



ICHTHYOSIS FOCUS

Vol. 16, No. 2 A Quarterly Journal for Friends of F.I.R.S.T. Spring/Summer 1997



F.I.R.S.T. GOES TO WASHINGTON

On April 15th, Haley Rice, age 5, traveled from her home in Texas to Washington, DC. She and her mom, Donna Rice, joined F.I.R.S.T.'s Executive

Director, Mark Levitan, in testifying before the House of Representatives; Committee on Appropriations; Subcommittee on Labor, Health and Human Services, Education and Related Agencies.

Haley, who has lamellar ichthyosis, presented some mounted photographs to the committee, which depicted several of the more prominent forms of ichthyosis. Donna, who is a Regional Support Network Coordinator and Vice President of F.I.R.S.T.'s Board of Directors, described Haley's medical history and daily care. She also discussed school and community related issues, and some of the ways that living with ichthyosis has affected her family, and other families that she's gotten to know through our Regional Support Network. She described to the committee how very lucky she was to have the support of her family and community and to have found F.I.R.S.T. shortly after Haley was born. Her compelling testimony and pride in her daughter elicited a very emotional response from those present.

Mark's testimony focused on research. He reviewed recent scientific advances and thanked the committee for their strong history of support for medical funding. He requested that they pay particular attention to these three areas.



Haley and Donna Rice at the capitol

1) Research that will translate new scientific knowledge, such as the location of specific genes, to practical applications for better testing and more effective treatment.

2) Continued support for the National Registry for Ichthyosis and Related Disorders. Current funding expires in 1999.

3) Increased funding for the programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), which is one of the National Institutes of Health.

While in Washington, Mark, Donna and Haley visited the offices of their local senators and representatives. They met with the staff responsible for health issues in the offices of Senators Rick Santorum (PA), Arlen Specter (PA) and Phil Graham (TX) and Representatives Bill Archer (TX) and Curt Weldon (PA). F.I.R.S.T.'s trip to our nation's capitol went a long way toward increasing awareness for ichthyosis and the need for skin disease research funding.

You Can Make A Difference

Get to know your local senators and representatives and their staff. It's easier than you think. Call or write to increase awareness for ichthyosis and discuss issues that are important to you. If you live near your senator's or representative's local office, or are planning a trip to Washington, D.C., schedule a brief appointment with your congressperson or their healthcare legislative assistant. F.I.R.S.T. can provide copies of our testimony, legislative contact tips sheets, and proper forms of address for letter writing. Contact the national office for more information.

**ICHTHYOSIS
FOCUS**

Vol. 16, No. 2
Spring/Summer
1997

Copyright © 1997
by F.I.R.S.T.

Ichthyosis Focus
is published quarterly by
the
Foundation for Ichthyosis
& Related Skin Types
(F.I.R.S.T.)

Anyone is free to reprint,
with credit to F.I.R.S.T.,
material contained in
Ichthyosis Focus.

P.O. Box 669
Ardmore, Pennsylvania
19003

610-789-3995
800-545-3286
FAX: 610-789-4366

Editor

Elena Levitan

Science Writer

Betsy Bates-Freed

Editorial Assistant

Betsy Wilford

Layout/Graphics

Amy Bottoms

Board of Medical
Editors

John DiGiovanna, M.D.
*National Institutes of
Health*

Carl Ehmann, M.D.
*Winston Salem, North
Carolina*

Philip Fleckman, M.D.
University of Washington

Karen Holbrook, Ph.D.
University of Florida

Joseph McGuire, M.D.
Stanford University

Neil Prose, M.D.
Duke University

Mary Williams, M.D.
*University of California,
San Francisco*

F.I.R.S.T. is a 501(c)(3)
charitable organization
supported by private
donations.

CORRESPONDENCE CORNER

Dear friends at F.I.R.S.T.,

Thank you so much for sending the packet of information. It contained much more than I expected.

I have had a lot of success treating my Ichthyosis Vulgaris with Eucerin Plus lotion, and Vanicream which comes in a 1lb. jar. To order it call the company direct at 1-800-325-8232.

I am doing fine now but growing up as a kid with this disease left some emotional scars. Sometimes talking or writing to someone with this awful disease helps. Thank you for letting me become a part of FIRST, a top notch organization.

Sincerely,
Bob Kuhn
Rochester, New York

Dear F.I.R.S.T.,

Both of my children, Merritt and Joe Jr., have ichthyosis.

They are now 27 and 24. Our daughter, Merritt, is an animator at Walt Disney World and has a wonderful personality and a great outlook on life. Our son, Joe, is a graphic designer in Miami with equal talent and personality. They both have had their share of ups and downs due to their condition and work hard to keep it under control with Aqua Glycolic Hand & Body Lotion, Lac-Hydrin Creme and Lubriderm (unscented).

Sincerely,
Marjorie P. Andrews
Salisbury, Maryland

Dear F.I.R.S.T.,

My son was diagnosed at birth with Bullous Ichthyosiform Erythroderma. Our doctors say it is a very rare

disease and haven't really been able to explain very much about it to us. We were very excited when we read about F.I.R.S.T. in a medical book but we couldn't find very much information on this disease. Our son will be four in July and we are concerned about how this disease will affect him as he grows older. We would very much like to become members of F.I.R.S.T.

We love our son greatly and want to be able to help him, and us, to deal with the every day aspects of ichthyosis.

Thanking you in advance,
Tracy and Tony Garcia
Cambridge, Ontario, Canada



*Merritt and Joe Andrews
with Mickey Mouse.*

Dear F.I.R.S.T.,

I've had ichthyosis since birth. Over the years, it's been more annoying or embarrassing rather than a medical

ICHTHYOSIS FOCUS is provided as a service to members of F.I.R.S.T. as a medium for the free exchange of information. Neither F.I.R.S.T., its Board of Directors, its Medical Advisory Board, nor the Focus Editor endorse any treatments or products reported on in ICHTHYOSIS FOCUS. Views and opinions expressed in this publication do not necessarily reflect the views of F.I.R.S.T. or Foundation officials.

problem requiring treatment. I've tried various lotions, but either they are too expensive for complete body treatment on a daily basis or else, if affordable, they are all but ineffective. Summer also seems to be more favorable than winter, possibly because I perspire more; cold weather seems to accentuate the flaking and peeling.

The literature you sent speaks well of alpha hydroxy types of lotions over others, so Sunday I went to a local drug store and inquired about such lotions. I was steered to the cosmetics section where, along with the usual Jergens, Lubriderm and Vaseline Intensive Care, they had many other lotions. One, St. Ives, was on sale for \$2.99 for 18oz. (normally \$4.39, I believe). I bought a couple of the peach-scented alpha hydroxy variety and found it to be not only pleasant smelling (I usually avoid scented lotions) but even more effective than anything I've tried for a long time. If nothing else, the literature you sent has not only given me a psychological boost, but has led me to a product of reasonable cost which is more effective than any I used previously.

MANY THANKS!!!

Sincerely,
 Ronald M. Landau
 Huntington Beach, California

Dear F.I.R.S.T.,

I am 62 years old and did not know there was a medical name for my skin problem until my daughter was a

patient at the University Hospital in Minneapolis. A physician was called to look into her skin problem, she was given a prescription (topical) but no tests were done. They named it ichthyosis vulgaris.

Upon receiving this month's Sat. Evening Post magazine listed under medical mailbox, an article from a reader asked the question of ichthyosis, and phone numbers were listed. I took a great interest in this and called both numbers. I since have received good information and materials on ichthyosis and also information about participating in the registry. The information has been very enlightening for me and makes me feel like I am not, after all, the only person with this problem.

There are fifteen individuals in my extended family that have ichthyosis, including my mother, myself, two of my four children, and two of my six grandchildren. I currently use Cetaphil lotion on my body and Jafra products on my face. I have a perfectly clear complexion, but I know that without using these products every day, it would not stay that way.

Just wanted to share this with you if it will help anyone else. I am anxious to learn all I can about this skin disease as it went for too many years without a name. It is nice to know I am not alone in this day by day struggle. I am happy that this has never stopped me from doing all things I want to do in this life.

Thank you,
 Rosella Olsen
 Alexandria, Minnesota

BOARD OF DIRECTORS



Michael Dunleavy
 President
 Philadelphia, Pennsylvania
 (12/97)

Donna Rice
 Vice President
 Katy, Texas
 (12/98)

Janet Weary
 Secretary
 Charlottesville, Virginia
 (12/98)

Phyllis Sanders
 Chief Financial Officer
 Ontario, California
 (12/98)

Gloria Flippin-Graham
 Atlantic Beach,
 North Carolina
 (12/99)

Tiffany Karst
 Shawnee, Kansas
 (12/99)

Leonard Milstone, MD
 Chairman
 Medical Advisory Board
 New Haven, Connecticut
 (12/99)

Michelle Petersen
 Metuchen, New Jersey
 (12/99)

Michael D. Pinnisi
 Ithaca, New York
 (12/97)

Deb Vilas
 New York, New York
 (12/97)



In Sympathy

Our sincerest sympathies to Steve and Laurie Crabtree of O'Fallen, Missouri who recently lost their month old son, Austin, due to complications of a very rare form of ichthyosis, Keratitis, Ichthyosis and Deafness Syndrome (KID). FIRST wishes to thank the friends and family of the Crabtrees for their contributions to the Foundation in Austin's memory.

CAMP HORIZON AND CAMP DISCOVERY- CAMPS FOR CHILDREN WITH CHRONIC SKIN DISORDERS

For the fifth straight summer, the American Academy of Dermatology is proud to offer an exciting, medically supervised camping experience for children with chronic skin diseases. Children with ichthyosis and several other conditions have attended camp in the past, each entering with feelings of nervousness and apprehension but leaving with wonderful memories and loads of new friends. The letters received from children after past camps are a testimonial to the quality of this rewarding, sometimes life-changing, experience.

Camp Discovery at Camp Knutson, for children 10-13 years old, is located on Whitefish Lake in northern Minnesota. This summer's camp will be held Saturday, August 9 through Saturday, August 16. Boating and swimming activities abound along with traditional camp activities. Camp Horizon, for children aged 8-13 years old, will be held Saturday, August 16 through Saturday, August 23. This camp, in the heart of Central Pennsylvania farm country, has a large fishing pond, outdoor pool, pavillions, and campfire pit. Paddle boating, arts and crafts, volleyball, animal awareness and countless other activities are offered through the week.

Both camps have a full complement of staff dermatologists and dermatologic nurses to see that all the medical needs of the campers are addressed, and no tuition is charged to attend. Counselors have skin

"It is one of the most beautiful compensations of this life that no man can sincerely try to help another without helping himself."

Ralph Waldo Emerson



diseases themselves and serve as excellent adult role models. Activities are individualized, emphasizing what the camper can do, rather than what they cannot do. Emphasis on each camper's value as an individual regardless of his or hers outside appearance is stressed.

If your child would like to attend camp or you would like to volunteer for the week, please call Howard Pride, M.D. (717-271-8050) or Debbie Kronke at the American Academy of Dermatology (847-330-0230).

VOLUNTEERS

F.I.R.S.T. thanks all of these volunteers who have so generously donated their time and talents to further our mission.

The Medical Advisory Board
Board of Directors
Regional Support Network and State Contacts
Ichthyosis Focus Staff
Board of Medical Editors
Members of the National Conference site
selection committee:
Gina Connors
Frances McHugh
Shelly Licursi
'97 Ichthyosis Awareness Week Coordinator:
Lynne Alba
Cookbook Editor:
Debra Butler
American Academy of Dermatology
conference assistant:
Jim Griffin
Web page designer:
Bob Clifton

New Product Takes The Sting Out Of Needle Sticks

San Francisco- The misery of needle sticks, biopsies, and intravenous line placement just adds to the pain suffered every day by children with ichthyosis.

But now, you can ask your dermatologist or pediatrician to prescribe an inexpensive, highly effective numbing cream that makes needle sticks painless, or nearly so.

Dr. Lawrence A. Schachner, director of pediatric dermatology at the University of Miami School of Medicine, told colleagues at the annual meeting of the American Academy of Dermatology that they should consider using EMLA cream before any painful procedure in a child with intact skin in the area to be treated.

"It's a humane thing to think about," he said.

He showed a slide of a child undergoing extensive scalp injections as a treatment for alopecia areata, a hair loss disorder.

The child's demeanor was calm, Dr. Schachner noted. "He's about six. And while he's not grinning madly, he's also not hysterical or in much duress," he said.

The EMLA used to cover the entire front of the boy's scalp cost less than \$10.

A mixture of two anesthetic agents (lidocaine 2.5% and primlocaine 2.5%), EMLA comes in a tube, available by prescription. The cream is often covered with an occlusive dressing for 1-2 hours over the area to be treated, blocking pain in the covered region.

Dr. Schachner suggested that when a procedure is anticipated, doctors can ask parents to apply it at home ahead of the appointment, covering the cream with a dressing or BandAid.

It works very well in most children if it is left on at least an hour, he said.

In a study conducted at the University of Miami, children pretreated with EMLA reported significantly less pain than those pretreated with a placebo cream, both in oral interviews and when asked to rate their pain according to a series of pictures of faces that ranged from happy to agonized. The youngest children sometimes reported pain when perhaps they were frightened, Dr. Schachner said. But no child over 5 reported any significant pain during procedures that normally would be quite painful.

Pediatricians also have been reporting on the benefits of EMLA at many recent scientific meetings, some advocating it for everything from

blood draws to circumcision.

EMLA is manufactured by Astra Pharmaceuticals, a division of Merck & Co., Inc., in Wayne, PA.

Also at the AAD meeting, a San Diego physician alerted dermatologists to another new product that may have applications for people with ichthyosis: Histoacryl Blue (HAB).

HAB is the "not so crazy glue" that is being tried at many centers as an alternative to traditional sutures in repairing wounds.

In a study of 61 children ages 1-18, using the tissue glue to repair cuts took just seven minutes, compared to the 17 minutes it took to stitch wounds together.

The glue might be especially effective as an alternative to stitches in patients whose skin tears easily, such as those with ichthyosis, said Dr. Lawrence F. Eichenfield, chief of pediatric and adolescent dermatology at Children's Hospital, San Diego.

Dr. Schachner is Professor of Dermatology and Pediatrics, and the Director of the Division of Pediatric Dermatology, University of Miami School of Medicine and has been a member of F.I.R.S.T.'s Medical Advisory Board since 1988.

Seventh Annual Newman's Own, Inc. and Good Housekeeping Recipe Contest

Do you have a winning recipe? Mrs. Carolyn K. Babcock of Dearing, Kansas sent us notice of this recipe contest. Winners will allocate a total of \$250,000 to their favorite charities. For a copy of the rules and entry form, write to:

Ichthyosis Focus
PO Box 669
Ardmore, PA 19003

Executive Director Mark S. Levitan

To Members and Friends of F.I.R.S.T.



Approximately six months have passed since I joined F.I.R.S.T. as its Executive Director. It has been a busy six months. We moved the office from Raleigh, NC to Ardmore, PA; our fund raising effort at the end of last year was successful; a group of our board members joined Elena and me to attend the American Academy of Dermatology meeting in San Francisco for some five or six days, where we exhibited and had the opportunity to meet with our Medical Advisory Board and others interested in ichthyosis and other skin diseases; Elena and I met with the Coalition of Patients Advocates for Skin Disease Research (CPA-SDR) at the National Institutes of Health in Bethesda, MD; and Donna Rice, Haley Rice

and I testified before the House Appropriations Subcommittee For Labor, Health and Human Services, and Education about the importance of government funding for skin disease research.

Work has begun for our family conference which will be held in June of 1998. Normally the conference would have been held this spring, but with all of the activity involved with a new management staff and moving the office it made more sense to move the conference to 1998 so we could do it properly.

Research into the causes of ichthyosis and its cure are slowly being made. While we all wish it were faster, the good news is that progress is being made. One of the initiatives that the Board is considering is how to further research into the causes and cures for ichthyosis. The Foundation has never funded research directly, although we have encouraged others in their research efforts. We are now reviewing our options as to how to further research about ichthyosis and, if we endeavor to support research directly, how to raise the substantial sums necessary to do it effectively.

Included in this issue of *Ichthyosis Focus* is a request for contributions. Without your membership dollars we would be unable to maintain our current programs and services and could not even consider a more active role in supporting research. Your help is vital to the work of FIRS.T. Please consider making an additional contribution at this time. A return envelope is included for your convenience. Your gift is truly appreciated.

Mark S. Levitan

President Michael Dunleavy

Dear Friends,

We have had a busy spring as the search team looked at sights and visited hotels to make a selection that would meet the needs of our members for the 1998 Family Conference. We wanted a location that had easy access for both local and long distance travelers, be somewhere that would be a great family vacation site and not be so expensive that it was not affordable. I believe that Deb Vilas and her committee (see separate report in this issue) have done a commendable job. They have picked Philadelphia, the Cradle of Liberty and the City of Brotherly Love. Or as our Mayor says-The City that Loves You Back. Also the Foundation's new home.

We need your input to make the 1998 Family Conference a success. In the last issue I asked that you tell us what you feel would be important to include in the program. We need your input, so please let us know your thoughts. Call, write, send us a fax or an E-mail.

Mark Levitan has been active in looking into how we can better organize our fund-raising activities. We should be able to report on that effort in our next issue. As all of you know, asking for money is not an easy job. We do not know what will be involved as we look further into raising money, but we do know that if we are going to expand our mission we will need additional funds to be successful. We will be looking not only at ways to increase our general funds, used to run our programs and maintain our national office, but also how to fund research in areas important to our members.

During the American Academy of Dermatology Conference in San Francisco, Tiffany Karst was able to secure a donation from NeoStrata Company to complete the video project that we have been working on for the past several years. As a result of that \$6,000 gift, Tiffany believes that the completed video will be ready for distribution just about the time school begins. A video crew was able to attend the Region Six Conference and obtained a good deal of valuable footage for the project.

We are also planning for another board retreat again this year after the success of the last meeting. We have tentatively selected the same weekend in November for 1997. It will give all of the board members a chance to spend several days together and will enable everyone to visit the conference hotel and local sights to get ready for the upcoming Family Conference.

Have a great summer.



Michael Dunleavy (right) accepts donation from Richard Wildenaur, Ph.D., President, NeoStrata Company.

Warmest Regards,
Mike

FOCUS ON... OVERHEATING

This is the first in a series of articles on topics related to ichthyosis, but not specific to skin care and management. The topic for the Fall issue will be Chicken Pox and any questions, suggestions or tips should be forwarded to the National office by August 10th.

The challenge to stay cool or to keep active children cool can be a daunting task during the summer months for people with ichthyosis. The following is a list of some "tried and true" methods to prevent overheating.

- "cool vests" -with either long lasting gel packs or circulated water are commercially available for adults and children over 3 years (contact the national office for a listing of companies).
- Freezer gel packs wrapped in towels and placed in strollers or car seats will keep infants and small children cool, or placed on "pressure" points for adults
- ice water in a "spritz" bottle (some are now available with attached fan) for frequent spraying
- damp clothing can be used outdoors-T-shirts, cloth hats and bandannas worn "cowboy" style or around the head
- a small wading pool filled with cool, clean water or a lawn sprinkler with a fine mist allows children to cool themselves while playing outdoors



Does your bathroom cabinet look like this?



If like most people with ichthyosis, you have tried everything under the sun, this **NEW Focus** column is for you. Tell us what works for you, how you use it, what it's for (scalp, elbows, blisters, odor, whatever) and how it has improved your skin.

This column is also to ask questions to help solve some of those skin care problems you just haven't found a solution for yet.

Please send your questions or skin care solutions (attention: What's New, What's Hot, What Works) to the National office.

The following treatment plan was sent by new FIRST member, Dana Abbott of Campbell, California. Dana is uncertain of her specific form of ichthyosis, but hopes others will find the information helpful.

Add 1/3 to 1/2 of a carton of table salt to your bath water and soak in it for 5-10 minutes. The salt helps your skin retain water. Pat your body dry, but leave it moist and apply lotion. I use a glycerin and water solution instead of lotion. The dermatologist recommended petroleum jelly, but that's very greasy and gets all over my clothes. Salt baths are very relaxing and inexpensive. I've found the combination of salt baths and the glycerin solution keeps my skin moist for much longer periods of time.



*Foundation for Ichthyosis
& Related Skin Types
(F.I.R.S.T.)*

P.O. Box 669
Ardmore, PA 19003

610-789-3995
fax: 789-4366
800-545-3286

**Annual Report
for the Fiscal Year 1996**

A Note on the 1996 Audit

The twelve month period which ended September 30, 1996 produced positive results from operations, primarily as a result of cost savings measures implemented by management in response to losses sustained in the prior year. F.I.R.S.T. was able to raise unrestricted contributions for operations of approximately \$79,500 and restricted contributions for the video production of approximately \$8,800. These revenues were offset by total expenses of approximately \$78,700, resulting in a positive change in net assets of \$9,600.

While operating on a frugal budget during 1996, much of our management services and administrative support for our core programs such as *Ichthyosis Focus* and our Regional Support Network was performed by volunteers. We have subsequently relocated our national office from North Carolina to Pennsylvania and added management and staff to run the operations of F.I.R.S.T. We will continue to need your support as we strive to meet our service goals for you, the members of our Foundation.

Phyllis Sanders, CFO
Board of Directors

The financial information contained in this Annual Report is extracted from the Audited Financial Statements of the Foundation for Ichthyosis & Related Skin Types (F.I.R.S.T.) for the fiscal year 1996, conducted by the Foundation's accounting firm of Cogen Sklar, LLP of Bala Cynwyd, Pennsylvania. Copies of the complete financial statements, with notes and auditor's opinion, are available upon request from the Foundation's national office.

FOUNDATION FOR ICHTHYOSIS & RELATED SKIN TYPES
(F.I.R.S.T.)
STATEMENTS OF FINANCIAL POSITION
September 30, 1996

ASSETS

Cash and cash equivalents	\$ 49 951
Investments - certificates of deposit	30 000
Furniture and office equipment	<u>1 892</u>
TOTAL ASSETS	<u>\$ 81 843</u>

LIABILITIES & NET ASSETS

Liabilities:	
Accounts Payable	<u>\$ 1 061</u>
Net Assets:	
Unrestricted net assets	75 988
Temporarily Restricted	<u>4 794</u>
TOTAL NET ASSETS	<u>\$ 80 782</u>
TOTAL LIABILITIES AND NET ASSETS	<u>81 843</u>

Extracted from audited financial statements of the fiscal year 1996 conducted by the accounting firm of
COGEN SKLAR, LLP, Bala Cynwyd, Pennsylvania

**FOUNDATION FOR ICHTHYOSIS & RELATED SKIN TYPES
(F.I.R.S.T.)**

**STATEMENT OF ACTIVITY AND CHANGES IN NET ASSETS
Year Ended September 30, 1996**

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>TOTAL</u>
Revenues:			
Contributions	\$ 67 944	\$ 8 794	\$ 76 738
Investment Income	3 666	-	3 666
In-kind Contributions	6 000	-	6 000
Other	<u>1 874</u>	<u>-</u>	<u>1 874</u>
	79 484	8 794	88 278
Net assets released from restrictions	<u>4 000</u>	<u>(4 000)</u>	<u>-</u>
Total support and revenue	<u>83 484</u>	<u>4 794</u>	<u>88 278</u>
Expenses:			
Program services	53 689	-	53 689
Management and general	18 317	-	18 317
Fund raising	<u>6 668</u>	<u>-</u>	<u>6 668</u>
Total expense	<u>78 674</u>	<u>-</u>	<u>78 674</u>
Change in net assets	4 810	4 794	9 604
Net assets at beginning of year	<u>71 178</u>	<u>-</u>	<u>71 178</u>
Net assets at end of year	<u>\$ 75 988</u>	<u>\$ 4 794</u>	<u>\$ 80 782</u>

Extracted from audited financial statements of the fiscal year 1996 conducted by the accounting firm of
COGEN SKLAR, LLP, Bala Cynwyd, Pennsylvania

GRASSROOTS

Knapp family bowls for F.I.R.S.T.

Colorado Springs, CO- On February 1, 1997 the Knapp family, Roxanne and Dave and son, Michael, ran a bowl-a-thon which raised over \$1,200 for F.I.R.S.T. More than 50 people came to bowl. Local businesses and individuals donated raffles and door prizes, including a hand-made porcelain baby doll in a white christening gown donated by Teresa Cordova.

Local radio personality, "Chuck MiVille", participated in the bowl-a-thon and interviewed the Knapps on air. They were also interviewed on a KKTV channel 11 news call-in program called Jennings and Jennings.



Christy Sawina and Michael Salazar at the Knapp Bowl-a-thon.

Thank you, Roxanne, Dave, and Michael for your dedication and hard work in raising funds for F.I.R.S.T. and educating those in your community about ichthyosis.

Fourth Annual Karst Garage Sale Raises Almost \$2,700 for F.I.R.S.T.

Shawnee, KS- The annual Karst family garage sale has turned into a much anticipated local event. It ran for three days, May 8-10, with family, friends, and neighbors collecting items for sale throughout the year, and lending a helping hand over the weekend. The children even get into the act by running a "Popstand".

A large portion of the funds used to develop F.I.R.S.T.'s educational video were raised by the Karsts through these sales. The project, which is nearing completion,

would not have been possible without their hard work and dedication. Thank you!



Jessa Karst and her friend, Devin Rudicel having fun at the Karst garage sale

Johnson Family Organizes Volleyball Tournament

Glenmora, LA- Jack, Penny, and Caleb Johnson held a volleyball tournament on May 24, 1997 which raised over \$1100 for F.I.R.S.T. Six teams participated in the event.



The winning team, the Vernon Panthers from Leesville, LA., were awarded F.I.R.S.T. t-shirts. Congratulations!

Thanks to Mr. Paul Poe for the use of the gymnasium at Hicks High School; Mr. Larry Paul for donating five cases of soft drinks; and, of course, to the Johnson family for their hard work and dedication.

Second Annual F.I.R.S.T. Bowl-a-thon in Pennsylvania

Norristown, PA- Harry and Lynne Alba held their second annual bowl-a-thon in May. Their efforts resulted in a donation to the foundation of \$1750.00. A raffle was conducted during the course of the evening and many of the participants went home with prizes donated by local businesses.

Thank you to Lynne, Harry, and their friends for organizing a spectacular event.

Tracie Pretak Raises over \$1500 and Educates the Public about Ichthyosis

Wilcox, PA- Tracie Pretak and her family and friends managed several fundraisers simultaneously during the month of May.

For their "Release the Butterfly" campaign they supplied colorful butterflies to local area businesses which sold them for a \$1.00 donation. They were signed by the donor and displayed by the establishment.

Tracie, her daughter Bailey and friends also presented a benefit concert at their church, consisting of sacred music and hymns. There were many performers including Bailey and Tracie. There was no admission charge and donations were accepted. The concert was recorded, and many attendees are purchasing copies of the tape, with proceeds to benefit F.I.R.S.T.

The Pretaks also conducted a 50/50 raffle on Memorial Day during a local parade. They started selling tickets at noon. They wanted to do the drawing at 5 p.m. but many people were still buying tickets, so they held off until after 6 p.m.

In conjunction with all these events, they distribute literature about ichthyosis and the foundation. Public education is as important to the Pretaks as fundraising. Thanks to close friends at the local newspapers, they were able to get front-page articles about National Ichthyosis Awareness Week. Video footage developed by their friend, Dave Beaver, was shown on their local community T.V. channel.

Tracie is already planning for next year, and would like to thank the many friends and family members who helped, especially her mother, Karen Jones, daughter, Bailey Jones, and her patient husband, Roger Pretak. Thank You Tracie!



DERMAL THERAPY ALPHA HYDROXY LOTION DEVELOPED FOR FIRST MEMBERS

What is different about Dermal Therapy's Alpha Hydroxy Moisturizer?

Dermal Therapy products combine 10% Urea and 10% Lactic Acid (Alpha Hydroxy Acid) to take advantage of Urea's hydrating potential and Lactic Acid's exfoliating ability. Not greasy. Fragrance free.

What if I don't like it ?

Money back, if this is not the best lotion you have ever used.

How much is it?

Your cost is only \$12.99 for 16 oz.. Free shipping if you order 2 bottles or if this is your first order of a bottle.

Where is it sold?

This effective product is not available in stores. Our regular products are sold to drug stores by BAYER.



Call us directly

☎ 800 668-8000

New Odorless Formula

FIRST neither recommends, nor endorses products or services advertised in the Ichthyosis Focus.

Happy 1st
Birthday
to:
Julia Levitan



Julia is the daughter of FIRST's Director of Operations, Elena Levitan and her husband, Ken and is the granddaughter of Mark Levitan, our Executive Director



IN MEMORIAM

F.I.R.S.T. has received generous contributions in memory of the following individuals:

Austin Steven Crabtree

Joseph D'Agostino

Edwin Eber

Elizabeth Arnold Eversull

Robert Foley

Charles Edward "Teddy" Hoffman

Clara E. Sobkowsky

All of us offer our heartfelt sympathy to friends and family.

NEWS AND NOTES

Saturday Evening Post **publishes information** **about ichthyosis**

A letter requesting information about ichthyosis was published in the May/June '97 issue of the *Saturday Evening Post*. The letter appeared in the Medical Mailbox section, and was answered by Dr. Amy Paller, Professor of Pediatrics and Dermatology at Northwestern University Medical School, head of the Division of Dermatology at Children's Memorial Hospital in Chicago, and a member of FIRST's Medical Advisory Board since 1988.

Dr. Paller defined ichthyosis, described common treatments, and listed F.I.R.S.T. and the National Registry as resources. We received quite a few calls and letters, many from adults with ichthyosis who were excited to learn about the Foundation, and our programs and services.

Family Travels from England to Find out More About ***KID Syndrome***

Gez and Helena Muir traveled from Middlesex, England with their four year old daughter, Sarah to consult with a team of physicians at Baylor College of Medicine and Texas Children's Hospital in Houston, Texas. Sarah is diagnosed with KID syndrome (Keratitits, Ichthyosis and Deafness) and the Muir's were in Texas to explore treatment options.



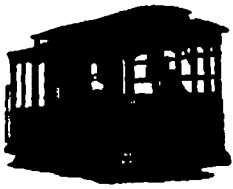
Helena and Sarah Muir.

In addition to the team of physicians, which included Dr. Moise Levy, Chief of Pediatric Dermatology at Texas Children's and FIRST's RSN volunteer physician for Region 6, the Muirs also met with a family from Amarillo, Texas with a young daughter with KID.

Region 6 RSN co-ordinator, Donna Rice, and her daughter, Haley, were pleased to meet with the Muirs before they left the Houston area for a vacation trip to Florida. Ms. Rice described the meeting as

"a wonderful chance to learn more about this rare form of ichthyosis". She described Sarah as a "lively, personable little girl with a wonderful mastery of British Sign Language."

FIRST appreciates the opportunity to meet with the Muirs and looks forward to seeing them at our next National Conference.



F.I.R.S.T Exhibits at Dermatology Conference

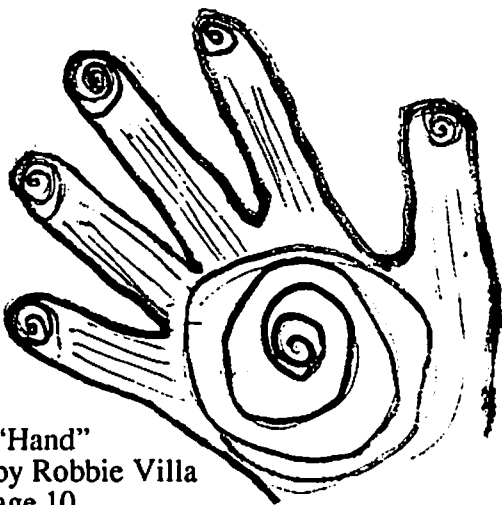
The American Academy of Dermatology (AAD) held their 55th Annual Meeting in San Francisco, March 21st - 26th. The AAD provided F.I.R.S.T. with a tabletop exhibit space which was staffed by several board members, our Regional Support Network Program Director, Executive Director, and Director of Operations. Our goal for this meeting was to generate interest and increased awareness among members of the dermatologic community. We shared literature and information with many physicians, including a large number of doctors from overseas. While in San Francisco, we were able to meet with our Medical Advisory Board and develop valuable contacts with representatives of many pharmaceutical companies.



Doctors Mary Williams (left), Amy Paller and Leonard Milstone at FIRST's annual Medical Advisory Board meeting.



Elise Johnson, Donna Rice, Elena Levitan, Michael Dunleavy and Mark Levitan at the AAD Conference.



*"Hand"
by Robbie Villa
age 10*

Skin-deep

Did I ask for it?
Do I like it?
Can I change it?

If you care enough to find the answers to these questions-
and look beneath my skin-
you will find the unique person that is trapped within.
Me.

*Denise Gass
age 13*

Young artists & writers wanted: F.I.R.S.T. is requesting drawings, poems, and prose from our young members for publication in future issues of *Ichthyosis Focus*. Mail submissions to: Ichthyosis Focus, c/o FIRST, PO Box 669, Ardmore, PA 19003

REGIONAL SUPPORT NETWORK (RSN)

PROGRAM DIRECTOR

Elise Johnson
18117 12th West
Lynnwood, WA 98037
206-771-7264

REGION ONE

NY, PA, VT, NH, NJ,
CT, RI, MA, ME
Shelly Licursi
311 White Birch Drive
Cinnaminson, NJ 08077
609-786-8766

REGION TWO

DE, MD, WV, VA, NC, SC
Robin Joyce
Route 1, Box 189-F
Sandy Ridge, NC 27046
910-871-3277

REGION THREE

TN, GA, FL, AL, MS,
LA, AR
Debra Bowie
3694 Shady Hollow Lane
Memphis, TN 38116
901-346-0513

REGION FOUR

KY, OH, IN, IL, MO, MI
Angela DelGrande
4408 Appleton Place
Kettering, OH 45440
937-643-9752
E-mail: toriedog@aol.com

REGION FIVE

WI, MN, IA, ND, SD, NE
OPEN

REGION SIX

TX, OK, NM, CO, KS
Donna Rice
2902 West Elm Dircle
Katy, TX 77493
281-391-4407
E-mail: dsrice@infohwy.com

REGION SEVEN

WA, OR, ID, MT, WY, AK
Sheri Gelivich
1344 S.E. Rex
Portland, OR 97202
503-236-3203

REGION EIGHT

CA, NV, UT, AZ, HI
Chris Beeler
1002 E. Gifford Drive
Tucson, AZ 85719
602-887-7188

CANADIAN CONTACT

Barbara Rockwell
3080 Ballydown Crescent
Mississauga, Ont L5C 2C8
905-896-9620

HARLEQUIN SUPPORT GROUP COORDINATOR

Patricia Steinitz
314 Richey Ave.
Pittsburgh, PA 15214
412-231-1201

STATE CONTACTS

Kansas

Tiffany Karst
913-268-3692

Kentucky

Cynn timer Bates
606-276-0142

Massachusetts

Susan Overstreet
413-259-1267

Mississippi

Charlene Wiggins
610-769-2454

New York

Cathy Lopez
718-842-7269

South Carolina

Nancy Bryant
803-559-9369

Wisconsin

Theresa Tremmel
414-538-4922

RSN information and resources

We are trying to build a collection of information about all of the various kinds of disorders. If you have some articles, books, or other material that have been beneficial to you and your family, please call your Regional Coordinator or Elise Johnson. We are also looking for people willing to organize this information within each separate diagnosis. We know a lot of you out there are experts out of necessity, *-please share the wealth!*

HELP WANTED-All workers unpaid, overworked, and greatly appreciated.

Regional Coordinators-Due to moves, new jobs and other changes we need new coordinators for several of our regions. No experience required. If you have ever thought you might like to become more involved in helping new parents, new members, and the rest of us, please call Elise Johnson. I will be happy to send you information, answer questions and see if this is a good fit for you at this time. Also call if you want to nominate someone.

We need Regional Coordinators in Regions 2,5,6, and 8.

We also need more State contacts.

FIRST/RSN International Liaison- We need someone willing to coordinate and correspond with various groups and people from around the world. This person must be willing to follow policy guidelines as set up by the Board of Directors and work closely with Elena at the office. Call Elise Johnson or Elena for a more complete job description. This could be an exciting opportunity for some person willing to put in a little time.

Internet-We also need people willing to regularly check bulletin boards and websites for medical information.

We need a person or people willing to do some follow-up calling of people we have sent information to. This would require a few hours each quarter. This person should have a fairly thorough knowledge of FIRST and the RSN.

We also need information about cool suits and cooling systems for children. We have a person looking for other individuals with adult onset PRP. If you have any information about these items call Elise Johnson.

*National
Registry for
Ichthyosis
and Related Disorders*

Hey, have you contacted
the Registry?

The National Registry for Ichthyosis and Related Disorders wants you to enroll. We are supported by the NIH, and are trying to encourage more research into diagnosis and treatment of Ichthyosis.

We will protect your privacy, and there are no requirements for participation in any projects. We would notify you of what projects are ongoing, and how to contact them if you are interested in participating.

Just give us a call at **1-800-595-1265** and ask about how to get enrolled. We will answer any questions you have, and it may provide an opportunity for you to become involved in research to find better methods of dealing with Ichthyosis.

Registry Director:
Philip Fleckman, MD
Registry Coordinator:
Geoff Hamill, RN

University of Washington
Dermatology/Box 356524
Seattle, WA 98195-6524

How I Avoided the Registry

By Elise Johnson

OK, I admit it, before this spring, I had not registered with the Ichthyosis Registry. I had planned on registering but it was something that was very easy to put off. I'll bet some of you can relate to this. Then I attended the Medical Advisory Board Meeting and the Registry Meeting with our dermatologists in San Francisco in March. Yes, I admitted to all these dear doctors working hard in our behalf, that I had not registered yet. I also vowed to do so and am in progress. It isn't as difficult as I thought. As many others have found, it can be very informative and even fun. There are basically two parts: 1) physician form-filled out by a physician. Geoff can refer you to one in your area if you do not have one. 2) phone interview with Geoff. He's the fun part! The Registry sends out a packet of questions. You do not have to fill this out and send it back (fortunately). It is more to help you assemble your thoughts in preparation for the phone interview.

Why Register? Why Now?

The Registry helps us in many ways. Geoff talks to people all the time who are referred to the Registry but have never heard of F.I.R.S.T. Most are very happy to learn of us and join. The Registry provides a solid number of (anonymous) people who definitely have various forms of ichthyosis. The more people on the registry, the more power we have in Washington, D.C. and with the pharmaceutical and research communities. Having a Registry means we are serious about attracting research that will benefit us. If we show lack of interest in important research, the research will go elsewhere. Because you are on the Registry you may find out about new products or treatments that you would not hear about until much later. The Registry makes it necessary to get an accurate diagnosis. Those of us who were first diagnosed long ago may not have gotten an accurate diagnosis. A proper diagnosis can give us proper genetic information for ourselves and our relatives and may ensure a more effective treatment plan. If you are interested, the Registry will tell you about new studies and how to contact the investigator for more information. There is a lot of interest as to how many people there actually are with ichthyosis in its various forms. People are already looking to the Registry to answer this question. Obviously there are many of us who are not showing up in these numbers. We are coming up to the time when the Registry funding will either be renewed or cut off. Many parents, siblings, grandparents and friends ask how they can help their friends and family members who have ichthyosis. Encouraging registration is one great way to help. Let's stand together and let our members show our strength.

If you have any questions about the Registry or the process, please call Geoff, myself, or your regional coordinator or state contacts.

Apparently some people have sent in permission forms to the Registry with no address or phone numbers on them. If you have partially registered and haven't

In the next issue of the Focus we will have an interview with Geoff complete with photographs-
WHO IS THAT MAN ON THE PHONE?

If you have had an experience with the Registry that you would like to share call Elise Johnson at:
425-771-7264 fax# 425-775-4953

Children's Success Story

BY Meade Piercey

It's that time of the year again in northern New York. The temperature is rising, the sun is shining more. I am wearing less clothing. The question on everyones mind is "do you have a sunburn?" Not everyone asks this, some people just stare or make faces. My family and I have gotten very used to it. My name is Meade Piercey. I am ten years old and have lived with ichthyosis all my life.

With my family's help I do very well at not letting my skin condition get me down. I have many friends and many hobbies. For instance, I love to swim, dance, skate, perform, and my favorite is snowmobiling. As for the performance part I love to enter many lip sync contests. I have many first place trophies. This is a lot of fun because my cousins and I meet with a lot of new people and my family really enjoys watching. I have always done this with my cousins, Morgan, Lindsey and Molly. I have my own snowmobile license. I had to take a class for two nights and on the last night I had to take a test. I have my own snowmobile. We get a lot of snow where I live and we can leave right from my back door and drive for miles.

I have a pool at my house. In the summer I go swimming a lot. I am very careful in the summer. I have to wear a white shirt so that I don't get a sunburn.

I also use a lot of sunscreen. My mom is a nurse and says "all kids should be careful in the sun," not just me.

I am in fourth grade and I go to Heuvelton Central School. I have a lot of friends in my class. I get invited to a lot of birthday parties. I have friends come over to my house and we play outside. When I go over to my cousins we do a lot of things outside too. They have a pool that I swim in and they have snowmobiles too. I never let my skin get me down or keep me from having a good time.



My skin requires a little more care than other kids. Every morning of the week I get up at 6:30 and take my shower. When I get out of the shower, I put on my lotion (my dad makes it for me). As I get older my skin gets better. When I was little my mom and dad used to have to put my lotion on me.

I get dressed and go eat breakfast. I go brush my teeth and put in my earrings, then the bus comes and picks me up. Even though I have ichthyosis I still have my ears pierced and I can wear any kind of jewelry.

My mom and dad told me that my skin condition will never go away, but with the continued support from my family and friends, I know that I can be or do whatever I choose. My mom says that there is only one guarantee in life, "that we will die", so make the best of the life you have.

Teen Newsletter

We are looking forward to starting a teen newsletter for teens from 12-18 (if you are a little older or younger-that's okay too). We hope to launch it this fall. We would like lots more input from all you teens out there. What kind of articles, columns or other things would you like to see in your newsletter? We need lots of guest writers, photographers, etc. First of all, we need a name!

Name the Newsletter Contest

Send us the name you think would be the best for the teen newsletter. The person whose name is chosen will receive \$25.00. Two \$10.00 prizes will also be awarded for creativity. Either call or send names to Elise Johnson or the national office. Be sure to include your name, phone number, and address so we can know where to send you the money! You can submit as many names as you like. Our mailing list does not list teens separately, so while we know some of you and where you are, we don't want to miss any of you. Call the office on the toll-free line to give your name and address so you will be sure to get your copy. We love to hear from you!



... out of the darkness, ©
into the light ...

N.O.R.D. REPORT

The National Organization for Rare Disorders, Inc. (N.O.R.D.), dedicated to helping people with rare (orphan) diseases.

NIH APPROPRIATIONS

The President's FY98 budget calls for only a 2.7% increase in NIH's funding. Several Congressional committee Chairmen have already decried this small increase and vowed to raise it between 7% to 9%. This remains to be seen in light of balanced budget efforts because the money will have to be taken from other programs. According to the President's budget, 57% of the money would be spent on extramural research grants, 10% on intramural research projects, 9% on research centers, 6% on research contracts, 3% on research training, 4% on management and support, 5% on other research, and 7% on other activities.

HMO LEGISLATION

Several bills that would control certain aspects of "managed care" health insurance have recently been proposed in Congress. The one that NORD is vigorously supporting is the Dingell/Kennedy "Quality Assurance and Patient Protection Act". Among other things, the law calls for the following:

-Patients would be guaranteed access to specialty care. Those with life-threatening, chronic, degenerative or "other serious conditions" must be provided with "access to the appropriate specialists or centers of excellence capable of providing quality care for the condition". If there is no appropriate specialist in the plan, the patient would have to be referred to a non-participating specialist at no additional cost.

-If an insurer uses a drug formulary (a list of drugs that are allowed to be prescribed), they must allow for "exceptions when medically necessary".

GENETIC TESTS NOT REGULATED

Genetic tests are not regulated by the FDA in the United States. This is why some companies are marketing genetic tests that have a high incidence of false positives and negatives. According to an expert panel, the Task Force on Genetic Testing, which was created by the Human Genome Project's Ethical, Legal and Social Implications (ELSI) project, a proposed "National Genetics Board" should be created to monitor genetic tests.

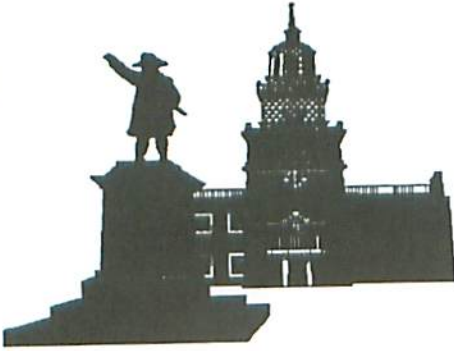
The FDA does not have a regulatory structure to control marketing of genetic tests, and does not seem to want another responsibility added to its mission without adequate appropriations to cover the costs. The Task Force on Genetic Tests published its recommendations in the Federal Register on January 30. The Task Force concluded that there is an intense need to develop genetic tests for rare disorders, but there is little commercial interest in this field. They suggest that a database should be created to list the academic laboratories that conduct genetic tests for rare hereditary diseases.

*Have you been tangled in **RED TAPE?***

Many of us encounter problems with medical insurance, school and work related topics, government programs, and legal issues. A new, regular feature of *Ichthyosis Focus* entitled "Red Tape" will address these areas. If you have an experience you'd like to share, or a specific topic that you would like more information about, please write to:

Ichthyosis Focus
F.I.R.S.T.
P.O. Box 669
Ardmore, PA 19003

CONFERENCE NOTICE



We are pleased to announce that the 1998 FIRST National Conference will be held at the "Hilton at Cherry Hill" in Cherry Hill, New Jersey on June 19-21, 1998. The hotel overlooks the Philadelphia skyline and is located along the scenic Cooper River. It is only ten minutes from Center City Philadelphia and twenty minutes from the Philadelphia International Airport. This location will provide conference attendees with the option of extending their stay to include an historic vacation. Not only is Philadelphia easily accessible, but Atlantic City, the Amish country in Lancaster, and Hershey Park are all within a few hours drive. Mark your calendars and look for your registration form and details in the next issue of FOCUS.

MANY THANKS...

...to Michael Pinnisi and Donna Heilweil for their gift of a (slightly) used computer.
...to Michael and Nancy Dunleavy for donating a color printer and file cabinet.

F.I.R.S.T.
P.O. BOX 669
Ardmore, PA 19003

SJ NJ 080 08 04 1997 #12

Non-Profit Org.
U.S. Postage
PAID
Ardmore, PA
Permit No. 61

|||||

