F.I.R.S.T.
Foundation for Ichthyosis and Related Skin Types

# ICHTHYOSIS FOCUS

Vol. 16, No. 3 A Quarterly Journal for Friends of F.I.R.S.T. Fall 1997

# Special National Conference Edition

## June 19th, 20th & 21st, 1998
## Philadelphia, Pennsylvania

## AN INVITATION FROM THE EXECUTIVE DIRECTOR

I'm pleased to invite all of you to join us in Philadelphia. Over the past year, we've communicated with many of you via phone, mail, fax, and e-mail. I'm looking forward to being able to match faces with these familiar names and voices, and to meeting so many others for the first time.

The conference will take place at the Hilton at Cherry Hill, in Cherry Hill, New Jersey, a newly renovated suburban hotel overlooking the Cooper River, with a view of the Philadelphia skyline. It boasts an olympic-size swimming pool and health club. Cooper River Park, with its miniature golf course and jogging paths, is just across the street. The hotel is 20 minutes from the Philadelphia International Airport and just 10 minutes from downtown Philadelphia.

We are building upon the success of our previous conferences, with two full days of seminars and workshops. Our distinguished volunteer faculty will bring us up-to-date with the latest in genetics, research and treatment for ichthyosis. We will have question and answer sessions, panel discussions and workshops for parents, teens, and adults. Our exhibitors will provide product information and you, our members, will provide them with valuable feedback on the use of their products.

Most meals are included in the conference registration fees. There will be an opening reception on Friday evening with a cash bar and light snacks. Continental-style breakfast will be

see **INVITATION** page 6

## PHILADELPHIA HERE WE COME...

Philadelphia is a truly unique city and one of the nations most historic destinations. It is the birthplace of the Declaration of Independence, the Constitution, the Bill of Rights and our nation's freedom. Independence Hall and the Liberty Bell are the most famous of its many historic attractions.

Philly is also a family-friendly destination, with great neighborhoods and dining spots in a safe, walkable city. Family spots in downtown Philadelphia (Center City) include The Franklin Institute Science Museum, the Please Touch Museum, and the Philadelphia Zoo. The city's Fairmont Park is the largest landscaped urban park in the country. The New Jersey State Aquarium is only five miles from the Cherry Hill Hilton, and accessible to Center City via ferry service.

New Jersey and Delaware beaches, Atlantic City, Longwood Gardens, and two theme parks-Sesame Place and Six Flags Great Adventure- are all within a one hour drive. Gettysburg, Hershey, and the Amish country are within two hours west of the city. Hershey features factory tours, a museum, theme park, gardens and great golf. New York City, Baltimore, and Washington D.C. are all within a few hours of Philadelphia and easily accessible by car or train.

*For additional information and Conference registration forms see pages **6, 7, & 8.***

F.I.R.S.T. wishes to thank NeoStrata Company, Inc., developers of NeoCeuticals™ Problem Dry Skin (PDS) Treatment, for their sponsorship of this issue of *Ichthyosis Focus*.

*ICHTHYOSIS FOCUS*
Vol. 16, No. 3
Fall 1997

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The editor invites correspondence. We welcome your comments, observations and suggestions. Please send your letters to us c/o *Ichthyosis Focus* at the address listed above.

# CORRESPONDENCE CORNER

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

Thank you very much for your spring/summer edition of *Ichthyosis Focus.* We found it very informative as well as interesting. Thank you also for the booklets and pamphlets you sent us. We obtained lots of helpful information and tips from them. We have also spoken to doctors on the Medical Advisory Board who have shared their knowledge and expertise in helping us. Time and time again we have called parents from the support group who have shared their experience with us, but more so they have inspired us and have made things easier to handle.

We live together as part of a close knit Orthodox Jewish community here in Baltimore. Our family and friends have constantly been at our sides the past five months since our son, David was born. Our networking effort is the least we can do to better treat and properly deal with David. We are particularly interested in finding someone within the Jewish community with ichthyosis. Whether they live here in the United States or abroad as far as Israel we would appreciate this contact.

Thank you so much!

David & Yehudis Hexter
Baltimore, Maryland

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

Thank you so much for just being there. I happened to find the organization by accident while on the internet. Like most others with EHK, I was looking to see if any research was being done with regards to treatment. I found that and much, much, more with you!

I know my skin condition is rare, so I thought there would be no chance to meet another with it. I am really looking forward to corresponding with others who have EHK and sharing experiences with them. I'd also like to correspond with parents whose child may have it. This is something I'm sure my mother could have used when I was born.

Thanks again for the Regional Support Network.

Lisa Ralston
Pearl City, Hawaii

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

I am 31 years old and I have lamellar ichthyosis. I was given a flyer about your Foundation by my new dermatologist. I was really excited to find out there was a foundation for people with my skin problem. I have been told all of my life there were others with ichthyosis but I have never met anyone.

My husband and I have been married for five and a half years and we have been blessed with three beautiful little girls. Brittany is four years of age, Courtney is two and a half, and Stevi is nine and a half months.

I have been very lucky in my life. My family has always been very supportive and has never treated me differently because of my skin. They also never let me feel sorry for myself. My mother has been my best supporter. As I have grown up my skin has gotten better and I am now on Tegison and having great results. My skin is clearer then it has ever been and the side affects are minimal.

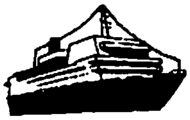
I would be happy to be able to help others by corresponding with them.

Thank you,
Bobbie Green
Florence, AZ

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

Thank you for the information packet you sent so promptly. Already, I have tried two products for bathing from your skin care tips sheet and found them much better than what I have been using.

Eva C. Thomas
Henderson, NV



## Come Aboard the Board

The F.I.R.S.T. Board of Directors is seeking new applicants for board membership. If you have skills in any of the following areas, please consider putting them to work for a great cause:

Development
Fund Raising
Marketing
Finance
Communications
Strategic Planning
Personnel
Education

If you are interested in joining a dynamic team of committed board members, please contact Deb Vilas at (212) 427-5904.

## Educational Video Nearing Completion

The educational video is designed to be used as a tool to introduce the school-age population to ichthyosis and educate them as to how it affects children. It is in the last stage of production and should be available by December of this year.

Appropriately titled "The Butterfly", it is a 6-8 minute video, which has been two years in the making. It is a natural adjunct to two of F.I.R.S.T.'s publications; *Ichthyosis: A Guide for Teachers* and *Release the Butterfly: A Handbook for Parents and Caregivers of Children with Ichthyosis.*

Thanks goes to all of the children and families who participated in the filming, provided artwork and home movies and their heartwarming thoughts of how ichthyosis has affected their lives:

Jasmyn Bowie
Rachel Freed
Katie Getz
Ethan Joyce
Jessa Karst

Keri LaBrandt
Ryan Licursi
Austin Milam
Meade Piercey

Haley Rice
Robbie Villa
Melissa Wiggins
Jasa Williams

and the Family of Teddy Hoffman

## BOARD OF DIRECTORS

# *Focus On...*
# Chicken Pox

*Focus On...* is a regular feature about topics related to ichthyosis but not specific to skin care and management. The answers to the following questions have been written by Dr. Amy Paller. Dr. Paller is Head of the Division of Dermatology at Children's Memorial Hospital in Chicago and Professor of Pediatrics and Dermatology at Northwestern University Medical School. She has been a member of F.I.R.S.T.'s Medical Advisory Board since 1988.

***My 5 month old has lamellar ichthyosis. Is it safe for him to have the chicken pox vaccine before he is a year old?***

Having lamellar ichthyosis in no way affects the safety of administration of the chicken pox vaccine or its effectiveness. In fact, decreasing the risk of high fever and extensive itchy skin lesions of chicken pox through vaccine administration is a good idea. Currently, however, it is recommended that the vaccine be administered at 12-18 months of age, preferrably at the same time as the measles-mumps-rubella (MMR) vaccine. During the first 6-9 months, your son should be protected from developing significant chicken pox because you have likely had chicken pox as a child and have antibodies that have been transferred to him. His own immune system is developed by the recommended time of administration of the vaccine.

***After my 7 year old son, who has CIE, recovered from chicken pox his skin was in terrible shape for several weeks. Why?***

Even children without pre-existing skin problems can have problems with their skin for several weeks after chicken pox. Children with CIE are probably at increased risk for secondary bacterial infection when they have chicken pox. The scratching associated with chicken pox will often increase the redness and scaling associated with CIE. Finally, some children with CIE worsen with stresses, including viral infections, and thus the stress of the chicken pox infection itself may lead to a worsening of the CIE. Not all children with ichthyosis have worsening, however. Dr. Anton-Lamprecht from Germany recently described improvement in congenital ichthyosis after varicella infection.

***My 2 year old daughter's pediatrician gave her Zovirax to keep her from getting chicken pox when her brothers were sick because she was already sick with a bacterial infection. How does this help?***

Early studies showed that high doses of oral Zovirax (acylovir) could decrease the associated fever and number of skin lesions of chicken pox, particularly if administered within the first 24 hours of the infection. Subsequently, it was demonstrated that administration of oral Zovirax for 7 days before the onset of the chicken pox (during the period of contagion) lowered the risk of developing chicken pox. The mechanism of this protection presumably is that the Zovirax limits the multiplication of the virus. It is not known whether the child treated with Zovirax before the clinical onset of chicken pox who does not develop clinical evidence of chicken pox has long term immunity to the disease.

***My baby was exposed to chicken pox at day care. How soon after she comes down with chicken pox do I need to start her on Zovirax?***

If you choose to start Zovirax, the earlier the better. You have the best chance of preventing significant fever and minimizing the number of lesions if started on day one. There is unlikely to be much of a helpful effect if the Zovirax is started as late as the third day, since the fever is often high by this time, and the lesions are actively erupting. Even when started in the first 24 hours of the illness, Zovirax does not decrease the rate of acute complications, itchiness, spread of infection, or the duration of absence from school. On the other hand, no significant adverse effects of Zovirax have been shown in otherwise healthy children.

***What can I give my preschooler to help the itching from chicken pox? Benadryl does not help.***

It is difficult to control the itching of chicken pox, but several oral and topical medications may be useful:

- The skin should be moisturized, particularly after baths. This is often soothing and may help to keep the ichthyotic scaling from getting worse.
- Many find that oilated oatmeal baths reduce the itching (Aveeno bath).
- Try an "anti-itch" cream or lotion. There are several available, such as Aveeno anti-itch cream, Prax, Sarna, and Zonalon (the latter is by prescription). You should avoid anti-itch preparations that contain topical Benadryl or "caines", since these can more commonly sensitize the skin to the development of rashes with later application.
- Oral antihistamines, such as Benadryl, can take the edge off of the itching. If Benadryl is not effective, your dermatologist may be able to recommend another antihistamine by prescription that may be more helpful.

## What's New, What's Hot, What Works!

If, like most people with ichthyosis, you have tried everything under the sun, then this column is for you. Ask about skin care problems you just haven't found solutions for. Tell us what works for you and how you use it.

Mathew Rusch, age 5, has lamellar ichthyosis. His mom Karen Rusch, would like tips on treating skin and wax build up in his ears.

*We currently put a few drops of mineral oil or sometimes Lac-Hydrin Cream 12% in each ear for several days before we see our pediatrician. He then uses a small (5cc) syringe with water rinse to rinse his ears out. This procedure does work. But it is usually several months between visits and it does take quite a bit of work and time to get his ears cleaned out.*

Ruth Brandhorst, of Cedar Falls, Iowa, writes:

*I have ichthyosis. For my face I use soap and clarifying lotion from Clinique, then Aquaphilic Ointment and Vaseline around my mouth and eyes. It really helps keep my face "undry".*

Send your questions and answers to Ichthyosis Focus, PO Box 669, Ardmore, PA 19003, Attention: What's New, What's Hot, What Works!

# F.I.R.S.T.'s 1998 NATIONAL CONFERENCE JUNE 19, 20 & 21 -- PHILADELPHIA

## *An Invitation from the Executive Director*

**INVITATION** from page 1

served Saturday and Sunday mornings. On Saturday, a luncheon banquet will include awards presentations and dinner will be followed by entertainment. There will be plenty of time to renew old acquaintances and meet new friends.

Childcare will again be available for all children over one year of age and we are planning many improvements to our childcare program. We will have much more space this year and we're developing separate activities and programs for different age groups. We are also recruiting outside volunteers so parents who have staffed the childcare room in the past can participate more fully in the conference program. We have budgeted more resources for snacks, beverages and supplies. Unfortunately, we will not be able to accommodate young infants, and request that parents of children under one year of age make plans to keep their child with them.

I am eagerly anticipating our biggest, most successful conference ever. I expect that we will all learn a great deal, not just from our professional faculty, but from one another, too. At the same time, it is also an opportunity to enjoy ourselves and one another.

I hope to meet you in Philadelphia.

Mark S. Levitan

Mark S. Levitan

## AIRLINE RESERVATIONS

US Airways has the most flights into and out of Philadelphia International Airport. As the official carrier for F.I.R.S.T.'s National Conference they are offering the following discounted fares on roundtrip travel from June 14, 1998 to June 26, 1998:

- **5%** off the lowest applicable published fares
- **10%** off the same fares with **60 days advance reservations**

To obtain these discounts, you must call US Airways' Meeting and Convention Reservation Office at (800) 334-8644 and refer to Gold File Number 34630417. There are also discounts on First Class and Business Class fares. Certain rules and restrictions apply. Call US Airways for details.

**RESERVE EARLY, AT LEAST 60 DAYS PRIOR TO DEPARTURE DATE, TO RECEIVE THE MAXIMUM DISCOUNT.**

## PRELIMINARY CONFERENCE SCHEDULE

**June 19, 20 & 21 (Fri, Sat & Sun)**

| | | |
|---|---|---|
| **Fri** | Registration | 5:00 pm - 6:30 pm |
| 6/19 | Reception<br>(Light snacks and cash bar) | 7:00 pm - 10:00 pm |
| **Sat** | Breakfast | 8:30 am - 9:15 am |
| 6/20 | General Session #1 | 9:30 am - 10:15 am |
| | Breakout Session #1 | 10:30 am - 11:45 am |
| | Luncheon & Banquet | 12:00 pm - 2:00 pm |
| | General Session #2 | 2:15 pm - 3:00 pm |
| | Breakout Session #2 | 3:15 pm - 4:45 pm |
| | Dinner & Social | 6:00 pm - 9:00 pm |
| **Sun** | Breakfast | 8:30 am - 9:15 am |
| 6/21 | General Session #3 | 9:30 am - 10:15 am |
| | Breakout #3 | 10:30 am - 11:45 am |
| | Lunch- on your own | 12:00 pm - 2:00 pm |
| | Panel Discussion / Close | 2:15 pm - 3:30 pm |

Registration on Friday should only take a few minutes to check in and pick up your conference materials. If you have a late flight in on Friday, you can pick up your conference material any time that evening or the next morning.

## HOTEL ACCOMODATIONS

**Hilton at Cherry Hill**
2349 West Marlton Pike
Cherry Hill, NJ 08002

For hotel information and reservations, call toll free at 1-800-HILTONS or the reservation desk in Cherry Hill at 609-665-6666 . Identify yourself as a F.I.R.S.T. member to receive our special conference hotel rate of:

- $80.00/night, single or double occupancy
- $10.00/night, each additional person

New Jersey state sales tax of 6% not included.

This rate is guaranteed from June 16th to 22nd. For extended stays, the rate is available on a *space available basis* so be sure to book your rooms well in advance.

There is an early check-out fee of $50.00, which may be avoided by notifying the hotel of any change in your reserved check-out date on or before check-in.

***The F.I.R.S.T. National Conference rate of $80.00 is only guaranteed for rooms booked a minimum of one month in advance of the conference date - by May 18th, 1998.***

If you have questions, or if you experience difficulties booking your room, please call F.I.R.S.T.'s National Office in Ardmore, PA at 1-800-545-3286.

# F.I.R.S.T.

## 1998 NATIONAL CONFERENCE

**June 19, 20, 21**

**Philadelphia, PA**

*Please Print*

**Name:** ____________________

**Address:** ____________________

**City:** ____________________ **State:** ________ **Zip:** ________

**Phone:** Day__________ Evening __________ **Country:** __________

| NAMES OF THOSE ATTENDING | adult | child | Birthdate of Each Child | Check here for those affected with ichthyosis |
|---|---|---|---|---|
| ____________ | ☐ | ☐ | ________ | ☐ |
| ____________ | ☐ | ☐ | ________ | ☐ |
| ____________ | ☐ | ☐ | ________ | ☐ |
| ____________ | ☐ | ☐ | ________ | ☐ |
| ____________ | ☐ | ☐ | ________ | ☐ |
| ____________ | ☐ | ☐ | ________ | ☐ |

Type of ichthyosis, if known: ____________________

**Number of Adults:** ________ x $95 = ________
**(18 & older)**

**Number of Children:** ________ x $50 = ________
**(1 through 17)***

TOTAL = ________

**Please Return Registration Fees With Your Completed Form**

**Make Check Payable to F.I.R.S.T. In U.S. Dollars, Please**

**Cancellations Will Be Honored With Full Refunds Until The Advance Registration Deadline:**

**MAY 18, 1998**

**There is no registration fee for children under one year of age*

Cut here and detach

here and detach

☐ I will need child care for ________ children (over one year of age).

| NAME | BIRTHDATE |
|---|---|
| | |
| | |
| | |
| | |

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☐ I am an adult willing to help at the conference for an hour or two (child care, reception table, etc).

| NAME |
|---|
| |
| |

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☐ I am a teen or young adult and I'd like to participate in a discussion group with others my age.

| NAME | AGE |
|---|---|
| | |
| | |

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PLEASE MARK THE APPROPRIATE BOXES

☐ This is the first National Conference I have ever attended

☐ I have attended National Conferences in the past (City/year): ________________

________________

________________

☐ I will be staying at the Hilton at Cherry Hill in New Jersey

☐ We are combining the National Conference with a family vacation

For hotel information & reservations, call 1-800-HILTONS or the reservation desk in Cherry Hill at 609-665-6666. Identify yourself as a F.I.R.S.T. member to receive our special conference hotel rate of:

$80.00/night, single or double occupancy

$10.00/night, each additional person.

***Your reservation must be made by May 18th, 1998***

Questions about the conference or hotel reservations? Call F.I.R.S.T. at 800-545-3286

**Please Complete and Return This Form to F.I.R.S.T. With Your Payment In Full**
***In U.S. Funds Please.***

**Mail to: F.I.R.S.T. / P.O. Box 669 / Ardmore, PA 19003**

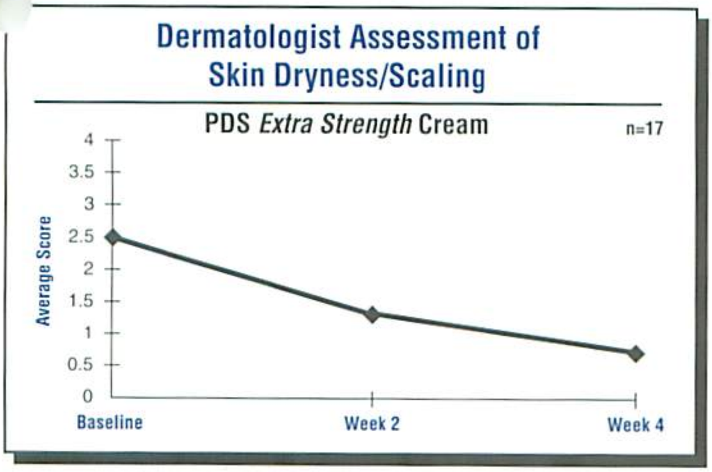
# NeoCeuticals™
# Problem Dry Skin Treatments

### NeoCeuticals™ Problem Dry Skin Treatments

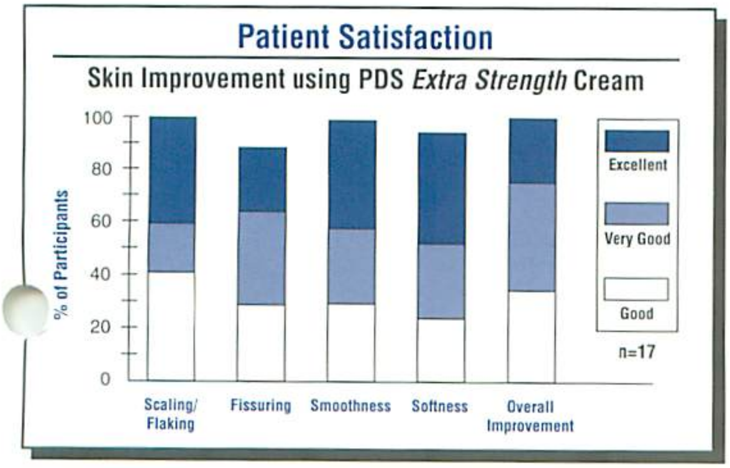
The alpha and poly hydroxyacids (AHAs & PHAs), a class of nontoxic, organic acids found naturally in the human body and fruits, have been clinically proven to alleviate the symptoms of **P**roblem **D**ry **S**kin (PDS). In a dermatologist-conducted clinical study of NeoCeuticals PDS creams, twenty individuals with problem dry skin conditions evaluated the safety and effectiveness of these new formulations. Products were applied twice daily to moist skin and included NeoCeuticals™ **P**roblem **D**ry **S**kin Cream: *Regular Strength* (3 participants, age 7-9) and *Extra Strength* (17 participants, age 26-66). A dermatologist assessed the participants' skin condition including dryness and irritation, initially (baseline) and after 2 and 4 weeks of product use. Study participants also assessed product effectiveness, and skin samples were collected using tape discs (D-Squames® ) initially and after four weeks of use to determine the extent of scaling and flaking.

### Results

- There was a significant reduction in dryness/scaling (weeks 2, 4) and redness (week 2) after treatment (see graph).
- According to dermatologist grading, nearly 90% of the subjects exhibited 'good' to 'excellent' improvements in scaling/flaking, fissures, smoothness, softness, and overall skin improvement by Week 4. Similar results were also noted by study participants (see Patient Satisfaction graph).
- 75% of *Extra Strength* users indicated that others noted an improvement in their skin.
- Skin samples collected using D-Squame discs revealed significantly less scaling after treatment.
- No participants discontinued the study due to adverse reactions. Some local irritation was observed including redness, burning, stinging, itching and rash, which resolved.


**Dermatologist Assessment of Skin Dryness/Scaling**

PDS *Extra Strength* Cream


**Patient Satisfaction**

Skin Improvement using PDS *Extra Strength* Cream

### NeoCeuticals™ Problem Dry Skin Treatment – *Regular Strength* Cream

This cream is best suited for first time AHA users, and for less affected or sensitive areas of the body. Adults who use the *Extra Strength* Cream may prefer the *Regular Strength* Cream for sensitive, tender areas such as the face, underarms, waistline, groin area, and behind the knees. The two strengths can be used at the same time on different parts of the body.

| | |
|---|---|
| *7 oz. jar* | *$40.00* |

### NeoCeuticals™ Problem Dry Skin Treatment – *Extra Strength* Cream

The *Extra Strength* cream is recommended for more severe conditions and those who do not respond adequately to *Regular Strength* Cream. The *Regular Strength* Cream should be used on sensitive or less affected areas of the body concurrently with use of *Extra Strength* Cream on the more severely affected and non-sensitive areas.

| | |
|---|---|
| *7 oz. jar* | *$40.00* |

### NeoCeuticals™ Problem Dry Skin Treatment – Scalp Solution

This product is specially formulated to treat the dry, flaking scalp conditions frequently associated with PDS. Contains the NeoHydroxy™ Complex to aid in the removal of dry scales, while moisturizing the scalp.

| | |
|---|---|
| *2.2 oz. bottle* | *$20.00* |

### NeoCeuticals™ Problem Dry Skin Treatment – Anti-Itch Ear Solution

This anti-itch solution contains 1% hydrocortisone and is recommended for the relief of itching associated with minor skin irritations, inflammation and/or rashes in the outer ear canal due to eczema relating to PDS. Contains alpha hydroxyacid to enhance removal of dry flakes and moisturize the skin.

| | |
|---|---|
| *0.34 oz. bottle* | *$16.00* |

Special Offer for Physicians and F.I.R.S.T. Members Only!

**50% OFF***

**suggested retail plus shipping & handling**

on orders placed directly through
NeoStrata Customer Service
1-888-437-9598

VISA MasterCard AMERICAN EXPRESS

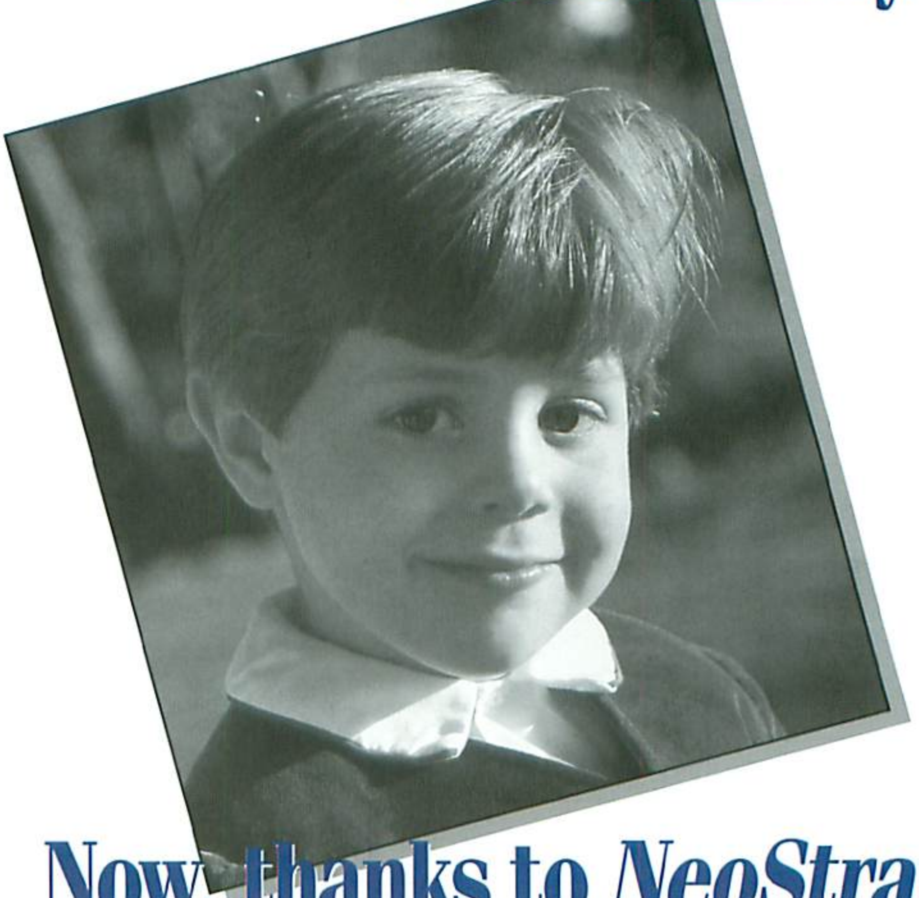
* Limited time offer

Developed by NeoStrata
4 Research Way
Princeton, NJ 08540

# When Timothy* grows up, his parents want him to be ordinary. Just ordinary.

Problem **D**ry **S**kin (PDS) Symptoms of Lamellar Ichthyosis
**BEFORE**

**AFTER FOUR WEEKS**



# Now, thanks to *NeoStrata*, he can be so much more.

Whether a child, or an adult you can choose from the new NeoCeuticals™ **P**roblem **D**ry **S**kin Treatment Products that are right for you. They are brought to you by NeoStrata, the company founded by Drs. Van Scott and Yu, long recognized leaders and patent holders in AHA and Poly Hydroxyacid technology. These new products formulated to aid in controlling the severe dryness and scaling symptoms associated with xerosis, ichthyosis and hyperkeratosis, are a culmination of nearly 30 years of dedicated research by Drs. Van Scott and Yu.

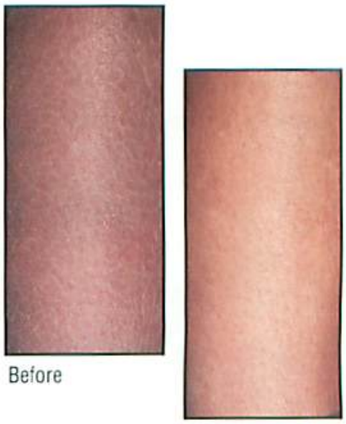
NeoCeuticals™ **P**roblem **D**ry **S**kin Treatment Products contain an optimum blend of Alpha and Poly Hydroxyacids in our exclusive NeoHydroxy™ Complex, combined with other skin conditioning agents. These non-prescription products include the *Extra Strength* and *Regular Strength* Creams, Scalp Solution and Anti-Itch Ear Solution.

A revolution in the treatment of **P**roblem **D**ry **S**kin, and a new quality of life for one afflicted. Discover THE breakthrough in treatments for **P**roblem **D**ry **S**kin from NeoStrata.

Before

After Four Weeks
(outer, lower leg)

**PDS Symptoms of Lamellar Ichthyosis**



Before

After Four Weeks
(outer, lower leg)

**PDS Symptoms of Ichthyosis Vulgaris**

Developed by NeoStrata

* Ficticious name. Consult a physician before using on children.

# NeoStrata Unveils New Treatment Line

*Dr. Eugene Van Scott is a founder of NeoStrata Company, Inc., and has been a member of F.I.R.S.T.'s Medical Advisory Board for many years.*

A unique new treatment regimen designed for people with severely dry skin, as occurs with ichthyosis, is being launched by NeoStrata Company Inc., pioneering dermatologist and NeoStrata cofounder, Dr. Eugene Van Scott, announced in August. He spoke to *Ichthyosis Focus* in a telephone interview from the company's New Jersey headquarters, where research into ichthyosis medications extends back more than 25 years.

Called NeoCeuticals™ Problem Dry Skin (PDS) Treatment products, the non-prescription agents take alpha hydroxyacids (AHAs) one step further, into multiple hydroxy groups. That means the products contain natural fruit acids not only from the alpha hydroxyacid group but also from the beta and other chemical families, as well as vitamins A and E. NeoStrata calls this proprietary mixture of AHAs NeoHydroxy™ Complex.

"The formula was created as the result of five years of intensive research," said Dr. Van Scott, whose aim was to find combinations of agents that would effectively loosen scales (a desquamation function) and hydrate problem skin, and normalize surface skin cell formation.

"I've treated just about every type of ichthyosis, with ichthyosis vulgaris and lamellar ichthyosis being the bulk of my experience. In those categories, particularly lamellar, the existing moisturizing products do not give a sufficiently satisfying answer to the problem," he said.

Dr. Van Scott said his experience in cancer research taught him the value of combining active ingredients for a greater cumulative overall effect: a concept known as synergy. "That was the thinking behind combining a wide spectrum of skin care ingredients in PDS products," he said.

PDS regular and extra strength cream, scalp solution, and anti-itch ear solution can be obtained by consumers through a toll-free telephone number (1-888-437-9598), although Dr. Van Scott strongly urged people to work with their physicians in beginning their treatment. "We don't want to deny a good product to anyone, but I feel there needs to be good medical supervision to get the best results," he said.

"Children and adult users who have not been using AHA creams should begin with the regular strength cream, which is also recommended for sensitive areas such as the waist and under the arms," said Barbara Green, R.Ph., M.S., Director, Consumer Education for NeoStrata. The extra strength cream is intended for adults with more serious conditions who have already been using AHA products. Both creams come in 7 oz. jars and are to be used twice a day after a shower, when the skin is still moistened. As with other alpha hydroxyacid products, PDS may cause redness or slight irritation at first.

Barbara Green oversees product testing for the company and coordinated a study of the product (both creams and scalp solution) on 20 patients, 15 with vulgaris and the remaining patients representing other types of ichthyosis.

The scalp solution is a clear liquid that comes in a 2 oz. bottle and is used as needed. It is rubbed into the scalp at bedtime and shampooed out in the morning. There is no need to wear a shower cap or occlusive covering on the head.

see **NEW TREATMENT** page 10

This issue of *Ichthyosis Focus* has been sponsored by NeoStrata Company, Inc. F.I.R.S.T. neither recommends nor endorses products or services featured in *Ichthyosis Focus*. As always, we welcome your feedback on the use of skin care products and treatments.

## NeoStrata Unveils New Treatment Line

NEW TREATMENT from page 9

Dr. Van Scott and Dr. Ruey Yu, who have worked together on many skin problems for many years, are credited by the scientific community for basic and clinical research that led to the first significant therapy for ichthyosis. By experimenting with hundreds of substances, they found that AHAs produced a response in various skin conditions with faulty keratinization processes. They founded the Neostrata Company which developed its own line of cosmetic and therapeutic AHAs, but their research did not end there. "I've been committed to a group of patients with ichthyosis who have a terrible problem," said Dr. Van Scott. "I have personal commitment to find the very best things possible for them that are also the safest."

## RESEARCH STUDY

**Investigators in the Genetic Studies Section of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, NIH, in Bethesda, Maryland are interested in locating large, extended families in which three or more individuals have been diagnosed with Ichthyosis Vulgaris. Eligible families will be invited to participate in an ongoing research study of hereditary skin diseases conducted by this group of geneticists and dermatologists. For further information, and to determine eligibility, please contact Dr. Sherri Bale at 301-402-2679 (COLLECT) or Mary Anderson, RN at 301-496-5499 (COLLECT).**

**RESEARCH STUDY**

. . . 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.*

### House Passes IDEA Reauthorization

During May the House of Representatives passed the reauthorization for the Individuals with Disabilities Education Act (IDEA). The law was initially entitled the Education for All Handicapped Children Act when it was conceived and enacted 20 years ago to guarantee every child with a disability a free appropriate education in the least restrictive environment. This year's changes to the law allow for more leeway for school officials to discipline children with disabilities who are protected under the Act. The Reauthorization legislation now goes to the Senate.

### Medical Privacy

Several pieces of legislation have been introduced in this Congress to protect an individual's right to genetic privacy. N.O.R.D. has been advocating for broader legislation to protect the privacy of all medical information about individuals. The Health Insurance Portability and Accountability Act, which was passed last year and goes into effect this year, emphasizes the risks to medical privacy because part of the law requires computerization of medical records without adequate safeguards against unauthorized usage of the information.

Senator Patrick Leahy is designing legislation which recognizes the right of medical privacy including (but not limited to) genetic information, the right of an individual to have access to his or her own medical records, and strong mechanisms to prevent unauthorized use or disclosure of individually identifiable medical information.

For more information regarding medical privacy issues, contact: Ms. Maggie Whitney, c/o Senator Patrick J. Leahy, Room 433 Russell Senate Office Bldg., Washington, DC 20510; phone (202) 224-4242.

### Children's Health Insurance

The Hatch/Kennedy children's health insurance bill failed to be added to budget legislation during May. The expense for the insurance premiums would have come from a tobacco tax, but the proposal was seen as a threat to the compromise budget agreement and it failed to pass the Senate.

## Media Update

Last winter, we shared a story about Dalton, an Ecuadorian boy whose story was reported locally, then aired internationally on CNN World Report. Dalton, his two brothers, and three other children in his remote village all have ichthyosis.

*Dalton, (center front) and sister with his parents (back) and a cameraman.*

*Jorge, 9 years old, and sister Yesevea, 11 years old.*

F.I.R.S.T. sent literature and some donated skin care products to the reporter, Ms. Maria Soledad Bejarano. Ms. Bejarano delivered this parcel to Dalton's village and provided us with these pictures. She has also identified a small town where there are four other affected children. We would again like to thank Ms. Bejarano and we'll continue to follow Dalton's progress.

## Membership Renewal Information

Any individual or family who has contributed at least $25.00/individual or $35.00/family in the preceding year is considered to be an active member of F.I.R.S.T. All active members will receive one annual renewal notice. This notice will be mailed in either March or September, depending on the initial contribution date. Our members will also receive two additional appeals, one in the Spring edition of *Ichthyosis Focus* and the other during the holiday season. These appeals are sent to our entire mailing list, which includes members of the medical community and our corporate supporters. We feel that by sending several appeals throughout the year, we make it easier for members who may wish to make several smaller contributions or who wish to do all of their giving in a particular season. Your feedback is very important to us. Please let us know if we're on the right track.

Your membership renewals and other contributions provide a large part (over one-half) of our annual operating budget. They don't come close, however, to covering all of the expenses associated with maintaining our office and 800 number, running our Regional Support Network, publishing our brochures, educational pamphlets and newsletter, and supporting our other programs and services. We actively seek and receive additional support from pharmaceutical companies and other corporations and foundations, and from grassroots fundraising events.

We are making changes to our membership database, which will result in better management of our mailings. In the meantime, it is possible that a small number of members have missed, or received duplicate mailings. We apologize for any errors. If you have any questions about your membership to F.I.R.S.T. please call the National Office at 1-800-545-3286.

*If you are not currently a member of F.I.R.S.T. and would like to become one, or if you would like to re-activate a lapsed membership, please fill out the form below and send it to F.I.R.S.T., PO Box 669, Ardmore, PA 19003*

✂ Cut here and detach ✂

**Name:** ______________________________

**Address:** ______________________________

**City/State/Zip:** ______________________________

**Phone:** Day ______________ Evening ______________

☐ New Member

☐ Previous Member

☐ I have ichthyosis

☐ My child(ren) have ichthyosis (#___ )

☐ A relative/friend has ichthyosis

☐ Type of ichthyosis

______________________

☐ I am a physician or other health-care professional

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|---|---|
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| ☐ Benefactor | $500 / year |
| ☐ Grand Benefactor | $1000 / year |
| ☐ Other ________ | |

F.I.R.S.T. is a 501(c)(3) charitable organization supported by public donations. All donations are tax deductible to the full extent allowed by law. Contributions of $100 or more are acknowledged in our newsletter, *Ichthyosis Focus*.

# HEALTH ALERT!!

## Skin-Cap tests reveal presence of superpotent topical steroid.

Skin-Cap is an over the counter treatment for psoriasis, dandruff, seborrheic dermatitis and other skin disorders, including ichthyosis. The American Academy of Dermatology joins the FDA and the National Psoriasis Foundation (NPF) in cautioning the public about using this product. It can be potentially harmful because it contains **prescription-strength** corticosteroids (clobetasol propionate), but had been marketed without disclosing this ingredient on the product label.

Numerous potentially harmful side-effects of clobetasol propionate include stretch marks, thinning skin and dilation of tiny blood vessels.

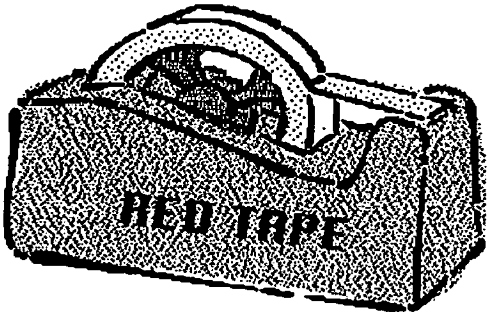
The FDA alert cautions, however, that users should not abruptly stop treatment with this product because of the risk of disease rebound.

Skin-Cap is manufactured by Cheminova International in Madrid, Spain and has been marketed in the U.S. as a non-prescription shampoo, spray, or cream.

The FDA has previously expressed concern about the marketing of these unapproved products in two warning letters sent to two U.S. distributors of these products. Further investigation recently confirmed that these products also contained steroids not identified on the product label.

"The potential health hazards are significant and should not be tolerated," said Roger Ceilley, MD, President of the American Academy of Dermatology. "We're fortunate in this country that organizations like the FDA and the NPF are watching."

Anyone using this product should consult his or her dermatologist to discuss other treatment options.



## Direct Dermatology Access Guaranteed in Florida

*An occasional series about insurance, employment, education, and legal issues.*
*Suggestions welcome.*

Schaumburg, IL (May 30,1997) -- Legislation allowing patients the freedom to seek care directly from their dermatologist without the necessity of a referral from their gatekeeper physician has become law in Florida. The passage of this legislation, effective immediately, is a monumental step toward protecting patient rights within a managed care setting.

The direct access bill passed both the House and the Senate with overwhelming bipartisan support despite opposition from the managed care industry.

Florida becomes the second state to pass a bill in favor of protecting patients rights to directly access quality dermatologic care. Georgia passed a direct access to dermatology bill in April of 1995.

Legislative efforts to allow direct access to dermatology are also underway in Illinois, Indiana, Mississippi, Missouri, Montana, and South Carolina. The Illinois House of Representatives, with a vote of 93 to 17, passed a direct access to dermatology bill, thereby also acknowledging the importance of protecting patient rights.

American Academy of Dermatology (AAD) President, Roger Ceilley, MD, said, "Studies have shown that dermatologists are more cost effective and provide higher quality of care to patients with skin diseases than non-dermatologists. Improper diagnosis of skin diseases results in additional costs from unnecessary diagnostic tests, office visits, possible complications from unnecessary treatments, and prolonged patient suffering. And, patients experience loss of income and productivity from missed work. In fact, skin disease is second only to trauma as a cause of occupational disability."

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# Region 6 Conference

*I'm going to Kansas City...*
*Kansas City here I come.*

Okay, Olathe, Kansas is actually a suburb of Kansas City. Nevertheless, on Saturday, May 31st, 25 people representing three states in Region 6- Texas, Oklahoma, and Kansas- gathered in Olathe for a mini-conference in the hospitality room of Crawford Sales Company.

The day's agenda included time for getting to know one another through family introductions, a barbecue dinner served at a local park and filming of the children for the educational video being produced.

*Tiffany Karst with Austin Milam.*

The kids got creative at the art table while the adults enjoyed the two featured speakers. Lenna Levitch, MS, genetic counselor, spoke on the genetics of inheritance of different types of ichthyosis, and Dr. Marty Barnard, Ph.D., spoke on coping with the grief associated with a chronic condition.

Those attending ranged in age from 6 months to over 60 years old, and everyone had an opportunity to make a new friend and get experience with others who are dealing day-to-day with ichthyosis.

*Richard and Betty Rossman (left) and Tiffany and Brian Karst.*

*Rosalie Castle (left), Velda Unruh, and Jodie Milam with Jasa Williams (front).*

A special thank you goes out to Mr. and Mrs. Richard Rossman for use of their wonderful hospitality room and to those families who made the effort to join us- some driving many hours to make the trip. It was those who attended that made the day a success.

"A lion"
by Matthew Rusch
Age 5

# REGIONAL SUPPORT NETWORK (RSN)

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OPEN

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***New York***
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***South Carolina***
Nancy Bryant
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***Wisconsin***
Theresa Tremmel
414-538-4922

# Who's that man on the phone?

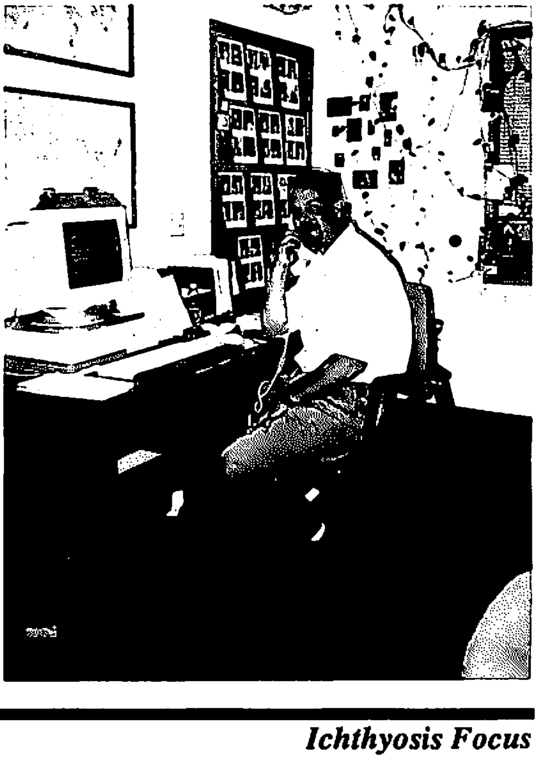
## AN INTERVIEW WITH GEOFF HAMILL, REGISTRY COORDINATOR FOR THE NATIONAL REGISTRY FOR ICHTHYOSIS AND RELATED DISORDERS

### by Elise Johnson, Program Director for F.I.R.S.T.'s Regional Support Network

On a sunny September day in Seattle, I drove over to the Registry to meet with Geoff. I have always enjoyed talking with him on the phone, but he is even more fun in person. He has pictures on his wall sent by people he has registered. I recognized some of those beautiful smiling faces from past conferences. Geoff was a little difficult to interview because he is such a good listener. I kept finding myself doing most of the talking. Here are some condensed excerpts from our conversation.

Q: "How long have you been in nursing?"
Geoff: "I graduated in 1985 from the University of Albuquerque. I practiced for six months as a neonatal nurse in Albuquerque. I then moved back to Seattle, my hometown, and started working at the University of Washington on a combined floor with high risk antepartal nursing, opthamology and research. I worked there as a staff nurse for four years (and still do on occasion). I then took a short hiatus to explore being a nurse in Alaska, and ended up just taking a break from nursing for a few months. On my return to the University of Washington I coordinated clinical trials with a research physician working to stimulate the immune system of people with low white blood cell counts. It was a great opportunity, and I learned a lot. I then ran a clinical drug trial for the Gastroenterology department for about a year and a half. At the end of that study, I met Dr. Phil Fleckman who had just gotten approval for the Registry grant.

I feel the primary role of nurses is patient advocacy. It's very important for people to find a physician they can communicate well with. People



need to share with the doctor all the information they have and to communicate their feelings about treatment plans. Good communication with the caregiver is essential because if you don't feel comfortable with your health professional, you will not be effective in providing needed information or in sharing the concerns that are important to you."

Q: "So how many people have you registered so far?"
Geoff: "We have about 250 people who have begun the registration process. About 150 of these are complete. The rest still need to finish enrolling."

Q: "What is your favorite part of this job?"
Geoff: "I love being able to talk to people and make them aware that there are resources out there to help them."

Q: "Is there anything you don't like about this job?
Geoff: "I do miss the hands-on personal contact with clients."

Q: "What do you like to do in your free time?"
Geoff: "Right now, I am remodeling a house. I also like to read a lot just for fun. I am a voracious fiction reader and like all types of books as long as they are well written. I read 2-3 books a week. I also like to play basketball, go fishing, and play golf or volleyball with friends. I also like to spend time with my family in Lynnewood, WA."

(It's a small world. Geoff's family lives just a few miles from me and his brother and my brother met in Alaska and are old friends.)

So when you call Geoff to get your Registry materials or to complete your registration, you might also ask him to steer you towards a good book. Geoff had a great time at the last national conference and is looking forward to the one next summer in Philadelphia.

## Who Should Register?

All persons in the United States with various types of ichthyosis and related skin types except those with ichthyosis vulgaris. If you have a question about inclusion, call Geoff.

## Why Register?

- This will give us a confidential way to be contacted about research and studies focused on our specific disorders.
- The registry will give us a better picture on related health issues and their incidence.
- Larger numbers of registered people give us political and economic clout with government and pharmaceutical companies.
- An active registry shows that we are committed to research on our disorders.
- In the process you may end up with a more accurate diagnosis, better treatment options and a chance to voice your concerns.
- You get to talk to "the man on the phone".

## How to Enroll in the Registry

- Call Geoff at 1-800-595-1265,
- Send him your signed consent form,
- Have your physician fill out his or her form and send it in,
- Schedule an appointment with Geoff for a phone interview.

Your registration can bring about a better future for yourself, others with your disorder and all those who will be born with your disorder in the future. Research is moving along, but without our cooperation, the research time and money could go elsewhere.

## *National REGISTRY for ICHTHYOSIS and Related Disorders*

Registry Director: **Philip Fleckman, M.D.**
Registry Coordinator: **Geoff Hamill, R.N.**

University of Washington
Dermatology/Box 356524
Seattle, WA 98195-6524
E-mail: ichreg@u.washington.edu
URL: http://weber.u.washington.edu/~geoff/ichthyosis.registry/

**1-800-595-1265**

The National Institutes of Health (through its National Institute of Arthritis, Musculoskeletal and Skin Disease—or NIAMS) is sponsoring a National Registry for Ichthyosis & Related Disorders. The goal of the Registry is to develop a clinical database of individuals affected with the ichthyoses and other rare skin disorders (that is, a roster that compiles information about people with these disorders).

The Registry's purpose is to create a list of affected individuals for the purpose of stimulating research about these disorders. This should have a profound impact on research in the ichthyoses and related disorders, since the greatest obstacle facing researchers doing studies on rare diseases is locating affected individuals willing to help them out.

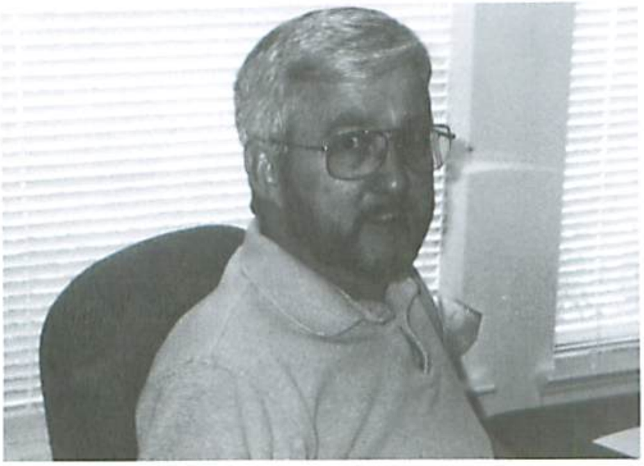
The Registry should solve this problem by creating a central resource containing diagnostic information about the individuals who have enrolled. Researchers can then easily locate affected individuals, as well as obtain information about the frequency and involvement of their disorders. In addition, even if you choose never to participate directly in research studies, the information you provide the Registry should prove valuable in better understanding these disorders.

The Registry will NOT give identifying information out to researchers. Instead, those enrolled in the Registry will be contacted ***by the Registry*** and informed of any appropriate research projects. At that time, you can decide for yourself if you wish to contact the researcher involved.

Please contact the Registry Coordinator, Geoff Hamill, to ask more questions and to obtain enrollment forms.

# F.I.R.S.T. COMES TO THE WORLD WIDE WEB

The Foundation's mission to "provide education, information and support to individuals and families affected by ichthyosis" has yet to reach the majority of the affected population. Our recently published web site will extend that reach through internet access.



*Bob Clifton, web site designer.*

The web site was designed by volunteer Bob Clifton of Houston, Texas. Its current scope is to provide basic information about ichthyosis and F.I.R.S.T. It will ultimately evolve into a site to be visited and revisited by F.I.R.S.T. members for up-to-date and newly published information, as well as announcements of upcoming events.

F.I.R.S.T. wishes to thank Mr. Clifton for the generous donation of his time and talents toward this project. Thanks also to Dr. Mary Williams of our Medical Advisory Board for providing the bibliography as a basis for the reference articles.

## Visit F.I.R.S.T. at http://www.libertynet.org/~ichthyos/

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