



ICHTHYOSIS FOCUS

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Published by The Foundation for Ichthyosis and Related Skin Types, Inc., (F.I.R.S.T.), PO Box 20921, Raleigh, North Carolina 27619-0921 (formerly The National Ichthyosis Foundation). Telephone 919-782-5728. 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 marked by excessive scaling. Letters, suggestions and contributions are welcome.

F.I.R.S.T. OFFICES MOVE UP -- NOTE NEW ADDRESS !!

We have good news and bad news. The bad news first: Charles Eichhorn, who has served at one time or another as President, Secretary and most recently as Executive Director of F.I.R.S.T., has resigned his post under the burden of family and business pressures. He urged other concerned Members to contribute their motivation and skills to the Foundation's growth. For almost two years, F.I.R.S.T. has operated from within Charles' law office in Oakland, California. That office is moving and Charles says, "I'm already way over my head" both at home and at work. So

Now the good news: To provide better service to Foundation members, and to coordinate F.I.R.S.T.'s activities more effectively, F.I.R.S.T. has moved its offices to Raleigh, North Carolina, closer to the home of F.I.R.S.T. President Ellen Rowe. The new address is: **F.I.R.S.T., PO Box 20921, Raleigh NC 27619-0921**. The new telephone number is: **919-782-5728**.

The new office is certainly modest, but has one tremendous advantage: **Mrs. Betty Batten**, who will be working there half of every weekday. This continuity represents a big step up from the volunteer time snatched here and there to accomplish F.I.R.S.T. tasks. Now you know why it's taken so long to answer your letters and requests of late! We apologize for the lateness of this issue of FOCUS, and hope its size makes up for its tardiness. The moving process was traumatic, but on the whole, the transfer is a success, and we're already back on track. (Only one chair became a casualty.) Moving costs were generously donated by a foundation member, which made the whole thing possible.

CORRESPONDENCE CORNER

"BB" would like to discuss his Pityriasis Rubra Pilaris with other adult patients, particularly those who are interested in research. Write to him c/o F.I.R.S.T., PO Box 20921, Raleigh NC 27619-0921 and we'll pass it on.

Parker and Debra Piercey are the parents of a 3 year old with CIE (congenital ichthyosiform erythroderma). They would sure like to be in contact with other parents of children coping with CIE! Their address is: **Rt. 3 Box 478, Ogdensburg, NY 13669**. Please write.

Sue Heaton has lamellar ichthyosis and would like to correspond with other adults: **13900 S.E. Highway 212, Space #89, Clackamas, OR 97015**. Or just call: (503) 658-8743.

David Freed is a parent with an infant with EH (epidermolytic hyperkeratosis). Are you a similarly situated parent with two seconds to share? Please write to him at **40876 San Rafael Avenue, Los Angeles, CA 90065**.

Jackie O'Connor and her 18 year old daughter **Jody** are very eager to hear from some Americans who can share their experiences coping with severe epidermolytic hyperkeratosis. They live in Tasmania (an island south of Australia, and Jody could use some encouragement, since they are so far away from almost everything. Their address is: **42 Ravenswood Road, Ravenswood, Launceston, Tasmania, Australia**.

MEMBERSHIP RENEWAL

It's May again - Membership Renewal month. While many members automatically renew each year, others have asked for us to remind them. Well, here's your reminder! F.I.R.S.T. needs your sustaining support more than ever. Please use the envelope in this issue to make your annual contribution.

A couple of other points about your membership contributions: If you wish to receive a thank-you or acknowledgment of your donation, please mark the envelope accordingly. Some members have asked us to save the cost of a thank you letter, postage, time, etc., and apply the savings to our other funding needs. We'll be happy to acknowledge your contribution, though, if you just mark the envelope accordingly.

Another point: sometimes a doctor or pharmaceutical company will ask F.I.R.S.T. if we know of members who would be interested in a new treatment, or an experiment, or catalog, etc. Sometimes a patient or parent will call and want to know about who they could talk to in their geographical area.

In the past, F.I.R.S.T. never released names to anyone for any purpose. On reconsideration, however, we think our members may be missing out on some potentially valuable information. Therefore we are reversing our policy.

Hereafter, if you do NOT want us to release your name to anyone for any purpose, or only for limited purposes, please drop us a card or letter by July 1 to let us know. We'll mark your file accordingly and keep it a secret just between us! After that date, if we haven't heard from you, we'll pass your name and address on if we think it would be in your best interest.

**'89 SF CONFERENCE CANCELLED --
1990 SUGGESTIONS?**

For seven years, F.I.R.S.T. has sponsored a National Ichthyosis Conference for patients, families and health professionals. Usually it has been held in conjunction with the annual meeting of the American Academy of Dermatology, which usually takes place in a major resort area or population center. It was the only conference of any kind, held anywhere in the world, to discuss and educate about ichthyosis specifically, and to focus on patients as well as health professionals. The 1988 Conference was held in New Haven, Connecticut, a location chosen because it is the center of the heavily populated New York-Boston corridor.

Member support and attendance at Conferences has always been disappointing, despite our efforts to hold them in convenient locations. When we asked members why they didn't attend a Conference in their area, the very few answers we received indicated that they had been out of town that week, or a family crisis had arisen. Those responses are

certainly understandable. But we never heard anything from all the rest of you who simply didn't attend.

The Board of Directors recently voted unanimously NOT to hold a Conference in December 1989 in San Francisco as originally planned. Basically, the event has been cancelled at least temporarily for lack of interest. It was decided to spend the time, energy and money on other services, since the Conference seems to appeal to so few members.

This was a difficult decision, since those members who DO attend a National Conference almost unanimously give it a rave review. Attendees are never sorry they came: Many feel the Conference changed their lives because of meeting other people and taking home so much new information.

But all is not lost! The Board will review the question of a 1990 Conference in December. Meanwhile, here are a couple of questions we'd like you all to answer:

- 1) What kind of program could F.I.R.S.T. provide in a Conference that would convince you to attend, assuming it was an accessible location? For example, a workshop on Social Security and ichthyosis.
- 2) What state, city, and location do you suggest? For example: Epcot Center, Florida.

Drop us a line and let us know what you think? Write to: F.I.R.S.T. Conference, PO Box 20291, Raleigh, NC 27619-0921.

ICHTHYOSIS PATIENT REGISTRY

Did you know F.I.R.S.T. has a computer Ichthyosis Registry? We try to include information about each member such as the particular form of ichthyosis involved. This is particularly important because we often get calls from researchers who want to work on a rare disease, but can't find patients, or even statistics on the disease. F.I.R.S.T. has the only Ichthyosis registry in the world, and is potentially a prime resource for researchers.

Unfortunately, our registry is far from complete, and we don't know the particular form of ichthyosis affecting hundreds of our members. Can you take a minute to help us update the registry? We need a name, sex, age, and type of ichthyosis to make a complete entry. A simple post card will do, or add the information to the dues envelope attached to this issue.

JIM BORDEN: A REALLY GOOD "SPORT"

I'm sure everyone at the Ichthyosis Conference in New Haven remembers Jim Borden. Jim became a coast-to-coast sensation in 1970 when he appeared in Newsweek Magazine. No, not for his ichthyosis. Well, not exactly. He was on the Sports Page!

Jim was the record-setting cross country runner at New Paltz State University in New York who just wouldn't let his ichthyosis get in his way. To beat the heat build-up, he'd make detours through ponds and had a regular bucket brigade of teammates who would douse him as he streaked by.

Jim has been a F.I.R.S.T. supporter from the start, and he made a real hit in New Haven with youngsters who wanted to be active in sports, but who were concerned about limitations caused by ichthyosis. Jim explained that the limitations are self-imposed, and that you can accomplish whatever you put your mind to. Patients, both young and old, know when they are overdoing it, and if everyone just cooperates, (like his bucket brigade!) nothing is impossible.

We were sorry to hear that Jim was involved in a car accident with a deer at 3:00 AM on his way home from the Conference. He escaped uninjured, although the encounter was fatal for the deer and Jim's car.

Sports-minded patients and parents can write to Jim at R.D. #1, Box 154, Schaghticoke, NY 12154.

1989 MEDICAL ADVISORY BOARD MEETING

The Medical Advisory Board of F.I.R.S.T. will hold its annual meeting on December 2, 1989, in San Francisco, CA, in conjunction with the annual meetings of the American Academy of Dermatology.

DOCTORS OVERSEAS

During the past year, our roving ambassador, Lois Richter, of Greenwich, Connecticut, visited a number of countries in the Far East. She met with a number of doctors and researchers overseas, who have since contacted F.I.R.S.T. to set up a dialogue with F.I.R.S.T. and other American researchers.

In recent months we have heard from Syria, Jakarta, Beijing, Australia, and South Africa. At the same time, we have heard of efforts to get an organization off the ground in the United Kingdom, as well as the announcement that there is now a Canadian foundation for ichthyosis patients.

HURRAY! THERE'S A BRAND NEW CANADIAN ICHTHYOSIS FOUNDATION

Hurray and Congratulations! There is now a national organization in Canada supporting ichthyosis patients and families! Contact Pat Choise at the C.I.F., at 11137 Fuller Crescent, North Delta, British Columbia, V4C 2C8 Canada. Telephone: (604) 594-6888.

RESEARCH PARTICIPANTS NEEDED IN N.Y.

Henry Sun, a researcher at New York University Medical Center in New York has made an interesting discovery relating to the bullous form of congenital ichthyosiform erythroderma, (bullous CIE), known more commonly as epidermolytic hyperkeratosis (EH). He needs some more skin samples. If you are in the New York area, please contact Dr. Irwin Freedberg at the Diseases of Keratinization Clinic in the Dermatology Department at NYU Medical Center. The telephone number is (212) 340-5245. Ask for Dr. Freedberg or Dr. Sun.

NEW ICHTHYOSIS VIDEO

Dave Beaver, of 168 Fairview Ave, Johnsonburg, Pennsylvania 15845, has produced a new video about ichthyosis, explaining different kinds of ichthyosis and treatments for it.

The video tape is available in BETA or VHS format for \$22.95. A portion of the proceeds will be donated to F.I.R.S.T. to support its programs.

For more information, or to place an order, call Dave at (814)-965-5195.

PATIENTS NEEDED FOR STUDY

The Pediatric Clinical Research Center at the University of California San Francisco is seeking volunteers (Age 6 through adult) for a study to improve our understanding of the emotional impact of ichthyosis. Participation in the study will involve interviews and standardized questionnaires which will be conducted with strict confidentiality. If interested, please contact: Mary Williams, M.D. (415) 750-2091, John Koo, M.D. (415) 476-4701 or Mary Jane Ott, R.N. (415) 476-2755.

F.I.R.S.T. 1989 BOARD OF DIRECTORS

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NEW RETINOID FOR ICHTHYOSIS PATIENTS

Long standing member of the F.I.R.S.T. Medical Advisory Board, and leading researcher in the use of retinoids in ichthyosis and psoriasis, Dr. Nicholas Lowe discusses the new retinoid, Acitretin.

Etretinate has been shown to be an effective oral treatment for a number of severe skin diseases including several forms of psoriasis, as well as some forms of ichthyosis. It appears to be particularly useful in lamellar ichthyosis and epidermolytic hyperkeratosis.

A major problem with Etretinate is that it is bound to the fat in the body and even after stopping the drug, there can be detectable drug levels for many years afterwards.

The major problem this presents is that this long term presence of Etretinate may cause damage to the developing fetus if a woman of childbearing years has been treated with Etretinate. This remains a problem for several years after stopping the drug.

A major potential advance is the acid metabolite of Etretinate known as Acitretin. Acitretin is apparently as effective as Etretinate in treating severe forms of psoriasis and the above two types of ichthyosis.

A major advantage over Etretinate is that Acitretin is rapidly cleared from the body. When Acitretin is approved by the Food and Drug Administration (anticipated in mid 1989) it may be available for use in ichthyosis patients.

A woman of childbearing potential being treated with Acitretin would be required to be on an effective form of contraception for approximately one month prior to starting the drug, during the drug, and for four weeks after stopping the drug. It would however, be possible for the woman to become pregnant if she waits four weeks after stopping the drug as Acitretin is rapidly excreted from the body.

Clearly other factors have to be taken into account prior to a woman with one of the inherited forms of ichthyosis becoming pregnant. One of the separate questions is clearly the risk of her child developing ichthyosis. It is advised therefore, that any younger woman in this situation should seek the advice of her dermatologist prior to being considered for Acitretin therapy.

SCLERODERMA NEWS

Speaking of fund-raising success: 300 people, including celebrities like Linda Gray and Sally Struthers, among others, recently spent a dazzling evening at San Francisco's famous Fairmont Hotel at a benefit for Scleroderma Research Foundation, founded by Sharon Monsky, a scleroderma patient. Would anyone care to volunteer to be the maitre d'hotel at a benefit for F.I.R.S.T.?

FINANCIAL ASSISTANCE

Marlene Huffman of Minnesota, a staunch supporter of F.I.R.S.T. and real help to other members she is in contact with, brought good news to us recently. The Minnesota Department of Health has a program called Services for Children with Handicaps. Her son, Patrick, qualifies for assistance with creams, exams, etc., because ichthyosis falls under the category of "Other chronic medical problems requiring extended care."

Programs such as this exist in other states, too, but you may have to look hard for them. Usually the problem is qualifying, since many programs will not specifically mention ichthyosis. You may need to find a general category like the one above to fit into the program. It's certainly worth a try!

GENETIC COUNSELING

The evaluation of a patient with ichthyosis and his or her parents does not end once a diagnosis is made and treatment starts. A major function is to inform the individual and family about the risk of recurrence of the hereditary disorder.

Genetic counseling may be provided by anyone trained in medical genetics and with in-depth knowledge of the disorder in question. Many medical centers today have this special service, although the comparative rarity of some of the ichthyoses often make it difficult to find knowledgeable counselors.

Counseling is available and recommended for any relative, including a potential mate. Counseling for prospective husbands and wives may be particularly helpful, since some types of ichthyosis, X-linked in particular, are carried but not expressed in females.

The best time for genetic counseling is usually before you have a baby, but often the birth of a child is the first indication that something may not be normal. Usually it is several months after a child's birth, after a period of adjustment and quiet, and after a treatment pattern is in place that successful counseling can begin.

It is very common for a parent or patient to misunderstand significant parts of the counselor's news in the first meeting. A followup visit is almost always needed to clarify and review the ideas brought up during the first visit.

The 3/20/89 issue of TIME Magazine published an interesting article on genetic research and the efforts of the National Institutes of Health. Because of the genetic basis of most ichthyoses, F.I.R.S.T. members should keep up to date on genetics developments, since a true cure will lay in that area.

NEW SKIN DISEASE RESEARCH CENTERS

Congress has approved \$1.2 million funding for each of two new Skin Disease Research Centers. One will be located at Case Western Reserve University in Ohio, and the other at New York University Medical Center. The purpose of the SDRC's is to speed up scientific and biomedical research efforts on skin diseases already underway at these locations by providing a forum to discuss new approaches from a multiple of disciplines, and to share physical resources, such as equipment, skin samples, etc.

F.I.R.S.T. members will be particularly interested in the work being done at Case Western on the genetic control of keratins. It is the lack of control of keratins that contributes to the scaling so evident in the ichthyoses.

F.I.R.S.T. members thank F.I.R.S.T. member and Director Terri Hall for testifying on their behalf before the congressional committees responsible for supporting this funding.

"SEED" FUND RESULTS TO DATE

In December, Charles Eichhorn wrote to hundreds of F.I.R.S.T. members, asking them to join him in donating \$50 each to reach a goal of \$100,000. Over 150 members responded and the Seed Fund is currently at just over \$7,000.

We particularly want to thank Jesse Doyle Deely for her generous response to our call.

Although we are still far from our goal, your generous donations have provided sufficient funds to hire a part-time office manager, which is more than we have ever had before.

If you are reading this newsletter, you have a stake in the future of ichthyosis patients and research for better treatments and ultimately, a true genetic cure. Ichthyosis is YOUR problem, not somebody else's.

If you haven't already made a special one-time \$50 contribution to our "Seed" Fund, please do so now. It is planned to enable F.I.R.S.T. to hire a full-time, professional executive director, who can implement a major capital development campaign to launch F.I.R.S.T. into the 1990's as an effective, professional organization and advocate for YOUR needs.

If you want to see more newsletters, faster response to your inquiries, and most important, more work toward a true cure for ichthyosis, vote with your wallet: Make a donation to the Seed Fund today.

SPECIAL THANKS

On December 11, 1988, **Henry Edward Cleary** passed away. When I first met Mr. Cleary, he knew nothing about ichthyosis. But he quickly responded to the plight of those who had to live with it, as he remembered a friend whose psoriasis was both devastating and frustrating.

In memory of her brother, **Miss Mary Margaret Cleary** has donated to F.I.R.S.T. 80 acres of land and mineral rights in Oklahoma. On behalf of all of the F.I.R.S.T.'s volunteers and members, I want to thank Miss Cleary for this most generous and compassionate gift.

Our sincere gratitude also goes to **Mr. Henry Kamps**, President of **Herald Pharmacal** of Richmond, Virginia. A long-time supporter of F.I.R.S.T., Mr. Kamps has donated brochures and product samples, and his company has now promised to provide a contribution of \$200 toward the production of each issue of the *FOCUS* newsletter this year. We hope other, larger and more affluent pharmaceutical companies will follow Herald's lead in promoting patient education, thereby supporting their buying public.

We want to thank **Joanne and Mary Ann Bauer** for helping with our brochures, and **Sonia Guragna** and her family for working on brochures and for the many hours of volunteer time in the Oakland office. We also want to thank **Valerie Lutters**, who has moved back to her hometown in Connecticut after giving three of the best years of her life to F.I.R.S.T., and more specifically, to each of its members. Thanks also to **Susan Shields**, who was always ready, willing and able to help stamp and fold and spindle and mutilate (just kidding) the newsletter to prepare it for mailing.

Another loyal member is **Suzanne Canter**, who has worked long and hard for F.I.R.S.T. and all of us in this fight by spreading the word, educating her community and giving generously. We want to thank one of our strongest supporters, **Karen Jones**, and her daughter, **Bailey**, for all their help. Over the last couple of years, Karen has organized and run a number of fund raising events, including the raffle of a beautiful quilt made by Bailey's grandmother, **Betty Jones**. Thanks very much, Karen, keep up the good work!

Heartfelt thanks, too, to all of the people who made an extra effort to donate a portion of their **United Way** contributions to F.I.R.S.T.. We also want to thank those members of the Board of Directors who have given generously of their time (and money) to represent F.I.R.S.T. at various functions and to plan and prepare for the coming decade.

Most of all we want to express our appreciation and gratitude to those who responded to our call for a "Seed Fund" to hire a full-time staff person as a launching point for additional funding opportunities, which would in turn allow us to expand our services and research efforts.

RARE DISEASE COMMISSION REPORT

The summary report of National Commission on Orphan Diseases starts with the following quotation:

Nature is nowhere more accustomed more openly to display her secret mysteries than in cases where she shows tracings of her workings apart from the beaten path; nor is there any better way to advance the proper practice of medicine than to give our minds to the discovery of the usual laws of nature by careful investigation of cases of rarer forms of diseases. For it has been found in almost all things that what they contain of useful or applicable nature is hardly perceived unless we are deprived of them, or they become deranged in some way.

- William Harvey 1657

The Commission was established in 1985 to learn more about the 5,000 rare and orphan diseases that affect 10-20 million Americans. An orphan disease is defined by law as one that affects 200,000 or fewer individuals in the U.S. Practically all of the ichthyoses come under this definition.

Since 1985, the Commission has held numerous public meetings and hearings, and has conducted interviews and surveys all over the nation. **Kathy Rogers**, F.I.R.S.T. Treasurer and Board Member, testified at one hearing on behalf of F.I.R.S.T. and its members. F.I.R.S.T. also prepared written testimony for the permanent records of the Commission.

The Commission's conclusions and recommendations were published earlier this year, and presented to the Secretary of Health and Human Services as well as the Congress. The report points out that in 1987, \$1.3 billion was spent on government research, of which fully half was spent on 200 rare types of cancer. That left only \$640 million for the remaining 4,800 diseases. The pharmaceutical industry spent \$51.6 million, and \$41.6 million came from private foundations like F.I.R.S.T.

The Commission's conclusion? Too little is known about these diseases which afflict in the aggregate as many as 1 in 10 Americans. There are simply not enough researchers working on these diseases, often because researchers never think of these unknown maladies. Patients and their doctors spend great effort and time to find accurate, understandable information, a correct diagnosis and an effective treatment plan. Often there is no insurance coverage, because the rare disease is not specifically listed as a covered ailment.

The Commission's recommendation? Create a Central Office of Orphan and Rare Diseases (COORD) in the office of the Assistant Secretary of Health to promote awareness and research on these diseases. Declare a "Year of Rare Diseases." Support the creation of Registries of rare diseases and patients.

Whether Congress acts on the recommendations of the Commission remains to be seen, but the blueprints have been prepared and your government representatives are waiting to hear from you for direction.

HUMAN GENOME INITIATIVE

The biomedical sciences of the next century will rely increasingly on our understanding of the structure and sequence of the human genome -- the complete chemical alphabet of DNA contained in human chromosomes. Our knowledge of evolution, growth, aging, disease, and human behavior will ultimately come from the information now being gathered as scientists unravel the mysteries of the human genome. Solid government commitment supports the public and private mapping effort, which is expected to take at least ten years of intensive effort. This effort will unlock answers to more than 3,000 genetic disease, including various forms of cancer, Alzheimer's Disease, ichthyoses, muscular dystrophy, cystic fibrosis, and others. The successful completion of the project holds promise for significant new advances in medical science far beyond those dreamt of in science fiction.

SUN JUNK TABLOID ARTICLE

Free speech is an important, even fundamental part of the American way of life. That's why tabloids like the SUN can get away with publishing garbage. Of course, if the public didn't buy the trash, it wouldn't be printed any more.

Anyway, I'm exercising my own right of free speech to criticize the recent *SUN* article (April 4, 1989) written by William Rock. The cover story shows young Abdul Makhim of Jabal, India, who suffers from severe ichthyosis with the typically accompanying ectropion. The *SUN* describes him on its cover as **REPTILE BOY: HE'S DOOMED BY PYTHON CURSE**. Abdul's father and three older brothers also have ichthyosis. The article says the family was cursed by a snake accidentally run over by Abdul's father, Abdul Jabbar.

Abdul Jabbar had more sense than the article's author, because he apparently went directly to a doctor to find out about the disease. A skin specialist with the Indian Health Organization let him know his family was dealing with a rare, incurable genetic disorder. The disease has shown up in Abdul's family because he married his first cousin, who shared the defective gene.

As soon as this *SUN* issue hit the newsstands, F.I.R.S.T. members reacted. All were horrified that the publisher would be so insensitive to the reaction of patients. Parents tried to protect their children from the callousness exhibited by the *SUN* just to shock the gullible public. Others simply removed the newspapers from the stand and threw them in the trash. Some took the fight right to the *SUN*, complaining to management that such yellow journalism was unacceptable. The *SUN* apologized and -- not surprisingly -- went right back to writing trash.

WHAT WORKS FOR ME - Charles Eichhorn

I have had ichthyosis of an unspecified type my entire life. It was more severe and localized when I was young, improved somewhat when I was a late teen, and is now getting worse again and "spreading" as I enter middle age.

I have dry blisters and granular scale in my flexural areas (inside elbow, back of legs), light colored, leathery scales all over my legs and thighs, and general involvement over most of my body including my neck and face. Lots of dust, lots of flakes. My symptoms look like a mixture of lamellar ichthyosis and epidermolytic hyperkeratosis, yet tests reveal that I have neither. My scaling indicates a hyperproliferative rate of scale growth and a hyper-retention of the stratum corneum. I am obviously ichthyotic, but the exact type is somewhat unique.

Like many patients, I have tried practically everything under the sun (including sitting under the sun, both the real one as well as artificial ones.) Actually, I have not tried any oral retinoids, such as Accutane (isotretinoin), Tegison (etretinate) or the new acitretin compound. The attendant risks and side effects did not seem worth the benefit to me.

Over the years, I have found a few things that work pretty well for me. Ask your doctor if they might help you.

My favorite treatment right now is a light coating of LacHydrin (Westwood) two evenings and mornings in a row, followed by a hot shower or bath on the third day. Old scale comes off by the handful with just a rough facecloth. Epilyt (Steifel) and Ultramide 25 (Baker-Cummins) are also very effective applied in the same manner. I usually follow up with a light coating of LacHydrin every day after a shower and rub down. Every day there is more scale, but every day LacHydrin keeps it loose enough to remove almost all of it.

The other method requires spending about eight hours, preferably overnight, in a plastic, occlusive, waterproof exercise suit, after coating myself with a mixture of 50% water and 50% propylene glycol. I use a spray bottle for total coverage. It really softens the scale so that it can be rubbed off in the morning shower by the handful. This is a great way to get down to the basic level of new skin. Next, I smooth on a coating of Lubriderm or Alpha Keri lotion to lubricate and lock in the moisture. If I am feeling more aggressive, I use LacHydrin as a moisturizer, and keep up the LacHydrin daily. Sometimes the LacHydrin has a temporary (10 minutes) sting, but it is certainly bearable, and always transitory. I feel the effect is worth it.

This is a conservative approach to scale management, yet is quite effective -- at least, for me. Nonetheless, I suggest you consult your dermatologist before beginning any kind of treatment.

SECOND CHANCE (LAST CHANCE?) TO 'READ ALL ABOUT IT'

We have a number of back issues of the *ICHTHYOSIS FOCUS* newsletter available. We keep two copies of each newsletter in our files, but the rest are available to members who would like to receive any of them. These newsletters date from as far back as 1980, and if you joined F.I.R.S.T. more recently, you probably didn't get a chance to read any of these issues.

We have arranged the list according to articles, clustering articles about local chapters, treatments, social-emotional implications, etc, so you can look under the categories that most interest you. We will send you the entire newsletter if we have it and, if we don't have any more spare issues of that newsletter, we will photocopy the particular articles that interest you and send you those.

Back issues/article reprints cost \$1.50 each, which includes postage. Please enclose your check made out to **F.I.R.S.T.** with your order. Please send your requests to:

F.I.R.S.T. Back Issues
PO Box 20921
Raleigh, NC 27619-0921

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