



ICHTHYOSIS FOCUS

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

F.I.R.S.T. wants to thank everyone who contributed to the Foundation this year. Some have given in the form of personal time and energy. Others have supported us with notes of encouragement and suggestions, and many have contributed financially to help keep the office running.

Thanks to all of you, the word is spreading about ichthyosis. We frequently get calls now from new parents and physicians who are interested in learning more about this disease. Perhaps someday ichthyosis will not be so unknown to the general public.

Special appreciation goes to those who gave at least \$100 or more during 1990. If we have overlooked you, please let us know. We want to thank each and every one of you for your continued support.

Elizabeth F. Adams, William and Claire Amwake, Carl and Shirley Anderson, David and Cynthia Ashton, Michael and JoAnne Barr, Reba and Becca Benson, Dr. and Mrs. Wilmer C. Betts, Gary and Mardel Bierwagen, Robert and Debra Bowie, Bill and Joanne Brunetti, Jean Cox, Jane Bukaty, Stephen Clark, Julie Corbin, Jessie Doyle Deely, Adam and Nell Dorazio, Charles and Diane Eichhorn, Dr. Peter Elias, Linette Finstad, Vera M. Finzel, Norene and Walter Foxe, Karolina Freed-Briggs, Mr. and Mrs. A.J. Galluccio, Larry and Sue Getz, Rose and Donald Gore, Ray and Margaret Haywood, Dr. and Mrs. H.R. Hudson, Paul and Janice Hudson, Thomas C. Hudson, Margaret Jacobsen, Richard and Jean Kelly, Randy LaBarbera, Mr. and Mrs. Joe LaBarbera, Gaetano and Mary Licursi, Valerie Lutters, Debra Luchansky, Michael Martinolich, Frances and

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Get set to celebrate in Williamsburg

Colonial Williamsburg, Virginia is the site of the upcoming F.I.R.S.T. Summer Celebration. This exciting event will be held on Wednesday, July 3, at the Williamsburg Lodge in the heart of the colonial area.

Because this is a popular tourist season in Williamsburg, we urge you to make your room reservations as soon as possible. Room rates range from \$65-\$85 per night in nearby hotels. Colonial Williamsburg also has reserved rooms for us in its own hotels. Rooms at the Motor House are \$75, and at the Cascades, \$85. Reservations can be made by calling (804) 229-1000. Tell them you are attending our conference in order to get group rates.

A few other hotels in the area include: The King William Inn 1-800-336-6126; The Patrick Henry Inn 1-800-446-9228; The Quality Inn 1-800-537-

2438; The Ramada Inn East 1-800-962-4743; The King George Econo Lodge 1-800-358-8003.

There are also several campgrounds located on the outskirts of town. Jamestown Beach Campsites, for example, offers full hook-ups, a river beach, pool, five bathhouses, putt-putt and bingo, and playground. Rates average \$12 to \$19 per night depending on hookups. Even though this campground has over 1,000 camp sites, reservations are already being taken for July 4th. Call soon if you want to reserve a spot. The number is (804) 229-7609. This campground is located 3 and a half miles from town near historic Jamestown Festival Park.

For those travelling by air, regularly scheduled airport limousine service is offered at three airports: Norfolk International Airport, Richmond International Airport and Patrick Henry Airport in

Newport News, VA. The Richmond and Norfolk airports are about a 45 minute drive from Williamsburg.

Williamsburg is located 150 miles south of Washington, D.C., approximately midway between Richmond and Norfolk on Interstate 64. Daily Amtrak, Greyhound and Trailways service also make Williamsburg easier to reach.

Colonial Williamsburg offers many interesting and fun things to do. An admission ticket is necessary to enjoy the full scope of the historic area. Nearby is Busch Gardens, an exciting adventure for both adults and children.

Please let us know if you would like a conference information packet sent to you. Registration deadline in May 1, 1991. Registration fees are \$40 per person, \$55 per couple, and \$15 for each child. Breakfast and lunch are included.

Tell Me, Doctor

By Melodie Buxman, M.D.

Q. Please discuss Pityriasis Rubra Pilaris. How is it related to ichthyosis?

A. Pityriasis Rubra Pilaris is actually more closely related to psoriasis than to ichthyosis, although an affected person may resemble ichthyosis in appearance. It is an acquired condition, not inherited, in which the skin thickens and becomes red; especially the palms and soles, and areas around hair follicles. It may last months to years, and can be treated with natural or synthetic vitamin A, or sometimes with anticancer agents.

Q. I don't perspire under my arms. When I get hot, I often break out with a bright red, itchy rash that is very uncomfortable. What can I

use to get rid of this rash? Is this a yeast infection?

A. With rare exceptions, ichthyosis patients do have normal sweat glands. However, because of the thickened skin, the sweat may not be able to exit from sweat pores, and they become blocked and may rupture (break) into the skin, releasing salty sweat into direct contact with the inside of the skin.

This causes inflammation, and red bumps called "miliaria" which are very itchy and take several days to go away. Although there is no good specific treatment, mild cortisone creams or soothing lotions may help. If you can use

antiperspirants to reduce sweating, and avoid getting overheated, this helps, too.

Yeast, of course, may occur on any body surface, particularly where skin folds, if damp. It normally produces raw and shiny areas, sometimes with small pustules containing white blood cells fighting the infection. Special anti-yeast creams are needed for this, obtainable from your doctor.

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.

Bubbly personality keeps Christy bouncing

Christy Cohan, age 7, lives in Marietta, GA with her mom and dad, Pam and Larry Cohan, and 14-year old sister, Jenny. Christy has a mild form of lamellar ichthyosis, but that doesn't stop her from being at the top of her second grade class and excelling in gymnastics.

"She has a bubbly personality," says her mom. "Christy has lots of energy and she is very resilient." This seems to be true of a lot of kids with ichthyosis!

Christy's parents have encouraged her to be normal in every way. Her hands get dry at times, but Christy uses Lac Hydrin twice a day as well as PolysorbHydrate. According to Mrs. Cohan, this

is a nonprescription cream similar to Pond's Cold Cream. A 16-ounce jar costs about \$14 and is made by E. Fougere and Co., Melville, NY.

The Cohans attended the Summer Conference in Florida where they met other families and were able to exchange ideas about skin care. "I found out everyone seems to use a different cream or lotion," says Christy's mom.

The conferences are also a good opportunity for children to meet other kids who have ichthyosis. Parents can share child-raising tips, and adults with ichthyosis make new friends with whom they have something in common.



Christy Cohan

A parent's viewpoint:

By Cindy Mac Eachern

How often do you hear the following question? "What happened? Did you stay in the sun too long? Is that why you're peeling?"

If you saw someone in a wheelchair, would you say, "What happened? Did you fall down and now you can't walk?" If you saw someone who was blind, would you say, "What happened? Did you get something in your eyes and now you can't see?"

Here's my point. If someone has a known and obvious handicap, it is easier to deal with than if someone has a skin disorder. When people have to deal with an unknown or unfamiliar sight, they seem to be less sensitive.

We are parents of a daughter, age 11, with lamellar ichthyosis. She is very knowledgeable

about her skin disorder. We feel that the more you know about a problem, the better you can COPE.

When she is asked why her skin looks different, she usually says, "I have a skin disorder called ichthyosis. Let me spell it for you."

Sometimes it is easier for her to say, "My suntan is peeling." Society can be ignorant about certain things... they fear the unknown.

Because ichthyosis is so rare, it is difficult to deal with. But children have the gift of positive thinking. When our daughter gets down, she does several cartwheels across the floor. Then she says, "It could be a lot worse. At least I'm not in a wheel chair!"

Editor's note: Parents can be very helpful when strangers approach children with

questions about their skin. What do you do to help your child over the rough spots? If you would like to share your ideas, please write to FOCUS. We also want to remind readers that some ichthyosis patients do use wheel chairs. The skin on their legs and feet is not flexible enough for walking. Many people with ichthyosis also have eye problems because the skin pulls the lids inside out. These folks also cope with rude stares and questions. FOCUS would like to hear how you handle these extra handicaps.

Correspondence Corner

Chris Dukes, age 10, would like to hear from other children with ichthyosis. He has Epidermolytic Hyperkeratosis. Chris's address is Rt. 1, Box 73A, Woodbury, GA 30293.

Vickie Nabors has an 8 year old daughter, Tina Scruggs, with lamellar ichthyosis. Tina would like to hear from someone her age or someone who could give her advice about dealing with other kids who make fun of her. Tina very much wants to meet someone with ichthyosis and hopes that people in her area will want to get together. Her address is 113 Grant St., Easley, SC 29640.

Joe and Marlene Huffman are interested in organizing a regional meeting in Minnesota. If you live in Minnesota or a neighboring state and would like to attend a meeting, please contact them. Their address is 1326 DeSoto Ave., Glencoe, MN 55336 (612) 864-4508.

Gloria Irwin has a 21-year-old son, Jeremy, with x-linked ichthyosis. She would like to hear from others who have similar skin problems. "I believe that by people communicating with each other their burden may be somewhat less to bear," she

says. Her son has good results using Ioniil shampoo on his scalp and LacHydrin. Write to her at Route 1, Box 32, Little Falls, Minnesota 56345.

Denise Gullickson, 89 Scarborough, Kalispell, MT 59901, wants to let folks know what helps the itching and bacterial odor for her 10-year old son. "We have fought the battle and for the first time we feel like we are winning." The product is called Melaleuca, a type of soap that smells good, according to Denise. "I'm sure that some of you like me have tried awful smelling stuff that seems to make things worse. At the same time he started using Melaleuca, he started Vitamin E. So I don't know if it is the combination, but it is working. The odor is down and the thickening is, too. As you all know, it's a hunt and peck game. The right combination someday will work. This works for us, and we've used it since August."

To contact a distributor of this product call: Stephanie Luehr at (406) 756-6159. Denise says she will be glad to talk to others. Her number is (406) 756-6075. "I just had to share this with the

newsletter. I've never written before to say how much this letter means to me. I look forward to every one of them. There is always something in the letter that pertains to us, and most of all, it gives me a good feeling of support."

Annette Martin, 19 North Court Road, Five Dock, New South Wales, Australia, 2046 writes to us about her son, Ben, age 5, who started school this year. Annette says, "I feel it's extremely important for parents of a child with this skin condition, or any genetic disorder, not to blame themselves." There are no support groups for families in Australia so Annette would like to hear from people here in the states. She has been teaching Ben to be independent and take care of his own skin.

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.

Let's face it

AboutFace is a non-profit support and information network for those who are facially disfigured and their families. This organization reaches out to individually who have been affected by congenital defects, such as ichthyosis.

Regardless of the cause, people who look different often face an insurmountable social challenge to overcome the stigma attached to being unusual. The AboutFace programs are dedicated to meeting the needs of its members and raising awareness within the general public.

One of the services offered is the opportunity to be in touch with others who share similar concerns and experiences. If you would like to join AboutFace write to: 99 Crowns Lane, 3rd floor, Toronto, Ontario, Canada, M5R 3P4 or call 416-944-FACE.

Researcher needs our help

By Amy Paller, M.D.

Can you spare a little skin? Just as a reminder, I am still seeking scale, as much as possible, from patients with ichthyosis. I am particularly looking for patients with epidermolytic hyperkeratosis, but would be glad to receive specimens from patients with any of the forms of ichthyoses.

Although I would most like to get untreated skin, I am also happy to receive treated specimens as long as I know the preparation that is being used as a treatment. This is so that I can test it for contaminants that may be relevant to my studies.

I need to know the location from which the scales are taken, the age and sex of the patient and, if possible, the type of ichthyosis. Scales can be collected over a period of time and kept frozen in a bag or plastic container in the freezer and later sent to me by mail.

Let me explain what I am doing. Gangliosides are chemicals with specific sugars and fat groups that are present in the membranes of all cells, including skin cells. The predominant ganglioside

of skin cells is called GM3.

Antibodies against this ganglioside have been found in normal skin scale. In patients with disorders of scaliness, like ichthyosis, the element in the scale to which the antibody against GM3 binds is absent or markedly decreased.

We feel that it is likely that this element may be important in regulating the growth of skin cells and may be deficient in patients with ichthyosis.

We will be using the scales from ichthyosis patients to compare with scale from normal individuals (from under casts and extracted by biochemical techniques). We will be looking for the amount of ganglioside GM3 in these preparations, as well as for other elements that may share a sugar structure that is recognized by the antibody against GM3, such as a protein or a fat that contains the sugar element.

If such an element can be identified, its deficiency may prove to be useful in diagnosis and recognizing new therapy for patients with



Dr. Paller

ichthyosis.

Editor's note: Dr. Amy Paller needs our support for her research to be successful. Please send your collected skin scale to her: Amy S. Paller, MD, Head of Division of Dermatology, The Children's Memorial Hospital, 2300 Children's Plaza, Box 107, Chicago IL 60614.

Genetic counseling can explain diagnosis

By Virginia Sybert, M.D.

Genetic counseling provides information about the correct diagnosis and natural history of inherited disorders, their treatment, recurrence risk and prevention, and referral for long term care. Genetic counseling requires communication of all this information so that it is understood and useful, and may require more than one visit.

As a rule, counseling is non-directive, that is the health care professional's function is to provide information which allows patients and families to arrive at their own decision based on their needs and beliefs. It is not the function of the counselor to impose his/her own value system on the patient.

While genetic counseling is usually given by a physician trained in medical genetics or by a genetics associate (an individual with a master's degree in Medical or Human Genetics), other health care providers may also participate in the process.

Accurate diagnosis is a prerequisite for genetic counseling. Disorders with similar manifestations may have different causes which may be genetic or non-genetic (phenocopy). If a disorder is genetic, mutations of different genes or different mutations of the same gene, may produce similar clinical appearances (genetic heterogeneity).

Autosomal dominant, autosomal recessive and x-linked genes, each of which has a different recurrence risk, can cause disorders that cannot be distinguished on clinical grounds alone. The natural history, treatment and recurrence risks may be different. For this reason, a physician expert in the disorder should be involved in the evaluation.

The most useful tool for the diagnosis of genetic disease is the family history. To ask appropriate questions, the counselor must be familiar with the major and minor manifestations of the disorder.

In most instances, information about first degree (parents, sibs, children), second degree (aunts, uncles, grandparents, grandchildren), and third degree (cousins) is sufficient. Ethnic origins are usually asked about because some disorders occur more frequently in one ethnic group than in others.

Some of the most useful questions in obtaining the family history are: "Is there anyone with similar problems in the family?" "Did anyone die young or unexpectedly?" "Did anyone have problems becoming pregnant or carrying a pregnancy to term?" "Were there any stillbirths or

malformed infants in the family?" "Is there anything traveling in the family, such as the 'Smith ear' or the 'Jones foot'?"

It is important to remember that someone may not recognize a specific problem as part of the spectrum of a given disorder.

A disorder may still be genetic in the absence of a positive family history. New dominant mutations, recessive disorders in families with few children and spontaneous x-linked recessive mutations may all give a negative family history and the erroneous impression that a disorder is not genetic.

Once the diagnosis is established, the counselor needs to explain the natural history or course of the disorder to provide a reasonable plan for

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health care maintenance and to allow for a rational assessment of the burden of a given disorder when decisions for reproduction are to be made. Decisions about reproductions are often based more on the severity of the disorder than on the risk of recurrence.

Treatment for genetic diseases may be specific for the given disorder, or non-specific for the symptoms of the disorder. Awareness of the usual course and common complications of a disorder allow for the practice of preventive medicine. Anticipation of problems circumvent them

Although the manifestations of some genetic diseases can be prevented by therapy, prevention of most genetic conditions is limited to the ability

to detect the persons at risk for the given disorder who can then use the information to make decisions about reproduction.

If an individual is found to be at risk for a genetic condition or at risk of having offspring with a genetic disorder, there are several options: 1. To reproduce despite risks 2. To not reproduce 3. To use prenatal diagnosis for selective reproduction.

The estimate of the burden of a genetic disease is a subjective one. Some couples are willing to assume the responsibility of having affected children because their desire to reproduce is greater than the burden imposed by the disease.

For other couples, even a small genetic risk for a serious disorder may be an insurmountable obstacle to reproduction.

For couples who choose not to reproduce, but desire children, several options should be discussed. Adoption and fostering are alternatives. Artificial insemination by a donor other than the father may be acceptable to some couples to prevent autosomal recessive disease or autosomal dominant disease contributed by the father. Similarly, donor ovum for autosomal recessive disorders or x-linked conditions carried by the mother can be utilized.

The principles of genetic counseling are simple. Generally genetic counseling should provide the necessary information to allow an individual to make choices regarding health care and to allow a couple to make their own decisions regarding reproduction.

This sort of interaction often requires more than one visit, since issues under discussion may be complex or prove emotionally difficult for the patient and family. A written summary of the advice, sent to the family, is extremely useful. Such a letter can be referred to at a later date, shared with other relatives potentially at risk, and given to other health professionals who are providing care for the patient.

More often than not, the outcome of genetic counseling is reassuring. Individuals' fears are often worse than reality. Many times, recurrence risks are not as high as the family believed, and the disorder is less severe than they had thought.

Editor's note: This article was printed in part in a previous issue of FOCUS.

Conferences help ease the pain of living with chronic disease

By Lisa Pullen

Last year I wrote an article about what it was like to grow up with ichthyosis. After I wrote the article, I received a phone call from Dave in Ohio who also had ichthyosis and had a childhood very similar to mine. I don't know if I can explain what that first phone call was like. For the first five minutes I was speechless. From then on it was like a wall had crumbled and we talked for about two hours. Since then, I have written to others who have contacted me through the newsletter.

When I found out about the Florida conference last summer, Dave and I decided to meet there.

The notice that there was going to be a conference was incredible to me because I finally would be able to meet others with ichthyosis for the first time.

The conference was amazing. The workshops were the best part from my point of view. In a way, it was painful remembering what it was like growing up and discussing this with parents who have children with ichthyosis. But after awhile of listening to others with the same problems, the same emotions, it was as if a burden was eased - a burden that I didn't even know I had. I don't

know if this makes any sense to you, but I know that those workshops helped me more than I can ever say.

The conference was everything I had hoped it would be, and more. I came away with lots of information, feeling better about myself, new ways to deal with my ichthyosis, and best of all, a whole bunch of new friends.

(Look for information about the upcoming Williamsburg conference elsewhere in this newsletter.)



Kathy Rogers and Karen Shouse

Off to Atlanta!

The American Academy of Dermatology met in Atlanta in December. F.I.R.S.T. hosted a Medical Advisory Board meeting at the Marriott Marquis. This meeting, chaired by Dr. Leonard Milstone, was well attended and several important issues were discussed. Plans are beginning for a national registry which will be an important tool for future researchers.

Ellen Rowe of Raleigh, NC, Kathy Rogers of Austin, TX, Jan Hudson of Peachtree City, GA, Justine Seman of Acworth, GA and Karen Shouse of Atlanta, GA helped with arrangements for the meetings and our exhibit at the convention center. Many thanks to all of them for the time and energy they so generously volunteered.



Jan Hudson

New ruling may change SSI benefits for children

On Feb. 2, 1990 the Supreme Court handed down a landmark decision in the case *Zebley vs. Sullivan*. Brian Zebley, an 11-year old child, suffers from congenital brain damage, mental retardation, eye problems and paralysis. In 1983, when he was 4, the Social Security Administration cut off his social security income (SSI) benefits saying he was not sufficiently disabled to qualify.

Unfortunately, the Social Security Administration's list of impairments does not include most rare disorders. The Supreme Court ruled that children are not being evaluated properly and have been unfairly denied individual assessments.

If your child has been denied SSI because ichthyosis is not on the list, or because the Social Security Administration has claimed that your child's ichthyosis is not severe enough to qualify

him/her for benefits, you should contact the Social Security Administration immediately. Tell them you would like your child's case re-opened and reviewed using interim standards and criteria established under *Zebley vs. Sullivan*.

Your child may be entitled to retroactive benefits including Medicaid in states where the SSI application is also a Medicaid application.

If your child has been denied benefits, the National Organization of Social Security Claimants Representatives (NOSSCR) may be able to help. This is a national organization of attorneys who specialize in Social Security law. If one of these lawyers takes your case, he will charge 25% of the retroactive payments when the case is won, or zero if the case is lost (except for any out-of-pocket expenses).

Please write to F.I.R.S.T. if you are having

problems with SSI. We would like to advocate in your behalf.

Privacy is important

In the last legislative session of Congress, Rep. John Conyers (D-MI) introduced the Human Genome Privacy Act (H.R. 5612) which would have safeguarded privacy of genetic information in an effort to avoid discrimination against people with genetic disorders.

This U.S. law would, however, apply only to government agencies and their affiliates. It is hoped that hearings will take place in the spring, and the law might be passed in the new session of Congress, providing model legislation for the private sector.

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

Please put me on the mailing list:

NAME _____

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Single \$20/year

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Please accept my donation of \$ _____

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

Ichthyosis type in my family _____ # Persons _____

Mail to: P.O. Box 20921, Raleigh, N.C. 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.

Flip your wig and enjoy life

Some people with ichthyosis do not have a head of hair like Farrah Fawcett's luxurious locks. In fact, some of us don't have any hair at all. The hair just doesn't seem to grow through the thickened skin on the scalp.

If you have this problem, and would like to learn more about buying a wig that looks natural, contact The National Alopecia Areata Foundation, 714 C Street, Suite 216, San Rafael, CA 94901. Alopecia Areata is a skin disease that affects the hair follicles anywhere on the body. Certain creams, ointments, injections and pills have been known to help.

Anyone who would like to share ideas for dealing with hair loss due to ichthyosis is invited to write to F.I.R.S.T. and we will print your suggestions in the next newsletter.

Dear Readers:

Wedding bells have been ringing for some of our members lately. Last year, John and Ann Rindosh were married and are now living in Brandon, Florida, where John is a teacher. John and Ann met each other through our newsletter. Both of them have ichthyosis and began writing each other after Ann's name appeared in Correspondence Corner a few years ago. Congratulations to you both as your first anniversary draws near.

Also, Debra Dorazio and Wayne Traina were married on November 17. Debra and Wayne have been dating for years. Debra has ichthyosis, and she brought Wayne to last summer's conference so that he could learn more about the disorder. They now live in Pembroke Pines, Florida.

Paula Lange of St. Charles, MN was married last spring and now has a new baby, Alicia Elizabeth, who was born with normal skin and a beautiful head of hair, reports Paula. Welcome to the family, Alicia!

Let us know about what is going on in your life. And keep us informed if you plan to move. The post office does not forward bulk rate mail. Just drop us a card.

Things at our office are going smoothly. We were recently given a Xerox machine which is now being repaired. We also had to replace part of our computer system this winter. Mail has been steady due to the printing of our address in Dr. Bruckheim's column all over the United States.

The office will be open Monday through Friday from 1 p.m. until 4 p.m. if you wish to call. And if you are ever in Raleigh, please come by and visit. The street address is 3824 Barrett Drive, Suite 205, Raleigh, NC 27609.

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