saturday. Some offer us free or discounted products or services, a some just put a check in an envelope.

Other members feel they can't afford to support F.I.R.S.T. with a direct donation because they have been under so much pressure to make a pledge to their local United Way or Combined Federal Campaign. Sometimes the budget can't stretch.

Did you know the United Way has a special program that allows donors to designate F.I.R.S.T. as the specific recipient of all or part of your United Way contribution? This can be accomplished through the United Way Donor Option Plan. The Plan is changing its rules, and may not be available in all areas, though. Many members have been successful in having their contribution sent to F.I.R.S.T. only after insisting that the local office do so. Check with your local United Way office.

The Combined Federal Campaign also allows donors who are federal employees to designate the charity which will get their donation. If F.I.R.S.T. isn't listed in your *CFC Brochure*, WRITE US IN! Be sure to get our full name and address right, or your contribution will never reach us.

Tell your co-workers and friends that their contributions can make a REAL difference when they are designated to go to F.I.R.S.T.

Often, we receive the contribution, but are not told the donor's name! Please let us know if you contribute through the United Way programs, and thank you for making the most of your charitable contribution.

A member recently asked whether it was better to donate to F.I.R.S.T. directly, or through the United Way. The answer is clear: Donate directly if you can. A direct contribution ensures that we receive the entire amount of your contribution and can put it to work right away. A contribution through the United Way is depleted by the administrative costs of the huge United Way organization. Also, it may take many months before we receive what's left of your donation. And, as we said, it's a much surer way for us to know the contribution came from you.

**PLEASE, MR. POSTMAN**

F.I.R.S.T. changed its address late last year from PO Box 410453 in San Francisco to our new office just across the Bay in Oakland. We notified the Post Office promptly so that mail would be forwarded. Unfortunately, however, the Post Office has frequently failed to forward our mail, returning it to the sender instead with a note that there is no forwarding address for F.I.R.S.T.! Although most mail gets through with no problem, we have heard of a number of cases where letters and donations have been returned. The Post Office has been unresponsive to our request for better service.

Here is our current address and telephone number. Please be sure to use it so that your letter won't get lost in the San Francisco "fog"!

**F.I.R.S.T.**  
**3640 Grand Avenue, Suite 2**  
**Oakland, CA 94610**  
**(415) 763-9839**

While you're at it, make sure we have your correct address and telephone number!

**F.I.R.S.T. ANNUAL REPORT**

A copy of the most recent Annual Report for F.I.R.S.T., including financial statements, is available to the public at no charge. Please address requests to: *F.I.R.S.T., 3640 Grand Avenue, Suite 2, Oakland, CA 94610.*

**COMPLAINT CORNER -**  
**DOCTORS AND PATIENTS**

In a majority of the letters we receive, there is a comment to the effect that the patient has been to see dozens or even hundreds of doctors, but that none of them provided any real help. Most of the doctors had never seen a case of ichthyosis before, and in many cases, the patient ended up explaining the disorder to the doctor.

Many physicians, even skin specialists, have never seen a case of ichthyosis. Others have seen only one or two cases in their entire professional lives. Why? Partly because there just aren't that many cases, and partly because patients who sought a doctor's advice years ago were told there was no cure, and they never bothered to go back.

When a parent or patient goes to a doctor, he or she is looking for a lot of answers, and, ultimately, a cure. The lack of answers and a cure is not all the fault of the physician: the disease itself is part of the problem. Most doctors don't have answers because they simply don't exist. There is no "cure" for a genetic disease, like most of the ichthyoses, only treatments for the symptoms. Treatment success varies widely from patient to patient. And remember, most doctors may not have another patient even for comparison. Just because a dermatologist doesn't know a lot about ichthyosis does not mean he or she is not a good doctor.

Remember, doctors are only people, too. Some are dedicated, competent, compassionate, and helpful; some are not. Some are knowledgeable and up-to-date; some are not.

In recent years, as our population increases, the total number of ichthyosis patients has also increased. Thanks to some treatment breakthroughs, patients are living longer. Recent research advances have enabled knowledgeable doctors to diagnose and treat various ichthyoses more effectively, so don't give up on doctors if you haven't seen one since FDR was President!

Doctors have their complaints about patients, too. (1) Patients with rare diseases like the ichthyoses should seek a reliable diagnosis, treatment plan, and genetic counseling from a knowledgeable specialist with the experience and resources needed to do the job properly, yet many do not. (2) Patients should LISTEN more carefully to their physicians. Often, as soon as the doctor gives a name to the disease, the patient starts thinking about all sorts of things and stops listening to the doctor. (3) Patients should be more diligent about following the treatment plan prescribed by the physician. Too

many patients try something for a few days and give up, or only use a preparation once a day instead of three times a day. If you don't follow the instructions, you shouldn't complain about the outcome.

In summary, make a careful search for the doctor who will be right for you. Don't expect any one doctor to have all the answers. The answers simply don't all exist yet (although F.I.R.S.T. is trying to remedy that with your help.) Listen to your doctor, and follow the advice: it's usually pretty good medicine.

You can help yourself, your doctor, and others by sharing your first-hand knowledge of ichthyosis with a doctor who seems interested. Tell him or her about F.I.R.S.T., ask him to request a supply of brochures from us; let him know there's a F.I.R.S.T. representative in your area (you, perhaps?), and tell him he can refer subsequent patients to us.

It's a two-way street.

**THANKS TO OUR SPONSORS**

F.I.R.S.T. wants to express its gratitude for the generosity of the following donors who supported F.I.R.S.T. with contributions of \$100 or more:

Stiefel Labs of Coral Gable, FL  
Glaxo, Inc. of Research Triangle, NC  
Neutrogena of Los Angeles, CA  
Verco Enterprises of Mt. Clemens, MI

The Meander Aerie of the Fraternal Order  
of Eagles, Austintown, OH  
The Milltown Lions Club, Milltown, NJ

Raymond Healey  
Janet Showers  
James and Elise Phillips  
Mary Bilger  
Suzanne and Larry Getz  
Mrs. Charles Rogers  
Eugene Van Scott, M.D.  
William & Joanne Brunetti  
F. Piercc & H. Lytken Olsen  
Suzanne Canter and family  
Carl & Shirley Anderson  
Walter & Norene Foxe  
Friends and Family of  
William Sponheimer

**AQUA GLYCOLIC LOTION OFFER**

We want to thank Henry Kamps, President of Herald Pharmacal, Inc., makers of Aqua Glycolic Lotion and other products for dry skin containing the alpha hydroxy acid known as glycolic acid, for providing F.I.R.S.T. with thousands of new brochures about F.I.R.S.T. and ichthyosis. We distribute this material to health care professionals at national conferences and exhibit halls.

Mr. Kamps has reminded us of his offer to provide free samples of the company's products to interested parties, along with special quantity prices for F.I.R.S.T. members. No prescription is necessary. Call Herald Pharmacal in Richmond, Virginia, at (804) 745-2880.

**HOT TIPS**

**NEW PRODUCT-->** Stiefel Labs, Inc. recently introduced a new product for dry skin care called Epilyt. The preparation contains the emulsifier propylene glycol, the moisture attractant glycerin, alpha hydroxy lactic and oleic acids, quaternium and a preservative. Samples of the non-prescription product were distributed to attendees of the F.I.R.S.T. Conference in May. It is a clear, non-greasy, odorless and colorless liquid that could be particularly useful on the scalp. The product is available in drug stores across the country. Early reports from users are very favorable. Let us know what you think of it after checking with your doctor.

**SCALP RELIEF -->** A reader has been using a product known as A-100 Lice for about five years and says it is as wonderful for removing scales from the scalp as it is for lice.

**BATH OIL -->** After the scales are removed, the tender skin below needs to be lubricated and protected from drying out. Bath oils are an often an effective way to provide an all-over covering. Most bath oils are mineral oil based. Hermal Dermatological Bath Oil is an exception. It is 85% natural soybean oil and especially compatible with the skin. Although it contains no soap, its detergent action makes it an effective cleanser, too.

**OCCLUSIVE SUITS -->** Moisturizing, then covering the affected area with a moistureproof covering such as a plastic or coated nylon exercise suit for several hours or overnight is an effective way to loosen thick scale for many patients. (Half propylene glycol and half water is a common moisturizer.) A complete head to foot exercise suit

can be too hot, so many patients cover just a portion of the body one night and another portion the next. A selection of occlusive garments (including the line of comfortable Sleep Sauna suits, gloves, caps, boots, etc.) is available from Rx Allstates Pharmacy Service, 360 W. Superior Street, Chicago, IL 60610 (Tel. (312) 280-7711). Allstates also carries a wide variety of topical and prescription products for dermatological diseases.

Check also with Verco Enterprises for their reusable Moisture Mitt product line. 52303 Chesterfield Road, Mt. Clemens, MI 48045. Tel. (313) 949-3672.

**HORMONES -->** Only a few members, mostly women, responded to our inquiry about the effect of hormones on their ichthyosis. Unfortunately, this survey did not provide any real conclusions because so few responded. Most who did respond, however, indicated that at some point in their lives, such as puberty, pregnancy or menopause, there was a significant change in their ichthyosis.

For example, a woman's first pregnancy may have caused an almost complete remission, but a second pregnancy might have had no effect at all. Most women who responded did indicate, however, that their skin became drier and scallier after menopause. It was pointed out, however, that this is more or less true for all women, regardless of whether they have a form of ichthyosis. The ichthyosis may make the skin changes more noticeable, however. We are still interested in this topic and would like to hear from all members who have seen their ichthyosis change due to a hormonal fluctuation. We'll print a followup report in a future issue.

**"COOL" TIP -->** Frances Ott, a Lamellar Ichthyosis patient, is the 7-year-old daughter of Nancy Ott of Charleston, SC. To beat the summer heat, Frances has a new "cool" suit designed by NASA and manufactured on a custom basis by Life Support Systems, Inc. It weighs about 25 pounds and includes a cap, "cummerbund" and luggage carrier for the pump and power unit. It cost about \$2,600, and Frances thinks it's . . . "cool!"

**IF THE SHOE DOESN'T FIT . . . -->** Call or write to the Comfoot Shoe Co., 4231 Johnson Road, Frankfort, MI 49635, Tel. (616) 352-4632 for their brochure on custom made shoes that can accommodate bandages and other problems.

**"WHAT WORKS FOR ME"**

[This column is a new feature of the newsletter. We hope to be able to provide readers with accounts of successful treatments brought to our attention by readers. In many cases, a treatment will work well for one person, but be useless, or even health-endangering, for another. For this reason, we insist that any reader wishing to try a new treatment first confer with his dermatologist. Neither F.I.R.S.T. nor the newsletter recommends or approves any particular treatment: our goal is only to keep our readers informed when we receive letters that say, "What works for me is . . . ."]

Eugene Lafosse is 47 and has Lamellar Ichthyosis. His dermatologist says that his care regimen -- using only over-the-counter products -- is exceptionally effective in reducing his symptoms. Here is a synopsis of his treatment plan, which consists of baths to remove scale and application of an oil to trap moisture in the skin.

Specifically, to remove the thickened epidermis, Eugene takes a warm bath with 1-1 1/2 cups of a washing powder for 1 1/2 to 2 hours. After soaking, he gently rubs off the skin with a Rubbermaid scrubbing sponge pad. He doesn't use the sponge on his face, however. He uses a very fine toothed comb to scrub his scalp. He then showers, using a rough washcloth to scrub his face and neck, as well as any other part of his body that needs more work. Next, a dry bath towel is used to rub off more skin, including rough spots on his back.

Before the skin loses any more moisture, Eugene applies a moisturizing compound all over, except for his scalp, which is treated with Brylcream ("A little dab'll do ya . . .").

Eugene's moisturizer is made up of 32 ounces of mineral oil and 160 grams of petroleum jelly from the drug store, 125 grams of paraffin from the grocery store, and some kind of oil base perfume, such as Jean Nate moisturizing Bath Oil, all heated in a double boiler, then poured into containers (like empty cold cream jars) to cool. The "recipe" makes about a three-week supply.

Eugene uses the moisturizing compound twice a day: mornings, and at night after a warm, no scrubbing shower. He sticks to synthetic underwear, socks and pajamas to avoid having other fabrics absorb the moisturizer.

When the weather is hot and dry, Eugene repeats the treatment cycle every two days. If the weather is cool and damp, the cycle is every four days.

Eugene reminded us that this regimen may not work for everyone, and that it should only be attempted under a physician's care. He also pointed out that it would be easy to overdo it by scrubbing too hard, and that a warm bath for a couple of hours could cause some patients to overheat.

If you would like a copy of Eugene's much more detailed explanation, send F.I.R.S.T. a self-addressed, stamped envelope with 45 cents postage with your request.

**MILITARY SERVICE**

Over the years, many members, mostly men, have had to deal with the military service and their ichthyosis. We are looking for a few good men (not necessarily Marines) to let us know their experiences. Did they pass the physical? Did anyone care about their having ichthyosis? Which service? Any restrictions? Turned down? Were there appeals?

Please tell us your story so we can prepare an article that is eagerly awaited by a number of young people interested in serving their country in the armed services, but who don't know what to expect or how to put their best foot forward.

**PEN PALS WANTED**

- |                  |   |
|------------------|---|
| MaryAnn Bauer    | 7 year old with Lamellar Ichthyosis<br>3301 High Street<br>Oakland, CA 94619    |
| Leslie Guragna   | 7 year old with Lamellar Ichthyosis<br>1928 LaSalle Court<br>Walnut Creek, CA   |
| Sue Heaton       | Adult with K.I.D. Syndrome<br>4426 SE Yamhill<br>Portland, OR 97215             |
| Nancy Browne     | Adult with K.I.D. Syndrome<br>1474 East 173rd Street<br>Cleveland, OH 44110     |
| Kathleen Gaffney | 5 yr. old dghtr with K.I.D. Syndrome<br>330 Burd Street<br>Pennington, NJ 08534 |

**BROCHURE NEWS**

We are about to implement the final part of our distribution plan for the first printing of our three new brochures: (1) F.I.R.S.T. (about the Foundation and its work), (2) ICHTHYOSIS, An Overview, and (3) ICHTHYOSIS, The Genetics of its Inheritance. Many members have already written to us for personal copies (\$1.00 postage and handling for a set of all three brochures). Soon, local representatives will begin canvassing their area doctors, hospitals, etc. delivering copies far and wide.

We plan to revise and update the brochures for another printing and would like your comments. Did we leave anything important or useful out? What would you like to see changed? Speak up!

Also, we are planning a new brochure for new parents. If you are a new parent: what would you most like to know? If you have been a new parent and survived the experience, please share your knowledge by telling us how you coped with all the problems. What would you have liked to have known? How did you handle the little things - hot days, bumps, bandages, baths, baths and more baths? Other children, siblings, other parents, teachers, principals, hospitals, the local pool, etc.? By collecting the wisdom of your experience we can make life a lot easier for those who will follow.

What about those of you who have some type of ichthyosis, children and adults alike? We know there's more to these disease than just skin and lotions. Share your comments and tips on other physical problems, social and emotional issues, day-to-day living.

Sometimes it seems we learn more from our failures than from our successes, so please let us know what doesn't work for you. Save someone else the money, time, frustration and pain of a failure you have already survived.

Please drop us a line and share.

**RESEARCH NEWS**

Two interesting projects are underway, and we look forward eagerly to their conclusions.

**Suicide:** Dr. Gary Peck of the F.I.R.S.T. Medical Advisory Board is working with other researchers in the Dermatology Branch of the National Cancer Institute at the National Institutes of Health in Bethesda, MD, on a project regarding the

psychological tendency toward suicide associated with certain forms of ichthyosis, particularly as Darier's Disease.

When we first learned of this project, half of the listeners were astounded that suicide should be a particular issue at all for ichthyosis sufferers, while the other half was happy to hear that there was perhaps some recognition of the potentially devastating psychological implications of these diseases.

**Retinoids:** Another series of experiments just starting will test the effectiveness and safety of retinoids applied topically instead of taken orally.

The oral retinoids, such as *Accutane* (generic name tretinoin) and *Tigason* (etretinate), both products of Hoffman LaRoche, are clearly effective therapies, but have been linked to serious potential side effects. The drugs were developed to treat acute cystic acne, unrelated to ichthyosis. It was learned, however that they were effective on some kinds of ichthyosis, and they have become the treatment of choice for a number of ichthyosis patients.

The oral retinoids were intended for short term use -- only until the acne cleared up -- and their use in managing a chronic condition like ichthyosis would have to be lifelong. Problems in bone growth and other internal organs have appeared in a number of cases where treatment was extended.

Another problem is that female patients who become pregnant while taking an oral retinoid (or for some time after they stop taking the drug), bear a very high risk of serious birth defects in their babies. This is a problem for women who are taking the drug in a maintenance dosage for ichthyosis, or just temporarily for acne treatment. Despite the strong warnings against becoming pregnant while taking the drugs, an alarming number of birth defects have been reported. The Food and Drug Administration recently conducted hearings to reconsider the rules surrounding their prescription and use.

Now research is being conducted on applying the retinoids topically in an effort to retain their effectiveness while increasing the safety of their use.

While F.I.R.S.T. joins with its many members and friends in dermatology who support the continued availability of oral retinoids for acne patients and ichthyosis patients in need, it is hoped that experiments with the topical application of related compounds will provide the effectiveness while eliminating the dangerous potential side effects.

## STUDENT PROJECTS

An important part of F.I.R.S.T.'s mission is to educate the public about ichthyosis. We think a grade school or high school science project or paper about ichthyosis would be a benefit to the student as well as the community. F.I.R.S.T. has lots of material about ichthyosis and would be happy to help any interested students with a good idea. Just write to us.

We have had a few such requests already and were pleased to respond. We'd welcome more!

## HOW COULD YOU FORGET MAY?

May was "*Renew Your Membership Month*," but a lot of members forgot. It was probably our fault for not reminding you. There's still time to catch up and be counted in the fight against ichthyosis!! Please use the envelope in this issue to send in your dues. We can't all be front line soldiers in the fight against ichthyosis, but we can all contribute in our own way. Be counted!

The Board of Directors has taken a long, hard look at our budget and decided we can no longer maintain the same low dues level. Although inflation has continued to move up, step by step each year, F.I.R.S.T. has kept the same dues level since the organization started in 1981. We can't provide the same level of support any longer without more money to pay the bill, and we certainly can't start on dozens of important new projects without additional funds from our members.

Effective August 1, 1988, basic membership dues will continue at the same rates, but a subscription to the newsletter will cost an additional \$5 per year. Single membership is therefore \$15 + 5 = \$20, and a family membership is \$25 + 5 = \$30. Members who have already paid this year are covered until next May at the old membership rates.

Starting in May, 1989 (next year) dues will rise to \$20 for individuals and \$30 for families with more than one patient, and an additional \$5 for the newsletter. (\$25 and \$35 respectively.) Donations over \$35 will automatically include a subscription to the newsletter.

Most members tell us that their ichthyosis is one of the most important things in their life, affecting them in countless physical, psychological and social ways, and that F.I.R.S.T. is the only resource available for providing moral support, promoting continued interest and progress in research, and

public information about this family of tragic diseases. F.I.R.S.T. symbolizes hope, making it a reality.

Members get a great deal in return for their support of F.I.R.S.T. Some benefits are immediate and obvious, like the newsletter. (Where else do you read about ichthyosis?) Some benefits are less obvious but no less important, like having a voice in Washington, DC, better educated nurses and doctors, and a compassionate ear of a F.I.R.S.T. representative when you need it. When you add it up, our dues are very low.

Nonetheless, we do not feel that our dues should be a barrier to anyone's participation as a member. Anyone who would like to be a member but cannot afford the cost of membership or a subscription can just let us know on the enclosed envelope that they would like to be a member and/or receive the newsletter, but can't afford the dues and subscription amount. We don't need to know the details: we just need to know you are interested and don't feel you can pay right now. We are happy to send the newsletter at no charge under those circumstances. We are trying to avoid the waste of money that occurs when someone doesn't pay their dues because they are just not interested in ichthyosis and our work.

## WHAT CAN I DO TO HELP?

1. Write to us - let us know how WE can help you. Give us your questions and criticisms as well as your tips.
2. Give a short informative talk on ichthyosis at a meeting of your local Kiwanis, Rotary, BPOE, Junior League, etc.. Get the word out, create interest and support.
3. Write to your state and federal representatives. Let them know of your interest in skin disease research in general and ichthyosis in particular. Let them know you look for their support in legislation for research or children's benefits. (They can't help us if they don't even know we exist.)
4. Pay your membership dues each May.
5. Think of us, F.I.R.S.T., in making out a will or trust.

**WHERE THERE'S A WILL . . .**

Death and taxes are said to be the only two things you can count on for sure. Actually, although death may be inevitable, you can beat taxes when you die by making a contribution to a charity like F.I.R.S.T. in your will or living trust. The amount you donate is taken out of your taxable estate, and may reduce your tax bracket as well as your taxes. You can give hope to thousands of children and families by extending your support of F.I.R.S.T. beyond your lifetime. Whether your gift is large or small, you can support our programs of education, research and support by remembering F.I.R.S.T. in your will or trust.

To make a bequest of cash or other property to F.I.R.S.T. your will (or supplemental Codicil, if you do not wish to make a new Will), should state:

*"I give and bequeath to F.I.R.S.T., The Foundation for Ichthyosis and Related Skin Types, Inc., a non profit corporation, organized under the laws of the state of California, the sum of (\$ \_\_\_\_\_) or ( \_\_\_\_\_ percent) of the rest, residue and remainder of my estate to be used for general purposes of the Foundation."*

Such a gift would mean a lot to so many. But you must have a will, otherwise, there's no way . . .

**CAN'T SAY THANK YOU ENOUGH**

F.I.R.S.T. wants to thank again the Westwood Pharmaceutical Company for printing our three wonderful brochures on ichthyosis. These are the first fully informative materials ever available to the public, and we are all grateful for Westwood's responsible generosity.

At the fifth F.I.R.S.T. National Conference (did we get that right?) in New Haven in May, Charles Eichhorn presented a plaque expressing the appreciation of all foundation members to longtime F.I.R.S.T. volunteer Valerie Lutters of San Francisco. Valerie has been with the Foundation since its first national conference in Chicago. (Back in the old National Ichthyosis Foundation days!) Ironically, although Valerie has attended every prior year's Conference, she missed this one, the first held in her home state, Connecticut! Ellen Rowe, F.I.R.S.T. President, accepted the plaque for Valerie in her absence.

Valerie is easily the most popular member of the Foundation's staff. She answers most of the mail, and many of the telephone calls. She authored the brochures and has served as both editor and

assistant editor of this newsletter over time. Valerie prepared the current wonderful display we set up at exhibit halls, and does most of our typesetting. She regularly supplies Lily and Cleo, the office bunny mascots, with lettuce and carrot treats, too.

There's more, but if we go on, she may get a big head and ask for a raise! (Actually, Valerie is our staunchest volunteer supporter.) The continued existence as well as the success of the organization is clearly due to Valerie's loyal support and efforts. We all thank her most sincerely, and hope she continues to keep us moving forward.

**F.I.R.S.T. RESEARCH FUND --  
AN IDEA TO REMEMBER**

From time to time, members have asked that their contributions be allocated specifically for research on ichthyosis. All such donations are used specifically to support and fund ichthyosis research. Earlier this year, F.I.R.S.T. was able to award its first direct research grant to Dr. Peter Elias for work related to finding the cause and cure for ichthyoses. Requests that a donation not be used for research involving the use of animals are also honored.

Effective June 1, 1988, F.I.R.S.T. created a F.I.R.S.T. Ichthyosis Research Fund to directly support future research activities. Initial contributions have been received in memory of William Sponheimer, the grandfather of a member from Seymour, Connecticut with EH. Mr. Sponheimer, died just a few days before the F.I.R.S.T. Conference in New Haven, Connecticut, in May. [Alese Kummer, Mr. Sponheimer's daughter, was the Conference coordinator and did a wonderful job despite the pressures and grief of her father's illness and death. -Editor]

You can honor the memory of a loved one or a friend through a gift to F.I.R.S.T. Donations may be made directly to F.I.R.S.T. for general purposes, or specifically to the F.I.R.S.T. Research Fund, at any time, or can be made as a memorial to a specific person. Such donations are a caring and meaningful way of expressing condolences. F.I.R.S.T. will provide an immediate acknowledgment to the individual or family you designate, with no mention of the amount of the contribution.



**WASHINGTON IN REVIEW**

Most research on skin diseases in America is done through the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS), a part of the National Institutes of Health (NIH) in Bethesda, Maryland.

This spring, as Senate and House Appropriations Committees deliberated over the 1989 budget for NIAMS, F.I.R.S.T. members Terri Hall and Linda Morgan gave them something to think about by bringing to the hearings their two-year-olds, Shandi and Ryan, each battling Lamellar Ichthyosis.

Terri and Linda stood up for all of us before the Appropriations Committees in a panel of representatives from the volunteer skin disease foundations including F.I.R.S.T., the National Psoriasis Foundation, D.E.B.R.A. and others. Here is the prepared statement they read into the official record:

*"Honorable Members of the Committee, I am a volunteer member of F.I.R.S.T., speaking for thousands of fellow members, and a parent, speaking for myself and my child who has had ichthyosis since birth.*

*"ICHTHYOSIS is the name for a group of almost forty related skin diseases in which severe scaling of the skin is a primary symptom. These are genetic diseases, part of the American gene pool, passed on from generation to generation. They affect over a million people.*

*"In the most severe forms of the disease, babies die shortly after birth from dehydration and infection. Some forms of ichthyosis cause mental retardation, immune deficiencies, deafness, lack of body temperature control, raw blisters, and bone deformities, as well as the psychological devastation that accompanies bodily disfigurement.*

*"Every year, almost 17,000 more people are born in the U.S. with one of these diseases, facing lives of limited productivity and social interaction because of their disability and disfigurement. Yet, there is very little research -- and certainly no cure -- for any of these diseases. Why? Because the research community never focuses on ichthyosis. It writes off tens of thousands of lives as though they don't matter.*

*"My child's life matters. You can help my child here today and thousands of children and adults all over America -- by insisting on a funding level of \$224 million for the NIAMS and by mandating and funding the proposed additional core skin research centers. You can help by using the power we the*

*people have given you to save and heal lives like those of these children by making the medical research establishment focus on ichthyosis at last. Thank you."*

As we await final word on the Committees' decisions, we hope they took these words to heart as strongly as we do.

Linda and Terri also spent time educating the committee members and their staffs about ichthyosis so that they could make a more informed spending decision. Thanks to Linda and Terri, as well as Shandi and Ryan, for speaking up for all of us.

**1989 NEW HAVEN CONFERENCE**

F.I.R.S.T. held its 1989 Ichthyosis Conference in New Haven, Connecticut, at the Yale Medical Center, on Saturday, May 18, 1988. About 65 persons attended, which was the largest turnout yet for a F.I.R.S.T. Conference.

The day's program began with a get-acquainted coffee hour during registration. A basic goal of this year's Conference was to give people an opportunity to meet and talk among themselves.

Dr. Sidney Hurwitz presented attendees with an overview of the medical aspects of ichthyosis and its diagnosis. His slide presentation brought into focus the clear difference in the skin's physiology that differentiates ichthyotic from normal skin. Dr. Leonard Milstone stressed the need to hydrate all ichthyotic skin types, both to loosen scale and to keep it flexible. He discussed up-to-the-minute research activities and treatments, admitting that dermatology has a long way to go before "curing" ichthyosis, and that patients have to share what they know with their physicians.

Drs. Hurwitz and Milstone are members of the F.I.R.S.T. Medical Advisory Board and practice in New Haven.

Mr. Joseph Castagnola, an Assistant School Superintendent whose son has ichthyosis, provided parents with insight to the rights of children who need -- or don't need -- help in the classroom because of their condition. In the ensuing discussion, it seemed the audience was torn between wanting to provide special help for their children and letting them be free to make it on their own. The only consensus was that it was a tough balance to keep.

Dr. Ajit Jetmalani, a psychiatrist from the Yale Medical School, provided a graphic breakdown of the various developmental stages children normally go through, and contrasted them with the situations that may occur in the development of a child with a disability. Again the theme of protecting and helping, but not overdoing it, came into the discussion. Attendees clearly appreciated the information and extended question and answer period provided by all of the panel members. Following lunch, Charles Eichhorn, F.I.R.S.T.'s Executive Director, presented the views of siblings who grew up with a child with a disability of one sort or another. In each case, it was viewed as though the affected sibling had ichthyosis, and the comments of the brothers and sisters were moving and insightful. It was good to hear from these important family members who are so often ignored in the concern over the affected child.

Next, everyone broke up into smaller groups: children, parents, and adults, for roundtable discussions on selected topics. This gave everyone a chance to interact with their peers and ask and talk about their own particular experiences, techniques, wishes and fears.

The children's group in particular, moderated by F.I.R.S.T. President Ellen Rowe, was a marvelous success. Kids say the darndest things, you know. The most startling revelation of the day came when one child stated that the best thing that ever happened to him was when he was four years old and figured out for the first time that, despite all the concern and worry that hung over him since he was born, he wasn't going to die, after all.

Next, Charles Eichhorn gave a summary of the way a topic or disease is chosen for research, and how funds are allocated for the work in the U.S. health system. Conference attendees came to a better understanding of why everything seems to take forever, and how they can support the Foundation in its goal of promoting research on this family of rare diseases.

He also reported the encouraging news that plans were underway for F.I.R.S.T. to co-sponsor an international conference next April in Washington, DC, on research into the underlying genetic causes of skin diseases like ichthyosis, psoriasis and epidermolysis bullosa that affect the epidermis. Such research is the only route that can lead to a true cure and eradication of ichthyosis, he said.

After dinner, Mr. Eichhorn continued with a look at F.I.R.S.T.'s past, present, and future. He commented that whenever he made a list of all of the unfinished projects and unrealized plans for F.I.R.S.T., he became discouraged, but admitted

that a review of the organization's considerable accomplishments to date always made him feel a lot better. After listing dozens of projects that F.I.R.S.T. wanted to work on, the audience seemed prepared to volunteer one and all for immediate active duty at the "front."

The highlight of the evening was a marvelous presentation of sight and sound by Ellen Rowe. Ellen and her brother, Thomas Betts, had set to music a wonderful collection of slides showing a series of ichthyosis families at work and play all over America and the world. It was clear that the sky was the limit for all ages, if you knew what you wanted and put your mind to it.

The program ran over by hours as no one wanted the day to end. The opportunities and promises of a great day had been fulfilled for everyone, it seemed. Finally, with the aid of a wonderful group of local volunteers, the site was cleaned up and the lights were out.

F.I.R.S.T. wants to thank Alese Kummer, this year's Conference Coordinator, and her family, for a wonderful job organizing this year's event. We also want to thank our panel members for the generous donation of their time and expertise to the group. Dr. Leonard Milstone deserves our special gratitude for making arrangements for us to use the facilities and catering services at Yale, and spending so much of the day with us. Last but not least, thank you to all of the members who helped out at every opportunity to make the day run smoothly. The result was a conference that was a success for all who attended.

The only disappointing note of the entire Conference this year was the low attendance figure, compared to the expected number. There are almost 1,000 ichthyosis families within a few hours of driving time in the New England/New York area, yet only a few dozen attended the Conference.

Can you help us with a serious problem? It would be extremely helpful if everyone in the Greater New York/New England area would drop us a quick postcard (signed or not) with a brief explanation of why they in particular didn't attend the Conference. Was it a bad time of year? Family illness? Too expensive? Boring program? Distressed at the thought of meeting other patients or parents? Please let us know. A tremendous amount of effort and time goes into preparing these Conferences, and attendees are always super enthusiastic, but we just don't seem to know how to get people to come in the first place. Before we consider cancelling future Conferences, we'd like to know your thoughts.

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