



ICHTHYOSIS FOCUS

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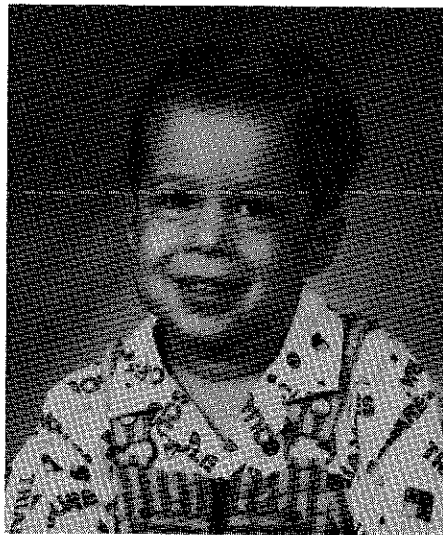
Spring 1990

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 ichthyoses, a family of primarily genetic skin disorders marked by excessive scaling. Letters, suggestions and contributions are welcome.

\$100 donors help boost F.I.R.S.T. into the 90's

F.I.R.S.T. would like to express deepest appreciation to everyone who made a donation this year. Among the 285 of you who contributed so generously, we would like to acknowledge those who gave at least \$100 or more. If we have overlooked you, please let us know. Thank you to all of you.

Wake Stone Corporation, Dr. and Mrs. Robert Harper, Mr. and Mrs. Bill Wilson, Valerie Anne Lutters, Eugene J. LaFosse, Robert and Debra Bowie, Ray and Margaret Haywood, Elizabeth Weller-Fiman, Justine LaFemina, Reba C. Benson, Charles Eichhorn, Henry and Martha Suski, Carl and Shirley Anderson, Herdis Olson, Michael and Melinda Jensen, Jensen Plastering Company, Brian and Joyce Conelly, Mr. and Mrs. William Amwake, Jessie D. Deely, Karoline Freed-Biggs, Walter and Norene Foxe, Lori Bowman, United Way of the Bay Area, Bill Blackwell, Margaret S. Vernet, A.J. Galluccio, Jr., Richard A. Kelly, Dr. Mary Williams, Dr. Frank Yoder, Floyd Evans, Dr. and Mrs. W.C. Betts, James T. Gaffney, Helen Iorio, Pat Wright, Dr. Leonard Millstone, Elizabeth Forbus Adams, All-Brite Sales Co., Inc., Joe and JaNeva Hart, Paul and Janice Hudson, Dr. Stephen A. Estes, Neutrogena-Kulkin, Mary H. Bilger, Margaret A. Haywood, Thomas C. Hudson, Marvin Stark, Susan M. Drake, Ms. Dale Wedel, Ms. Charles C. Rogers, Ruby Boles Smith, Mr. and Mrs. H.J. Bukaty, The Karen Jones Family and Friends, Dr. Marvin



Ryan Licursi

Firestone, Dr. Peter Williams, Becca Harris, Dr. Eugene Van Scott, Janet Lynne Showers, Else H. M. Phillips, Mr. and Mrs. William Brunetti, W. Blair Pride, Jean A. Cox, Donald H. Gore, Dr. Laurence H. Miller, Sween Corporation, Lynn M. Swierczek, Marion M. Stanton, Elliot and Phyllis Shulman, Kenneth and Marge Boyd, The Rogers' Family and The Licursi Family.

Join us for Disneyworld extravaganza

Get ready for the incredible F.I.R.S.T. National Conference and Family Reunion coming up next summer, on Saturday, June 16, 1990, just four miles from Disneyworld in Kissimmee, Florida.

The one-day conference and reunion will take place at the Hilton Inn Gateway, 7470 West U.S. 192, Kissimmee, Fla. 32741. Room rates will astonish you - only \$55 per night

Ryan is a budding young artist

Ryan Licursi, a cute 4 1/2 year old, lives in Cinnaminson, NJ with his parents, Paul and Shelly, and his 6 1/2 year old brother Kevin. Ryan has Epidermolytic Hyperkeratosis, but that doesn't stop him from being the star of his class at Little Friend's Nursery School three mornings a week.

Father's Night was coming up recently and Ryan's teacher had each child draw a picture of his or her father without signing a name. Each daddy was to try and identify his own child's drawing. To assist the dads, the teacher had each child give her a clue about the father which she then wrote on the picture.

Ryan, a bit concerned that his dad might not choose the right picture, asked his teacher to write, "My Daddy creams me every night." With that clue, Ryan's dad had no trouble picking out his picture! Now, how many other kids get "creamed" every night? All of those with ichthyosis, we bet!

for the first 25 rooms. Children under 18 stay free.

After the first 25 rooms have been booked, the rates jump to \$61 per night. To book your rooms, call 1-800-327-9170.

Conference registration fees should be sent directly to F.I.R.S.T., P.O. Box 20921, Raleigh, NC. 27619. Fees are \$35 per person or \$50 per couple, and \$15 per child.

DEAR READERS:

I just want to thank each and every one of you who has supported us during this very transitional year. I am looking forward to a year of growth and success for F.I.R.S.T. and I hope you will join me in this endeavor. As your president, I am proud to say that I have never enjoyed getting to know so many enthusiastic folks more.

As a mother of two (James, 12, and Libby, 9), I can understand how hard it is to be a parent. Although my children do not have ichthyosis, we've had our share of ailments and worries. However, I always try to look on the bright side of things. Having ichthyosis has helped me to better understand other people and to be more accepting of those who are different. Someone once said to me, "God don't make no junk," and I think that is true. We are all special, and we all have something special to offer this world while we are in it.

I thought you might like to know that our office expenses are running an

average of \$1,500 a month. We have 2,257 members and received donations from 285 of them in 1989. The total amount of contributions for the year amounted to approximately \$15,000. You can see that we have a shortfall of about \$3,000 for 1989. Believe me, we are trying to cut corners in every way we can. Some of our members have been extremely generous, giving up to \$800 personally. Some send \$5 a month. Every little bit helps.

A donor recently wrote to ask where and how the money is spent, and why we spend money sending people to conferences. Many times our hotel expenses are paid for by one of the pharmaceutical companies. Board members who travel to conferences go at their own expense.

We do not make money off our national conferences, and we sometimes do not even break even. The largest part of our budget is spent on postage to mail you the newsletter,

and to mail brochures and information to those who request it. We do not pay physicians who come to our conferences. Our board members serve free of charge, as a gift from their hearts.

I am excited about the upcoming year and am honored to serve as your president again. Thank you for continuing to support F.I.R.S.T.

Sincerely,



Ellen Betts Rowe,
President

New treatments may help scalp disorder

Board members from F.I.R.S.T. who attended the December American Academy of Dermatology conference in San Francisco, would like to let you know about new treatments which may be helpful for people with ichthyosis.

International Health Technology has designed a whirlpool style scalp hydrobath which automatically shampoos, rinses and delivers medication to the scalp. So far, the machine has been used in the treatment of psoriasis, seborrheic dermatitis, and other related scalp disorders. Duke University is using the technique on one of our members right now and we hope to have results for you in the next issue.

If you are interested in finding out more about the treatments, contact International Health Technology, Inc., 2119 24th Avenue North, Nashville, TN 37208. Phone: (615) 726-3630. The hydrobaths are located in a number of

large hospitals throughout the United States.

"Many patients whose scalp problems were difficult to treat or failed to respond to other treatments, responded to the shampoo machine treatments," according to Lloyd King, MD at Vanderbilt University Hospital.

Another new product for ichthyosis was unveiled at the meeting in San Francisco. NeoStrata AHA Skin Smoothing Lotion, Cream, and Hand and Foot Gel contains alpha hydroxyethanoic acid which has been found helpful in some cases of ichthyosis.

For more information about this product, contact the NeoStrata Company, Inc., 360 Sackett Point Road, Box 658, North Haven, CT 06473-0658; phone: 1-(800) 628-9904 or (203) 281-4242. Although this is not a prescription formulation, you may want to check with your dermatologist before application.

Mail scale to help researchers

Dr. Amy Paller, a pediatrician and dermatologist at Children's Memorial Hospital in Chicago, is studying changes in the composition of certain sugars and fats in the membranes of scale from patients with ichthyosis. Early research suggests that these elements may participate in the growth of skin cells.

In order to do meaningful research, Dr. Paller needs to study lots of scale. If you are interested in helping, all you need to do is send scale to Dr. Paller by regular mail.

What she needs is: 1. At least six tablespoons of scale from an affected area that has been untreated by any greasy preparation for at least two weeks. (A local area can be untreated and scale collected for a few weeks). The more scale, the better! Scale should be packaged in a plastic bag and sealed well, then pop it in an envelope and send to: Amy Paller, M.D., Division of Dermatology, Children's Memorial Hospital, 2300 Children's Plaza, Chicago, IL 60614.

Dr. Paller says she would also be glad to receive scale from treated areas to compare, as long as the greasy preparation is clearly identified to her for testing.

Volunteers needed for area network

Terri Hall, F.I.R.S.T. board member from West Virginia, will be undertaking the project of redesigning our regional representative network this year. Our goal is to have a representative for every major population area in the United States.

These representatives will be responsible for providing information, referrals and support to individuals, families, health and education professionals, public and private agencies and the media regarding ichthyosis.

Because our organization is small, we have not been able to utilize regional representatives very well in the past. However, many of you have generously offered to help and we feel that the time is now right for building a network of interested folks from one

side of the country to the other.

If you have been a rep, are still interested, or have never volunteered, but would like to do so now, please contact Terri Hall at (304)562-5003 or write to her at 21 Woodclyffe Rd., Hurricane, WV 25526.

There are also several vacancies on the Board of Directors. If you are interested in becoming more involved with F.I.R.S.T., contact Ellen Rowe, President, P.O. Box 20921, Raleigh, NC 27619-0921. Board Members participate in national conference calls several times a year and are asked to attend national conferences at least once during their three-year term. We need people who are willing to help the Foundation move into the 90's successfully. We need You!

CORRESPONDENCE CORNER

Dave Baucom, age 28, would like to hear from others with vulgaris ichthyosis. His phone number is (513)625-2121. Dave's address is: 6631 Manila Rd., Goshen, OH 45122.

Anonymous has written to ask what can be done if a family member with ichthyosis constantly picks at himself in public. This is a touchy situation. Should parents discourage picking in the same way they discourage passing gas and picking one's nose in public? If you would like to respond to anonymous, write to FOCUS, P.O.Box 20921, Raleigh, NC 27619-0921. Another reader has asked what we feel about parents who pick their children's skin. Let us hear your thoughts about that one too.

Donna Balsavich of Orland Park, IL has a 7-year-old son named Daniel who has x-linked ichthyosis. She would like to hear from other parents about topical treatments that help this disorder. She would also like to hear from other parents who have problems with children who won't cooperate with skin care routines and who shy away from participating in sports because of the way they look. Her address is 13817 Lincolnshire Dr., Orland Park, IL 60462.

MaryAnn Bauer, age 9, would like a pen pal her own age (or close to it) who has lamellar ichthyosis. She lives in California. Her address is 3301 High St., Oakland, CA 94619.

Catherine E. Arbush would like to be a sticker pen-pal. She likes to share stickers with others and would like to establish new friendships. Catherine, who is 39, promises to write back if you write to her. She says she knows what it is like to be different and not belong. Catherine's address is 388 Hill Street, Xenia, OH 45385.

Dorothy Keller, 1296 E. Gibson Rd., Unit E., Woodland, CA 95695, wants to let us know that she has finally found relief after 61 years of enduring ichthyosis. She is happy to report that Aqua Glycolic Lotion by Herald Pharmacal keeps her scale to a minimum and enables her to enjoy smooth-feeling skin. "I want to share my enthusiasm for this product with others who may have given up hope of ever finding help", she says.

Carol Reid, 4621 Lamont St., Apt. A-7, San Diego, CA 92109, (619)270-6792, writes that her dermatologist tells her to always put water on her skin before applying lotion to it. She wanted to pass along this helpful hint.

Little ballerina receives honors

Parents can be instrumental in helping children with ichthyosis develop a strong self image. Joanne and Bill Brunetti are certainly proud of their daughter Katie's accomplishments. Katie, now 8 years old, has Lamellar Ichthyosis, but she doesn't let that slow her down. She has been taking dancing lessons (tap, jazz and ballet) since she was 2 1/2 years old. She just received her 5-year trophy and has also been chosen to participate in a competitive jazz dance group.

"I think her participation in dance from such a young age and being exposed to so many people has really helped her", says Katie's mom, Joanne. "Her teacher has been wonderful and is really to be credited with Katie's positive self image. She has done so much for her and has always praised her and encouraged her to go on."

Congratulations, Katie, and keep on dancing!

Parents can help children develop good feelings about themselves by encouraging participation in dance, sports, and after-school activities. As one adult with ichthyosis told FOCUS, "My Mom always told me that no one in the audience could see my ichthyosis from that far away anyway, so I danced my little heart out."

Another adult who loved sports says, "I just soaked my T-shirt with water when I got overheated and ran back out on the field." Still another, a swimmer, shrugs and said, "Who cares what you look like underwater?"

So go for it kids! If your child is excelling in a special event, please send us his or her picture (black and white). We would love to let the rest of the F.I.R.S.T. family know about our kids.

Due to lack of space in this issue, the continuation of "Fears are Often Worse Than Reality" by Virginia P. Sybert, MD will be printed in the next issue. Dr. Sybert is a member of the F.I.R.S.T. Medical Advisory Board.

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	_____

Registration deadline: May 1, 1990

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.

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