



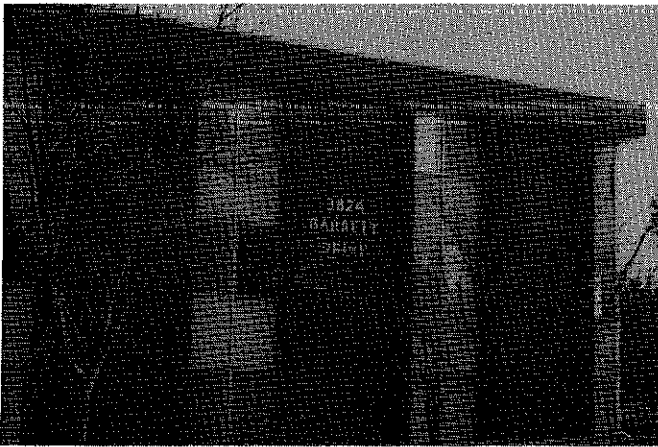
ICHTHYOSIS FOCUS

Volume 9, No. 2

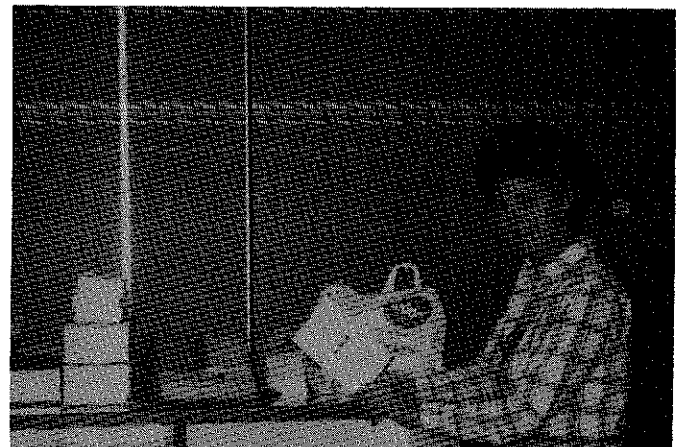
Summer 1990

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 corporation for the benefit and education of its members and the public regarding medical, psychological and social aspects of the ichthyosis, a family of primarily genetic skin disorders marked by excessive scaling. Letters, suggestions and contributions welcome

There's no place like home!



We are on the second floor in a nice sunny spot. After many years of having our files in people's homes, it is wonderful to have our own office. Come see us sometime!



F.I.R.S.T. is lucky to have BeBe Blades as office manager and administrative assistant five afternoons a week. BeBe also serves as the foundation's secretary.

You're invited to our F.I.R.S.T. family reunion & conference

The F.I.R.S.T. Family Reunion and National Conference are just around the corner. If you have not mailed in your registration form, please send it along to us as soon as possible. The deadline is May 1. Late registrations will be accepted, but in order to reserve your place for lunch, we need to know if you are coming.

The meeting will take place on Saturday, June 16, 1990 in Kissimmee, Florida at the Hilton Inn Gateway, 7470 West U.W. 192, Kissimmee. Make your own hotel reservations. Room rates are only an amazing \$55 per night. Children under 18 stay free!

To book your rooms, call 1-800-327-9170. Be sure to say you are attending the F.I.R.S.T. conference and ask for special rates.

Keynote speaker for the day will be Dr. Lawrence Schachner of Miami, Fla. Joining him will be Dr. Mary Spraker of Atlanta, Ga. and Dr. John Koo from San Francisco, CA. Some of the topics that will be covered include various psychological problems related to Ichthyosis, parenting issues, different therapies for treating the disease, and genetic aspects of Ichthyosis.

The day will also include a question and answer period and small group

discussions. Most importantly, we will have chance to meet and share with others our own experiences.

Some people have been reluctant to attend a conference in the past for fear that it may be upsetting. Those of us who have gone have found just the opposite to be true! We have made new friends. We have discovered we are not alone. Children have been delighted to play with others like themselves, and some not like themselves.

It is truly a learning experience with many good feelings and memories. We hope you won't miss it. Please come!

Eczema association provides helpful tips for patients

Cosmetics can hide redness

Some patients with ichthyosis also have problems with eczema and atopic dermatitis. If you are one of those people, you may be interested in contacting a new foundation called The Eczema Association for Science and Education, 1221 SW Yamhill, #303, Portland, OR 97205. Phone: (503)228-4430.

The Eczema Association has printed some excellent literature about atopic dermatitis which includes information about how to prevent dry skin.

A few of their helpful hints include: use warm, not hot water; avoid excessive use of soap, scrubbing and towelling, and apply your moisturizer to the skin within three minutes after bathing.

Atopic dermatitis, like ichthyosis, is not contagious. It is a disease which causes itchy, inflamed skin and typically affects the insides of the elbows, backs of the knees and the face. For more information, contact the Eczema Association at the above address.

Some patients with ichthyosis experience a great deal of redness. In fact, strangers may comment, "My goodness, you have a bad sunburn." If this sunburned redness is bothering you, you might want to try some of the cosmetics that are now on the market which are designed for both men and women with skin discolorations.

Dermablend Corrective Cosmetics, P.O. Box 3008, Lakewood, NJ 08701, is one which makes cover cremes, powders and leg covers which can conceal birthmarks, burns, broken veins, scars and general redness. The cosmetics are waterproof, non-greasy, smudge-resistant and fragrance-free. They are light, lasting and natural-looking and come in eight shades that can be blended from ivory to brown/black.

Please check with your dermatologist before trying anything new on your skin. These cosmetics are available without a prescription, but you may want to discuss their use with your doctor first. There are several other companies who also manufacture cosmetics which camouflage skin problems.



Ellen Rowe, president, left, hands Charles Eichhorn, a plaque in appreciation of all of his hard work for the organization. Charles recently resigned from the Board of Directors after being an active supporter for many years.

New program studies related skin type

The Department of Dermatology at New York University Medical Center has received an anonymous contribution to begin a research program on Pityriasis Rubra Pilaris, one of the related skin types to ichthyosis. Anyone interested in participating in this program should contact Irwin M. Freedberg, MD, Chairman, Department of Dermatology, New York University Medical Center, 550 First Avenue, NY, NY 10016, (212) 340-5245.



Dr. Mary Williams, left, is presented with a plaque from F.I.R.S.T. "Second" Vice President, Frances McHugh, right, in honor of the many years dedicated service to the foundation as Medical Advisory Board Chair.

Researchers help harlequin infants

If any families with harlequin ichthyosis are interested in participating in current new and exciting research, Dr. Virginia Sybert would appreciate receiving your name and address.

Dr. Sybert explains that, "we have recently confirmed, at a biochemical level, heterogeneity within harlequin ichthyosis. As some of these infants are now being treated with retinoic acid and have survived into the first few years of life, we

are interested in restudying them. We have access to several patients through our work, but suspect that there are others in the United States and abroad of whom we are unaware."

All names will be kept confidential. If you want more information, contact Dr. Sybert at Children's Hospital and Medical Center, 4800 Sand Point Way NE/P.O. Box C5371, Seattle, WA 98105.

New treatment can help remove scales from scalp

By Beverly Robison, PA-C

Duke University's Dermatology Division is using a whirlpool type scalp hydrobath designed by International Health technology. The unit automatically delivers a medicated shampoo, rinses the scalp, and applies a conditioning rinse. Temperature, water pressure, length of cycles, and medicated solutions may be tailored to each patient's needs.

We have used the unit in treating patients with psoriasis, seborrhea, dermatitis, and ichthyosis. Average treatment time is 10 minutes, and patients are treated once or twice a week.

The unit has been quite effective in loosening and removing scale, even in some patients with significant scalp involvement. Advantages of treatment include increased exposure time of medication to the scalp, even applications and rinse, and convenience.

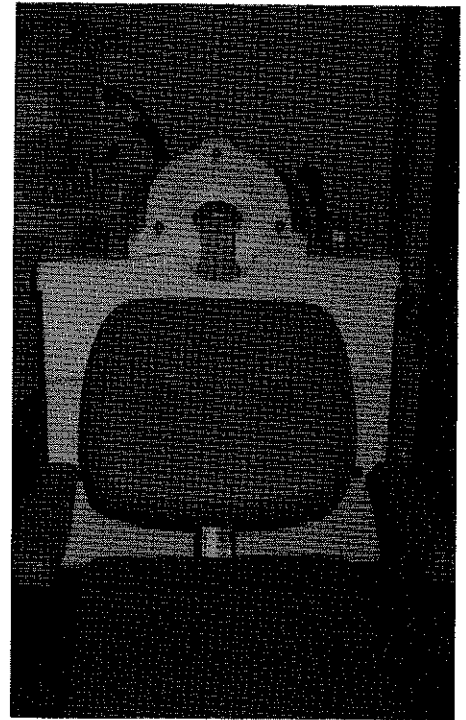
Some patients believe that vigorous



Beverly Robison

brushing or combing or even picking the scalp is helpful in controlling scale. However, this may actually increase scale production in some patients, and certainly increases the risk of secondary infection. The hydrobath is a more effective and safer method of debriding the scalp.

More information about treatments may be obtained from: International Health Technology, Inc., 2119 24th Avenue North, Nashville, TN 37208. Phone: (615) 726-3630.



The scalp hydrobath can be relaxing and comfortable experience. Treatments can be designed to fit each patient's needs.

Correspondence Corner

Ruby B. Smith would like to correspond with parents who have children with Lamellar Ichthyosis. Her daughter, Mary, has this type of disorder. Mrs. Smith says that she is very proud of Mary, now 42, and would like to pass along helpful tips to others. "Mary has always been accepted by everyone. In fact, everyone says she has never met a stranger," says Mrs. Smith. You can write to the Smith's at 301 N. Bridge St., Jonesville, NC, 28642. Phone: (919) 835-1809.

Randy J. Brown, 721 St. James Ave., Henderson, KY 42420, is interested in meeting others with Lamellar Ichthyosis. Randy, age 39, has Ichthyosis, and is also the father of three children, ages 9, 11 and 13, who have normal skin. He is a tool and die maker and copes with his condition well. He wants to know how others deal with summer heat. He says he is looking forward to hearing from all you folks out there.

Louise Szymanski, 593 Clearview Drive, Charleston, SC 29412, writes in response

to Anonymous who wondered what to do about children who pick their scales in public. Says Louise, "My son Craig, age 9, has x-linked ichthyosis. This isn't a severe form of the disorder, but we do have trouble with scales in his scalp. It seems like he constantly scratches his head! Like most little boys his age, his fingernails are usually dirty. The combination of scratching and fingernails has led to many staph infections on his scalp. The infections were treated with antibiotics, but I've been left with more scratching and further infections.

I've found that several things have helped with our problems: 1. He wears a hat (of his choosing) much of the time. 2. He scratched his head in his sleep so wearing cotton gloves at night helps. 3. I spoke with his teacher and explained the problem. When she notices his scratching, she quietly reminds him to quit. 4. We have a "secret signal" to remind him not to scratch in public. I look him in the eye and put a finger to my scalp. This reminds him not to scratch without embarrassing him.

I hope that as Craig gets older, he will realize that scratching and picking at his scalp in public aren't proper. But in the meantime, I try not to embarrass him. He doesn't do it consciously; it's just gotten to be a habit."

A reader has written to let us know that his company will match any gift he makes to F.I.R.S.T. The purpose of the matching gift plan is to encourage employees to provide personal financial support to non-profit, tax-exempt organizations, like F.I.R.S.T. Check and see if your employer has such a plan. Your donations help keep this newsletter alive.

If you would like a pen pal, have a comment to make, or would like to be in touch with others who have your type of Ichthyosis, write to Ichthyosis Focus, and we will include your name and address in Correspondence Corner. We do not release names and addresses without permission.

Name: _____
 Address: _____ New Address? _____
 City: _____ State: _____ Zip: _____
 Phone: (AC) _____ (No.) _____

THANK YOU!

Here's my 1990 Membership Contribution to F.I.R.S.T. to help with education, support and research.

_____ \$50 **ONE TIME "SEED" FUND CONTRIBUTION TO LAUNCH F.I.R.S.T INTO 1990'S**

_____ \$20 Single membership _____ \$35 Family membership

_____ \$50 Sustaining Member _____ \$100 Sponsor

_____ \$250 Patron _____ Other Amount

_____ I can't afford dues now, but please keep me on the mailing list. (Please check.)

_____ CALL ME. I can make time to help as a F.I.R.S.T. Volunteer.

Ichthyosis type in my family: _____ # Persons _____

**All contributions to F.I.R.S.T. are fully tax deductible to the extent allowed by state and federal law.
 F.I.R.S.T. is a 501(c)(3) charitable organization supported entirely by private donations.
 A copy of the F.I.R.S.T. Annual Report is available to anyone on request.**

1990 CONFERENCE AND FAMILY REUNION

Hilton Inn Gateway • Disneyworld, Florida
 Saturday, June 16, 1990

Registration

	Number attending	Total \$
_____ \$35 Per Person	x _____	_____
_____ \$50 Per Couple	x _____	_____
_____ \$15 Per Child (under 18)	x _____	_____
	Total amount enclosed	_____

Please send remittance to: **F.I.R.S.T.**
 P.O. Box 20921
 Raleigh, NC 27619

Registration includes continental breakfast, lunch, afternoon snack and admittance to all lectures and workshops. Room reservations must be made directly with the Hilton Inn Gateway or hotel of your choice.

F.I.R.S.T.
 PO Box 20921
 Raleigh, NC 27619-0921
 Return postage guaranteed

Non-profit Org.
 U.S. Postage
PAID
 Raleigh, N.C.
 Permit No. 2209

