



# ICHTHYOSIS FOCUS

Vol. 9, No. 3

Conference Edition 1990

Published by The Foundation for Ichthyosis and Related Skin Types, Inc., (F.I.R.S.T.), PO Box 20921, Raleigh, North Carolina 27619-0921 (formerly The National Ichthyosis Foundation). Telephone 919-782-5728. F.I.R.S.T. is a non-profit corporation for the benefit and education of its members and the public regarding medical, psychological and social aspects of the ichthyoses, a family of primarily genetic skin disorders marked by excessive scaling. Letters, suggestions and contributions are welcome.

## Summer Conference is huge success

The 1990 Summer Conference and Family Reunion took place June 16th in Orlando, Florida. Approximately 100 people attended the day-long event. The festivities actually began the night before with an informal pool party where people met and made new friends. In fact, one F.I.R.S.T. member commented, "It's like we have known each other all our lives." For many, however, the conference was the first time they had ever met anyone else with ichthyosis.

Guest speakers for the morning sessions were Dr. Lawrence Schachner of Miami, Fla., Dr. Mary Spraker of Atlanta, Ga., and Dr. John Koo from San Francisco, CA. Details of their presentations will be included in later issues of FOCUS.

The Foundation was pleased to present Dr. Koo with a \$500 F.I.R.S.T. Travel Award to defray expenses. Dr. Koo addressed the conference on the psychological aspects of having ichthyosis. He is a psychiatrist as well as a dermatologist.

The afternoon sessions consisted of eight small workshops which included such topics as "Hot Tips and Helpful Hints," "Who Am I? Discover the Person on the Inside," and "Playing the Hand We've Been Dealt." Everyone was able to attend two workshops prior to gathering back together as a large group. The day concluded with a video presentation, several spur-of-the-moment speeches, many hugs and hearty handshakes.

Keep watching for news of our next conference. This conference is tentatively set for Williamsburg, Virginia on July 3, 1991. There will be more information in your next issue of FOCUS.

F.I.R.S.T. would like to thank everyone who helped make the Florida conference a success. Among those who contributed much time and energy were: Andrea Thorn, BeBe Blades, Frances and Pete McHugh, Ellen Rowe, Mark MacNaughton, Cynnie Bates, Denita Elkin, Tony and Ali Escobedo, Debra Dorazio, Kathy Rogers, Julie Corbin, Ann and John Rindosh, as well as a host of others.



Ellen Rowe presents F.I.R.S.T. travel award to Dr. John Koo

And thanks to all of you who came and participated. We truly had a family reunion, one that we won't ever forget. Hope we can see you at the conference next year.

## Correspondence Corner

**Liza Marquez**, 1901 Halford Ave., #66, Santa Clara, CA 95051 would like to talk with others in her area who have ichthyosis. Her home number is (408) 296-2457 or work (408) 721-3082.

**Debbie Veroeven** has an 8-year-old son with lamellar ichthyosis and would like to talk with others who have children with this problem. You can call her in the evening at (507) 245-3779 or write to her at P.O. Box 161, St. Claire, MN 56080.

**Paul Stoppenbach**, 1511 Boylston, #3, Seattle, WA 98122 has Darriers and wants to communicate with others who have this disorder. Call him at (206) 322-8129.

**Geraldine Schooler** has Pityriasis Rubra Pilaris and ichthyosis. She says that she has been treated with methotrexate and has much improvement. If anyone would like information, please contact her at 3410 Wellington Drive, Dayton, OH 45410. Phone: (513) 256-7559 at home or (513) 263-9517 at work.

**Melissa Soliday** has a new baby son with ichthyosis. He may have CIE but the diagnosis is not finalized. She would like to talk with other parents. Her address is 763 Cedar Dr. Ashburn, GA 31714.

**Vera Carrisal**, 217 S. Sherman St., Bay City, Mich., 48708, also has a new child with lamellar

ichthyosis. Cassandra is 10 months old. Vera would like to talk with other parents and with adults who have ichthyosis to find out about what to expect in the future. Her number is (517) 892-3781.

**Maria das Gracias Bonfim Tanaka** writes to FOCUS all the way from Brazil. Her son, Diego, age 4, has ichthyosis. He has delayed motor development. She writes, "I will never give up the fight for my son although in Brazil there are lots of difficulties, and there is no association for ichthyosis. I would be very grateful if I could correspond with a person or family which has a

(Continued on page 4)

# Life has a way of working out

By Barbara Straw

I want to echo the words of Ruby Smith (see FOCUS, Vol. 9, No. 2) whose daughter, Mary, has lamellar ichthyosis. Having lamellar ichthyosis does not have to be the end of the world. I do not know what the correct formula is, but I have a fair idea of what helps.

My parents and family never treated me as different. I was loved and accepted. I was lucky enough to have a best friend through grade school, high school and college. I learned early on that if people could not see past my skin condition, then they weren't worth knowing.

I had a school nurse in high school who introduced me to our State Vocational Rehabilitation Office and Dr. Paul Gross who is affiliated with the University of Pennsylvania

Hospital. There was no cure for my ichthyosis, but the state did pay for my college education at Pennsylvania State University where I graduated with honors.

I stayed in contact with Dr. Gross, checking every five years or so to see what is new in treating lamellar ichthyosis. Today, I am a division director with 10 people working for me. I am listed in Who's Who of American Women and probably am in the top 5 percent in earning power of all working women.

I am a wife and mother of two, My son, Jonathan, is 12 and my daughter, Jamie, is 3. They both have normal skin and are wonderful children.

My husband has been supportive at home

and at work. If Dr. Gross had not reassured us to go on and have children, we would not know the happiness of our family today.

What have I learned? To aim high. You can do whatever you set out to do. Get second opinions... ichthyosis is so rare that not many doctors really know about it. Hang tough, things will work out.

It hurts to read about others who have not been as lucky as I have been. Maybe this will provide encouragement to others.

## Write your Senator

The Senate Appropriations Committee will be marking up its bill in early September, so there is not a minute to lose in writing your senators asking for approval of an additional \$50 million for the National Institute of Arthritis Musculoskeletal and Skin Disease (NIAMS). This institute which was formed in 1986 and represents the first time our federal government has paid any attention to

skin. F.I.R.S.T. has supported NIAMS and continues to push for more funds for skin research.

Members often ask, what can I do to help? "Write your senators," says Fran McLugh, F.I.R.S.T. vice president. "This is what you can do to help. It's better to light one candle than to curse the darkness," says Fran.

Fran says that at least 10 letters to one congressman will surely get attention, so make a copy of your letter and send it to your friends and

relatives. Ask them to send it to your senator, too.

If you do not know your senator's address, call your local library for help. If you can visit your senator while he or she is on recess, that would be even better.

Be sure to ask for their support in appropriating additional funds for NIAMS. More money in research may some day lead to a cure for ichthyosis.

## Prejudice and discrimination can cause pain and heartache

By Cathy L. Jones

I have lamellar ichthyosis and recently received the F.I.R.S.T. literature. I am in a rather unique situation. In the past I received treatment that was very successful. But because of a medical problem with my liver, I had to discontinue use of the drug. Now my doctors, along with the company that produces the drug, have decided it is not an immediate threat to my overall health, so I have once again begun use of this drug. The drug is Accutane. I wonder why it is not mentioned as a possible treatment in F.I.R.S.T. literature...

I was sorry to see that on the Ichthyosis Fact Sheet it says "People with this disease face a life of limited productivity and social interaction." I obviously live a very sheltered life. I was, of course, made fun of and shunned. I often wanted to run and hide from the world (and still do.) And although I work very hard and consider myself fairly intelligent, I have been unable to gain employment.

Before I began treatment, I was unable to believe that people could be so ignorant and prejudiced against this disease. But after the drug began to work its magic and I began to look more normal, I noticed a drastic change in the attitude of people around me. Most disappointing was the attitude and comments of friends and family who

I mistakenly believed did not care that I was "different" but loved me for who I was inside. Apparently, that is not entirely true.

Because of this experience, I will never look at the world the same again. Although I agree that your statement is true, and I must admit to the prejudice of many, I still feel (and I think others may, too) that this is an insult to us all. It may be that there are things that many people with ichthyosis cannot physically do (as well as other people in the world who have normal skin but are injured, handicapped, fat or just plain lazy). But to imply that we face a life of limited social interaction is just giving those of us (myself included) an excuse to hide, as if in shame.

That is the one thing we do not need, a reason to stay in bed, to lock ourselves away from the world and all the pain. We are our own worst enemy. We need to force ourselves out into the world and break down the barriers of prejudice and show the business people and others that we have worth, so that we can some day believe in ourselves.

I hope to instill in others with ANY handicap, some pride and a feeling of self worth. I think this should be the main concern of the FOCUS newsletter, and not to say that we are

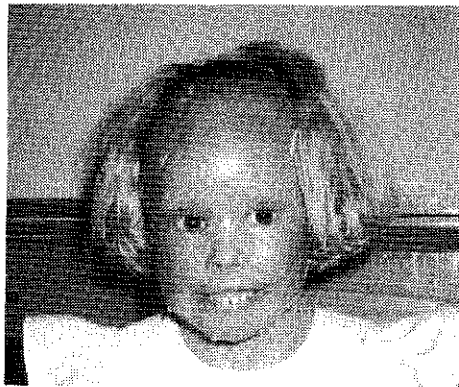
psychologically devastated, disfigured, or that we are limited in productivity and social interaction. Even if this is true, I am only afraid it will increase prejudice in those who read this newsletter and know nothing about the disease. Not to mention causing feelings of hopelessness and despair in many people who are suffering emotional scars.

I believe the truth must be told. Too many times people are given misinformation by doctors who mean well and want to help but are unable because they lack knowledge and information about ichthyosis. The truth must be told in an encouraging way. It would be nice to give the readers a feeling of hope. After all, there is little else to give... signed Handicapable, not Handicapped.

*Editor's note: We appreciate hearing from all of our readers and thank Cathy for her thoughts on ichthyosis. Yes, hope is important. Each person has a unique story to tell and may experience life a little differently. For some, ichthyosis, even the mildest case, can be devastating. For others, even those with severe forms of ichthyosis, it can just be a minor inconvenience. Attitude has a lot to do with how we look at things. We invite other readers to share their views on how ichthyosis has affected them personally.*



Nester Lopez, New York



Laura Ashton, Bermuda



Becky Hudson, Georgia

## Our kids have a positive outlook on life

By Andrea Thorn, F.I.R.S.T. Board Member

It was an honor for me to conduct the "Kids Only" workshop at our 1990 Summer Conference and Family Reunion in Orlando, Fla. Most of the children had ichthyosis themselves, but there were a few siblings who proved to be very beneficial in our discussions.

We covered a wide variety of topics in our workshop, and I would like to share the highlights. During introductions, we told everyone our names, ages, hometowns, hobbies and family membership. From there, we moved on to "Pass the Cup" which had different questions on slips of paper. We took turns reading the questions, and everyone had a chance to respond to every question, if they so desired.

Some examples were: How do you handle

rude people? Some of the responses were: "I just say hello. How are you doing?" or "My brother beats them up!" How do you handle the heat when you play sports? "I just take my spritzer bottle." and "I soak a bandana in water and wrap it around my neck."

Next, we made a chart and brainstormed about how we are the SAME as most people on one side, then on the other, how we are DIFFERENT. The kids mentioned such things as legs, arms, eyes, heart, laughter, brain, etc.. when talking about sameness. The different side was not so easy. "Dry skin" and "very wild" were their thoughts. The term "ichthyosis" was only listed because I had to pull it out of the air. They literally did not list it themselves!

We summed up our workshop by saying, even though we all wish ichthyosis didn't exist, when given a choice, we would choose ichthyosis, any day, over being blind, deaf, paralyzed, etc...

These children (about 20 all together) had a very positive outlook for themselves and their peers. I congratulated the parents of these children for the wonderful job they have done with them. Yes, we all make mistakes, but let's dwell on the good, not the bad. It is OUR RESPONSE to a situation that makes it good or bad. Let our response as parents to ichthyosis always be GOOD!

*(Andrea Thorn lives in Jackson, MS and is the mother of two girls, Christina and Anna. Both Andrea and her daughter, Anna, have EH.)*

### Special thanks to a creative member

Many thanks to Sue Tiffany of Stonington, Connecticut for her donation of a beautiful handmade quilt which was raffled off at the summer conference. The quilt raised \$149 in donations for the foundation.

### Help with research

Dr. Amy Paller still needs scale from untreated areas. If you are interested in helping with this research project, contact Dr. Paller at the Division of Dermatology, Children's Memorial Hospital, 2300 Children's Plaza, Chicago, IL 60614.



A family portrait of our kids at the 1990 Summer Conference

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

THANK YOU!

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

\_\_\_\_\_ \$50 ONE TIME "SEED" FUND CONTRIBUTION TO LAUNCH F.I.R.S.T. INTO 1990'S  
 \_\_\_\_\_ \$20 Single membership \_\_\_\_\_ \$35 Family membership \_\_\_\_\_ \$250 Patron  
 \_\_\_\_\_ \$50 Sustaining Member \_\_\_\_\_ \$100 Sponsor \_\_\_\_\_ Other Amount  
 \_\_\_\_\_ I can't afford dues now, but please keep me on the mailing list. (Please check.)  
 \_\_\_\_\_ CALL ME. I can make time to help as a F.I.R.S.T. Volunteer.

Ichthyosis type in my family: \_\_\_\_\_ # Persons \_\_\_\_\_

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

## Correspondence Corner

(Continued from page 1)

member who has ichthyosis in order to get some information about their lives, relationships and experiences to help me look after my son in a better way. Together with this letter I am sending a photo of Diego, and if possible, I would like to receive one from people who correspond with me." (Diego's picture is adorable, but it is in color so we could not print it. FOCUS will send the photo to the first person who calls us and wants to contact Maria.) Maria's address is Rua Almirante Luiz Penido Burnier 529, Parque Residencial Bandeirantes, Sao Paulo - SP Brazil

Joan E. Harris, 1906 Kratha Drive, Augusta, GA 30906, has had a frustrating time with getting an accurate diagnosis for her skin problem which resembles ichthyosis. Her main concern now is how to deal with society's reactions to her appearance. This is an ongoing problem for many of us. Joan

would like some support with this so please contact her if you have time.

Becky Hudson, age 6, and Jeffrey Hudson, age 9, would like to hear from other children who have ichthyosis. You can write to them at 526 Pinegate Road, Peachtree City, GA 30269.

Heather Carroll, age 8, would like to have a penpal. She wants to correspond with a girl around her age who also has lamellar ichthyosis. Heather's family is stationed in Germany and she has never met anyone like herself. Her address is HHC, 10 En Bn, Box 381, APO, NY, 09701.

Eiman Azim writes to FOCUS concerning her brother who has ichthyosis. Her family has migrated from Egypt, to London, to California to find a climate suitable for his skin. He now has a B.S. in Physics from the University of San Francisco, but cannot find a job because of his appearance.

"Every time he applies for a job, no one accepts him, and they ask him to go and find a cure for his skin." Eiman would like to correspond with others who have experienced job discrimination. Her address is 4817 San Gordiano #B, Santa Barbara, CA 93111.

Wendy Cappello recently had a new baby with ichthyosis. If you would like to write her, her address is 7 Pine St., Kane, PA 16735.

Cathy L. Jones would like to hear from others who are using Accutane. Her address is 618 Dogwood Rd., Tazewell, VA 24651.

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

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