



ICHTHYOSIS FOCUS

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Coalition puts spotlight on skin disease research needs

by Lowell Goldsmith, M.D.

When it comes to testifying to Congress, few health organizations have greater impact than lay persons suffering from or representing skin diseases. They are armed with facts, figures and a persuasive advantage: the testimony of their visible skin.

Lay organizations in dermatology are best known for their role in educating patients and the public about specific diseases, and for their support of research through contributions from their members and the public. Many of the lay groups have resources that can be used by physicians and, on a wider scale, can provide a uniquely important service to dermatology.

Today, for example, the 17 organizations making up the Coalition of Patient Advocates for Skin Disease Research (CPA-SDR) continue to make an effective case for increased federal support of research. Recent help from the Society for Investigative Dermatology and The American Academy of Dermatology has strengthened the Coalition's effectiveness. According to Gail Zimmerman, founding chairperson of the Coalition, this cooperative relationship could lead to combined efforts toward improving insurance reimbursements and other treatment-access questions. In these days of shrinking resources, the ability to protect patient benefits will increase when there is combined strength.

F.I.R.S.T. is a member of the Coalition which is made up of 17 different skin groups. In 1986, the CPA-SDR



Vice President Frances McHugh, standing sixth from the left, represents F.I.R.S.T. In Washington at Coalition meetings, testifies before Congress, and visits senators and representatives in their offices to give them information about Ichthyosis. She has a grandson with Ichthyosis.

was created as a formal organization to more systematically, and forcefully, present testimony to the Congress during hearings in the House and Senate as a panel, and to develop teams representing several disease concerns.

Each organization pays its respective travel expenses to Washington, D.C. and prepares its own testimony. Individuals from each organization in the Coalition accept the daunting but all-important task of treading the halls of Congress to see their senators and representatives. This cooperative effort of physicians and lay members of the Coalition provides an excellent opportunity to accurately depict research needs, portraying them in scientific and human terms.

While it is not possible to attribute legislative success to any one element, in Fiscal Year 1991, the appro-

priations for NIAMS (the national institute that includes skin) were increased by 14.4 percent, the largest increase in the history of the Institute. Everyone is enthusiastic about the next effort.

Additionally, as lay and professional groups work together, their message to Congress is expected to hold considerable and increased weight.

Editor's note: Dr. Goldsmith is an active supporter of F.I.R.S.T. and has served on our Medical Advisory Board for many years. This article was reprinted, in part, from the American Academy of Dermatology Bulletin, vol. 9/no. 2/March-April, 1991. Vice President Frances McHugh represented F.I.R.S.T. at the Coalition meetings in Washington, D.C. this year and testified for us before Congress.

Tell Me Doctor

by Melodie Buxman, M.D.

Q. During the past two years, our company has been involved with installing a manufacturing facility in Simferopol, USSR. I have spent approximately 40% of my time in the USSR and have become acquainted with many people.

A captain in the Soviet army asked if I could be of assistance regarding his daughter, age 7, who has been diagnosed on several occasions as having the CHILD syndrome. What is this and is there any known cure?

A. The letters of the word CHILD stand for the characteristic appearance of the syndrome: Congenital Hemidysplasia with Ichthyosiform Erythroderma and Limb Defects. The ichthyosis is limited to one side of the body, sparing the face. It may be associated with hair loss and deformity of the nails. Failure of development of all or part of the arm and leg on the side of the body involved with ichthyosis also occurs. There may be associated internal organ involvement on the affected side as well. The condition usually occurs in females, and seems to be passed directly from generation to generation. There is no known treatment, but surgery may help with deformed limbs.

Q. I have had a rash on my right hand for several years (on and off). I thought it was from my dishwashing detergent, so I was treating it from this aspect. I recently left it under the hot water tap in order to help heal it. I believe this only made it worse.

Interestingly, I have a large scar on the top of my right hand from a grease burn some years ago. The rash does not affect this area. Is it possible to intentionally scar the hands, say with acid peel, to treat a condition like this? (I probably have Ichthyosis vulgaris).

A. It sounds like you have either irritant dermatitis (red raw rash from excessive exposure to soaps and/or water), or a contact allergy to something you are applying to the surface of your skin. In either case, applying hot water, although it will make your skin temporarily more flexible by abruptly increasing moisture in the skin, will soon worsen your condition. Heat increases evaporation of water from the surface of the skin, causing excessive drying and cracking. Wearing lined rubber gloves while doing wet work and applying cool moist soak for ten minutes followed by an emollient cream, especially overnight, will help. If you think you are allergic to something, testing can be done for this by a dermatologist, who can also recommend specific appropriate treatment and avoidance of the offending substance. I don't think you would want to intentionally scar your hands. It would limit the motion of your skin and might make you susceptible to skin cancer in the future.

Q. I have tiny red/brown dots that seem to rise to the skin surface, then the skin flakes off for an inch or more in all directions. When (once out of each 3 or 4 times) the skin doesn't flake off, it instead forms a translucent crust over painful, tender skin and rips off painfully days later. The red/brown dots occur only on the soles of my feet and the palms of my hands. This all started during a doctor-monitored weight loss program, (75 lbs. over two years). The

only way I've found to control them at all is with a very unhealthy high fat diet when they appear. I've put on a hundred pounds in 13 years! Great diet!

A. The dots you are describing sound like blisters underneath the epidermis, or living surface layers of the skin. These are filled with fluid and if they are close together, they may break and crust. Several days later, the skin begins to heal underneath and the old dead layers peel. When they are forming, they may itch or hurt. Causes for these include fungal infection ("athlete's foot") or contact allergy. There is also a condition called pompholyx, in which blisters suddenly appear on the hands and occasionally feet, sometimes as a result of emotional stress. Your doctor should be able to help you make the correct diagnosis and should be able to prescribe appropriate treatment. I can't relate your diet to the skin rash you are describing.

Melodie M. Buxman, M.D. is a dermatologist on the F.I.R.S.T. Medical Advisory Board. She will be happy to answer your questions. Please send your questions to the F.I.R.S.T. office and we will forward them to her.

Search for an illusive gene

In the 31 years since Andrea Thorn was born with ichthyosis, her family has been haunted by the question: What caused this condition so rare that it affects only one person in 300,000?

Andrea, a board member and vice president of F.I.R.S.T., recently took a step towards finding the answer to that question. She and her family became part of a National Institute of Health study to determine the causes of ichthyosis. The research project is being conducted by Dr. Sherri Bale, a geneticist who is investigating the origin of a variety of hereditary skin diseases. "What we are doing is tracking genes from parent to child to grandchild."

The goal of the project is to locate the gene that causes the disorder, find out what it does and fix it. "The ultimate goal is gene therapy, fixing the gene in the germ cells of the affected parent (so it isn't passed on to the child). But that is dreaming. You and I won't see it. The first step is understanding what's happening, so we can direct treatment much better."

Andrea explains that her contribution to the study was a little bit of blood and a piece of skin no bigger than the head of a pin. "And we all enjoyed a trip to Washington!"

If you are interested in participating in this study, please call Dr. Sherri Bale at (301) 496-4375.

Don't worry, be happy

by Katy McMasters

Hi. My name is Katy and I am 12 years old. I also have a light case of lamellar ichthyosis. It's the pits, but I keep on with life like a normal child. Just because I have this disorder doesn't stop me from doing things I like best, like playing the piano, flute, or dancing, and breeding hamsters.

To tell you the truth, I really don't have to cope with it very much anymore because the people I live with and are friends with know me very well. But, when I was younger, it was hard to cope with people calling me names or backing away from me when I passed by.

When a kid called me a name, I just

ignored it and walked off. People also asked me if I was burned in a fire. I always answer no and lift my head high because I am proud of what I am today.

I say be happy and enjoy life instead of being miserable. If someone you thought was a friend puts you down, ignore them, because they are not your real friends. A real friend is someone who doesn't care about your outside, but knows you inside and knows your internal self.

If someone cuts you down, or makes fun of you, do what I do, and ignore them. Lift your head high so they will know that you are proud to be you. I hope to meet some other people with ichthyosis soon.

Cosmetics can improve your image

by Debra Traina

Looking good takes time and effort. First of all, I use Clinique products. They are expensive when you first begin to use them, however, I usually run out of one thing at a time and the average price for these products is about \$12.

To take away the dryness, I use an exfoliating scrub. If your skin is sensitive, this may hurt a little bit because there are granules in the scrub. It works quite well if you can stand the roughness.

To cleanse my face I use Clinique's extremely gentle cleansing

creme. It is like a lotion that removes all the dirt and makeup off your face. Right after this, I apply the Dramatically Different Moisturizing Lotion. I use this product every morning and every night, and sometimes in between if my face is particularly dry.

I also use a base makeup. Clinique's base for extra dry skin feels just like silk. Then I use a little blush and lipstick, but this is not necessary unless you feel like it.

Some sales people will tell you that you have to use their products in a certain way. However, I use it in the way that is best for me.

For example, I have a lot of dryness around my eyes. I just keep my eyes shut real tight when applying the scrub and nothing has ever happened.

I have tried many other types of cosmetics, but have never had the kind of results I have with Clinique. Whatever makeup you prefer, it is easy once you get into a routine. And don't be afraid to ask for help. There are special types which tone down redness and conceal trouble spots. I also asked my dermatologist what would be best for my type of skin. You may want to do this, too.

Poetry helps ease the pain

by Wendy Vaughn

I am 16 years old, and it is really tough being a teenager going through high school, wanting to fit in. I moved and was it ever hard to adjust. I write poems about my feelings of having ichthyosis and coping with it. I recently wrote a poem and became a semi-finalist in a poetry contest.

This poem expresses what was in a previous newsletter about depression. I got depressed about myself, and hated myself for being here. I know how children feel with this problem and how hard it is to cope with it because I have been through it!

I hope that this poem will show others that they, too, have a special talent and can deal with their problems of having ichthyosis.

Dreams

What are dreams?

Dreams are like waves crashing upon a shore;

Birds soaring in the big, blue sky;

Trees swaying in the wind or;

Tears falling like a waterfall.

Dreams come in all shapes and sizes,

Dreams are of future and of goals;

Dreams are of life and of love;

Dreams are of sadness and of happiness;

But most of all dreams are of the impossible.

A dream is like the wind,

Passing through carrying a new one on,

But for me it will always be the same.

My dream is of light,

But darkness surrounds me.

My dream is of beauty and loveliness,

But these are but dreams of the impossible.

I ask God for light upon me to cure me of this disease;

A sickness has fallen upon me,

But not a physical sickness, But that of hardships.

God is Creator;

God gives life to all,

But where is my life that I ask of?

For my life is of suffering, And I may soon die.

I am trapped in my own shadow,

And I cannot get out.

Tears fall from my eyes day after day.

My life is that of a dream,

And a dream is my life.

Dreams

Run

Excitedly

And Mysteriously like

Seagulls in the sky.

Correspondence Corner

Tonja Harris, 406 E. Genesee St., Flint, Michigan 48505, has a one-year old son who was recently diagnosed with lamellar ichthyosis. She wants to hear from other families who have children with this disorder and from adults who have it. Her phone number is (313) 239-2592.

Susan Stevens recently found out about F.I.R.S.T. "It is an answer to my prayers to know that an organization for ichthyosis exists. I am 33 and have felt alone all my life with my ichthyosis. I have never met anyone else with it, and never could find out more about treatments, but now I have a chance. Your newsletter was so informative. Now I feel that I am truly not alone. You have made me so happy," she says. Susan would like to know if others live in her area. Her address is 36 Mountain Vista Drive, Asheville, NC 28804.

Helen Moran, M279 R.S.D., Clarkes Hill, VIC, Australia 3352, has three children, ages 4, 22 months and 10 months. The youngest two have lamellar ichthyosis. Helen writes that, in Australia there is no support group. Both children were collodian babies. "At present we use Urea Cream and Wool Alcohol Ointment on Erin and only Amber Petroleum Jelly on Luke. Their skin sometimes cracks, mainly on their hands and feet, and also around their eyelids. Erin has very thick scaly skin on her scalp which seems to get very itchy, particularly at night. She wakes up scratching her head madly." Helen would like to hear from other members who have experienced these problems.

Sister Celine Courtney of the Holy Family Church in Fulton, NY recently sent us a donation from a card party. "We have a couple of people from our parish who suffer from this disease. God bless your good work." Many thanks to the sisters for their contribution.

Sheila Wadman, 4 Crescent Terrace, Saugus MN 01906, would like to correspond with others who have ichthyosis. She is 50 years old, has a husband and one child and her hobby is making porcelain dolls.

Andy Frederick, P.O. Box 3897, DeLand, FL 32723, has a special request. He would like to hear from some young women who have ichthyosis. Actually, Andy, we've had one couple who met through this column and are now happily married. Who knows what can happen? Andy is 32 years old and has x-linked ichthyosis.

Tracey Hensley, 122 Colonial Drive, Apt. K,

Harrisonburg, VA 22801, has let us know that she is currently writing a book about ichthyosis and people who have it. She enjoys getting the newsletter. "The article on depression was informative, and most important, let me know that there are others out there whose skin and life situation gets them down." Tracey has Congenital Ichthyosiform Erythroderma (C.I.E.). Good luck with your book, Tracey!

Carol Reid, 4621 Lamont St., Apt. A-7, San Diego, CA 92109, says that she uses cortisone ointment on her hands when she has a rash. She has ichthyosis vulgaris and finds that sometimes the rash will clear up on its own. "I sometimes have swelling around my eyes in dry weather... I have miliaria around my eyes which are caused by the sun. They shrink sometimes and get hard and itchy," says Carol. She was glad to find out from one of our earlier newsletters that these bumps may be from clogged up sweat glands. **Editor's Note:** *President Ellen Rowe suggests checking with your dermatologist before treating rashes from unknown causes. For instance, cortisone can make certain rashes, like yeast infections, worse.*

Betty McMasters, 1838 So. Muskogee, Sapulpa, OK, 74066, has been a supporter of F.I.R.S.T. from its early days. "I get so excited to see the newsletter when it comes. I have almost 90 newsletters and I wouldn't trade them for anything!" Betty's daughter, Katy, who has ichthyosis, is now in sixth grade and doing great. We thank Betty and many others who helped F.I.R.S.T. get on its feet 10 years ago.

Linda Lucas has a 13 year old son, James, with lamellar ichthyosis. He has been using a product called DermaGuard to help his skin and has noticed a lot of improvement. If you would like to ask her about it, write to her at HCR 26161, Box 136, New Martinsville, VA 26155.

Bob Sipper, P.O. Box 127, Hwy. 10, Rutledge, AL, 36071-0127, has a toddler named Zebulon who has ichthyosis. "For three years we've used Polysorb Hydrate on him. We bought it from the pharmacy at a price range between \$11 to \$13. Recently, we found a pharmacist who suggested that we make the cream from the ingredients for about half the price. It took 2 or 3 tries before they got the exact mixing formula, but it was worth the trouble," says Bob. "We pass this helpful hint on to other readers in hopes that they, too, can find a pharmacist willing to work with them in bringing the costs of skin care down," he explains.

Debra Traina is interested in going back to school to become a teacher and would like to teach kindergarten or first grade. "But I'm so scared about how the children will react to my skin. I know we are encouraged to do whatever we want, no matter how anyone will react to us, but I am just a little nervous about it. Plus, sometimes, parents can act even more childish than their own children," says Debra. How about it all you teachers out there? Debra would like to hear from you about what it is like to be a teacher with ichthyosis. And we do have quite a few teachers amongst us, believe it or not. Debra's address is 400 Palm Circle West #204, Pembroke Pines, FL 33025.

Lynne Alba has discovered that her grocery store will make donations to F.I.R.S.T. through its Community Cash Back Program. If you have a Genuardi Super Market in your area, ask them about this program says Lynne. Also, Lynne wonders if anyone has children who have arthritis as well as ichthyosis? Her address is 917 Pierce Road, Norristown, PA 19403.

Andrea Thorn tells us that P&S Liquid by Baker Cummins has removed lots of the scales from her daughter, Anna's scalp. She says others might want to give it a try. Andrea is co-vice president of F.I.R.S.T. She and her daughter both have EH (Epidermolytic Hyperkeratosis). And she is a kindergarten teacher, besides being mother to Anna, age 6, and Christina, age 9. She and her husband, Jim, live in Jackson MS. Their address is Rt. 2, Box 346-D, Jackson, MS, 39209.

Chris Dukes wants a pen pal. "I am 10 years old and would like to hear from other children with Ichthyosis. My address is Rt. 1, Box 73A Woodbury, GA. 30293. Thank you."

Mrs. J.E. Nash, Sr., 86 years young, has used a mixture of one percent Boric Acid powder in a 6.5 ounce bottle of Keri Lotion for 30 years. "My legs are as smooth as anyone's. There are no scales on them. I use the lotion every morning and every night." Mrs. Nash hopes this may help someone else with Ichthyosis. Her address is 2109 Sundowner Drive, No. 7, Birmingham, AL. 35216.

If you would like a penpal, have a comment to make, or would like to be in touch with others who have Ichthyosis, write to: Ichthyosis Focus, PO Box 20921, Raleigh, NC 27619, and we will include your name and address in Correspondence Corner. We do not release names and addresses without permission.

Duke hosts spring conference

Duke University Medical Center was the site for a regional spring meeting on May 4. The meeting focused on the genetics of ichthyosis, as well as the psychological aspects of coping with the disease.

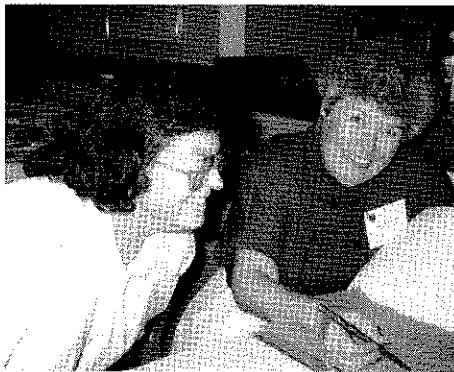


Edna Atwater, R.N. takes a coffee break.

Speakers included dermatologists Neil Prose, M.D. from Duke; Steven Resnick, M.D. from the University of North Carolina at Chapel Hill; Michael Smith from East Carolina University; Susan Dally, M.D., a child psychiatrist; and John Currie, Ph.D., psychologist.

Dr. Dally planned special therapeutic activities for children which included a walk in the Duke Gardens and throwing pennies in the wishing well.

The children also created a 12-foot mural to decorate the walls of the clinic. "Some of these children have a lot of unexpressed anger and could be helped by



Julie Corbin, left, and Georgie Betts help out with registration at the spring conference held at Duke Medical Center.



Beverly Dillehunt gets a peck on the cheek from daughter, Darin, before she skips off to join other children at the Duke conference.

counseling or play therapy," commented Dr. Dally.

Dr. Currie also cautioned parents of teenagers with ichthyosis to be aware of signs of depression, such as increased irritability or significant and abrupt changes in eating or sleeping habits.

Small group discussions gave participants a chance to ask the dermatologists many questions about skin care and treatment. "I'm really glad I came," said Beverly Dillehunt of Fayetteville, NC. Beverly's daughter, Darin, age 5, has lamellar ichthyosis. "It was great to meet some other people and find out how they cope with their ichthyosis."

Mom begins to believe her own pep talks

by Mary Stefanos

I am a 27 year old woman with a very obvious form of EH. I have always been "lucky" in that I have met every ignorant, insensitive, and inconsiderate person possible. (Thankfully, some wonderful people too.) However, most of the time, like all people with Ichthyosis, I was able to "act" cheerful around people that made me feel uncomfortable.

It was only until I had a child with EH that I became frustrated, angry, and bitter. The problem started when he was old enough to sense people's reactions. (Usually my anger) I could handle it when people stared or refused to serve me, or kicked me out. However, when it came to my son, I was not a pleasant

woman to be around. It was not their reactions that made him aware of his "difference," but mine. He started to become paranoid when we left the house, or when someone looked in his general direction. I was the cause. In this case, my maternal instincts were not helpful.

I always told him not to worry about other people's reactions, yet I did. He was confused because he heard me tell him one thing, but saw me do another.

When I started receiving your newsletter and noticed all of your positive outlooks. It helped me immensely. I recognized the fact that I was an angry and bitter person, despite the fact that I was married to a wonderful man and I had a beautiful boy, both of whom I love

very much. Most people don't even have that, so why was I so unhappy? It was because I was letting the insensitive people control my moods.

Today I received another of your newsletters and I read it cover to cover, and I decided to start enjoying what the three of us have together and not to place any importance on "their" opinions. Maybe now if I start believing the pep talks that I've been giving my son all these years, I'll set a better example for him, and maybe undo some of the damage to his self-confidence I caused.

I value all of the input in your newsletters and as long as I'm around, I'll keep donating to the cause to keep them coming. Also, please continue with the conferences, because when we can finally afford to attend, I want there to be one to attend.

I want to help F.I.R.S.T. in the fight against Ichthyosis.

Please put me on the mailing list:

NAME _____

MAILING ADDRESS _____

CITY _____ STATE _____ ZIP _____

Donor Category

Single \$20/year Family \$35/year Sustaining \$50/year

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I don't wish to join now, but please accept my donation of \$ _____

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

Ichthyosis type in my family _____ # Persons _____

Mail to: P.O. Box 20291, Raleigh, NC 27619-0921

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 upon request.

The next best thing to being there

If you were unable to attend the Summer Celebration and Conference in Williamsburg, VA on July 3rd, you might want to order a video of the afternoon events. The 3 hour video includes lectures by Virginia Sybert, M.D., William Rizzo, M.D. and Eileen Enny Leach, B.S., R.N. as well as a panel discussion by various leading dermatologists.

You might see a few familiar faces in the audience if you have ever been to previous conferences. The video also gives you a chance to watch some of our special children in action. Talk about some cute kids! You will wish you had been there, but this is the next best thing.

To order a copy of the video, send a check for \$25 to: Davenport Photography/Video, 4453 Powhatan Crossing, Williamsburg, VA, 23188.

Dear Readers,

We have had a very busy spring at the F.I.R.S.T. office. Our spring conference was very successful and plans for the Summer Celebration have moved along smoothly. By the time you read this, that event will be over. If you weren't able to come, you might want to consider ordering a video of the event.

Mother's Day for me this year was particularly memorable since that was the day I graduated and received my master's degree in social work from the University of North Carolina. I could never have accomplished this without the support of my ever-patient husband, Stephen, my children, James and Libby, my mother, Georgie Betts who stepped in to help out at F.I.R.S.T., the other F.I.R.S.T. board members who contributed their time and ideas to keep the office running, and Bebe Blades who staffed our office on a daily basis. Thanks to all of you for hanging in there with me through all the exams and term papers.

I am excited about how fast we are growing these days. We enjoy getting letters



President Ellen Rowe with James, age 13, and Libby, age 10.

from all of you. Let us know what we can do for you and your family. We are here to help in any way we can.

*Ellen Rowe, M.S.W.
President*

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