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

ICHTHYOSIS FOCUS

Vol. 20, No. 4 A Quarterly Journal for Friends of F.I.R.S.T. Winter 2002

Ichthyosis Research

The last few years have seen considerable advances in our understanding of most of the major forms of ichthyosis. A few years ago knowledge was limited to a number of clinical descriptions, many of which were rather verbose and imprecise. Now, however, we are starting to get a much better appreciation of the specific inherited biochemical, structural and genetic abnormalities that change the function of the skin barrier resulting in scaling, redness, water loss or itching, skin thickening or peeling.

Discovering the underlying genetic cause of a particular form of ichthyosis is the first and crucial step in developing and applying technology to help affected people and their families. Precise gene abnormalities have now been discovered in several of the ichthyoses, although the cause of the most common form of inherited ichthyosis, ichthyosis vulgaris, remains a mystery. For those conditions in which the genes are known, the immediate benefits relate to being able to establish a precise diagnosis and to improving genetic counseling, which may also include discussions about antenatal diagnosis. In the longer term, discovering an abnormal gene has implications for the development of newer forms of treatment, including gene therapy.

Almost 5 years ago, a group from Stanford University in California reported their initial experiments aimed at developing gene therapy for lamellar ichthyosis. Their findings, published in the journal Nature Medicine, described engineering copies of the transglutaminase 1 gene (one of the abnormal genes in lamellar ichthyosis - there are others) and inserting the gene into skin cells (ketatinocytes) taken from a patient with lamellar ichthyosis. These cells were then grafted onto a mouse that lacked an intact immune system, so it would not reject the human tissue, and the behavior of the new, modified skin was observed. Dramatic improvements of the function of the skin were seen with elimination of the skin scaling and restoration of the epidermal barrier function with less water loss. Unfortunately, these exciting initial observations could not be maintained and the new gene function was lost after a few weeks. Since that time, this group of researchers and several others from around the world, have continued to try to refine the methods of delivery of new genes into keratinocytes. Efforts have focused on the delivery package (e.g. modified forms of viruses capable of getting into the cells in high numbers), the keratinocyte target (i.e. "stem cells" that give rise to all the other cells in the epidermis), and regulating the expression of genes (control switches for turning genes on or off, up or down).

continued on page 8

Register Now!!!

2002 Conference

A Family Affair: Caring, Sharing & Support

July 5-7, 2002
Seattle, Washington

Early Bird Registration
Deadline for Reduced Fees
March 15, 2002

See page 14 & 15 for details

Ichthyosis Focus

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Request to reprint information contained in Ichthyosis Focus should be directed to the editor.

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

Correspondence Corner

Hi F.I.R.S.T.!

A couple of days ago after our "Christmas in July" concert, I met an elderly woman with ichthyosis. Her ichthyosis is mostly on her arms and legs. We met her at a local theatrical production. She came over to us at intermission to find out who Bailey's dermatologist is and what kind of lotion she uses. I kept thinking, "She looks so familiar." So after the play I asked her who she was. Talk about a small world… She was my guidance counselor in elementary school!!

We stopped to visit her yesterday and gave her a jar of PDS to try. We also gave her one of the tri-fold brochures for F.I.R.S.T. She would like to become a member. She handed me the money so I am forwarding it and her info to you. She is a wonderful lady, and it was so interesting to hear what it was like for her growing up with ichthyosis. Times have definitely changed!

I can't wait to hear her reaction when she gets her first newsletter. She didn't know there was an organization out there, and I know she'll be amazed and overwhelmed when she sees all the information! It's like she's found a whole new world to explore!

I realize once again how blessed and fortunate we were to find you within a week of Bailey's birth. And it proves the desperate need we have to increase awareness, not only about ichthyosis but about F.I.R.S.T. I can't help but wonder how many other people there are in the world that thought they were the only one.

Thanks so much for all you do!! We really need you and we greatly appreciate your support and assistance!

God bless you all,
Tracie Pretak
Wilcox, PA

I was so glad to get a response from someone who could help me determine the cause of Folliculitis. I had never heard of it before and your foundation was quick to reply and then give me additional information the next day. Maureen, your Program Director, thought of something else after her reply and was quick to mention it to me. She even helped me determine the cause. I am so happy you are on the internet for people like me who have been diagnosed but who do not thoroughly understand the meaning and what to do about it. This was so great. My thanks go to you and your staff for being the only one to reply to me after searching for 2 days to find information. Thank you again for being there.

Sharon Smithers

Dear FIRST,

Well, it's the holiday season again - the time to be with friends and family. Even though you may know everything about your friends and family (or maybe because of that), it's often wise to have some planned activities on hand. (When you're on your fifteenth hour of togetherness, even sorting the recycling starts to look fun). Here are some affordable options for indoor activities to do with kids, family or friends for fun or for gift production. The web site http://www.make-stuff.com/gifts.html offers a ton of do-it-yourself craft projects that use common household items and recyclables. You won't see many items from this site at Neiman Marcus, but you've got to admit that a soda can snowman and a toilet paper tube wreath pique your curiosity!

Happy Holidays!
Margie Henderson
New Castle, PA

Maury Povich Show

F.I.R.S.T. cuties Hunter Steinitz, and Magui and Isabella Santos, appeared recently on the Maury Povich Show. Magui and Isabella, who both have Netherton Syndrome, appeared on the show previously to talk about how their disease affected them and some of the challenges they have faced. The girls are teenagers, and as you might imagine, they have experienced some isolation and cruelty from their peers. They are each other's best friends and don't have many friends besides each other.

The girls were invited back to the show and were introduced in a surprise visit to Hunter Steintiz. Hunter, age 7, with Harlequin ichthyosis, was thrilled to make friends with Magui and Isabella and to show them that there was someone else in the world who looks and feels like they do. The show treated the girls and their moms to a limousine ride and lunch at the Hard Rock Café. The Hard Rock Café staff treated the girls to all kinds of surprises along with a cake for Hunter's 7th birthday. It was quite an experience for all.

F.I.R.S.T. extends its appreciation to the staff of the Maury Povich Show for its generosity to the girls and their families, and for highlighting the challenges that children ichthyosis face.

In Memory of Mary J. Benak

F.I.R.S.T. extends its sympathies to the family of Mary J. Benak. Mrs. Benak died on September 20 at the home of her daughter, Judy Williams, in Coatesville, PA. She is survived by her daughter and two grandchildren, one of whom has ichthyosis. Mary was a member of Grace Lutheran Church, Phillipsburg, PA, and was a devoted volunteer to the Mountain Lake Fire Company Ladies Auxiliary, Mountain Lake, NJ, and the Safety First Volunteer Fire Company of Easton, PA. F.I.R.S.T. is grateful to receive donations in Mary's memory from family and friends totaling $230.

Coping with Disaster

By Audrey Kron, M.A., CGP

It is so hard to believe what happened to us on September 11. It is a day we will never forget. Many of you with chronic illness are asking how you can cope with a disaster of such magnitude. Believe it or not, you may already have some of the coping skills that are necessary to get through this difficult time and the uncertainty of the days ahead. After the attack many of you had feelings of helplessness. Terrorists rely on methods of creating feelings of fear and helplessness in the whole country. Many of you will recognize these feelings as being, to a smaller extent, the same ones you experienced when you were first diagnosed. As time went on you learned to get your life back in control. That is our mission now. Continue being courageous.

Here are a few ideas to help you get some semblance of control back in your life:

1. Make sure you take care of your body. This is a time of additional stress, which can aggravate most illness. You need to pay extra attention to getting enough rest, proper diet, and appropriate exercise.
2. Spend extra time on what gives you emotional or spiritual support. It may be appreciating nature, listening to music, reading uplifting material, or finding solace in whatever your religious beliefs are.
3. Be prepared. Obviously no one can prepare for these disasters, but there are some things you can do. It is important to have a sufficient supply of your medications or equipment readily available in case deliveries are temporarily disrupted.
4. Find a supportive community where you can share feelings. It could be a group at your church or synagogue, your chronic illness support organization, a toastmaster club, a special interest group, etc. If you don’t have at least one group that can be supportive at this time, it’s a good opportunity to find one.
5. Be more understanding of family and friends. Everyone is affected and some people can react with intensified feelings.
6. Spread love not terror. Everyone needs love, especially now. Love is something that, the more you give it away, the more you get it back.
7. Call the Red Cross to make an appointment to give blood or volunteer. Helping others has always been a good way to cope and it’s even more important now.
8. Send money to the various groups that are working to help the families that have been devastated by the attack. You might even organize some type of fund raising event. It could be on a grand scale or it could just be something simple, like selling baked goods. Use your imagination.
9. Teach your children to love and not to hate. Everything starts in the home. You can at least influence the people in your life.
10. Try to live your life as normally as you can. We never know what the future will bring. That’s familiar to us. We can’t just hide and try to avoid all disaster.
11. Be creative. Write a poem, story, article, paint a picture, compose a song or some other music. Put your feelings into some artistic form. It will be therapeutic for you and others can then enjoy it as well.
12. Get accurate information. Now is not the time to accept or pass on unsubstantiated rumors.
13. Have faith in our country. It may mean investing or shopping. If we all run in fear, the terrorist will have won and our economy will be badly hurt.
14. Laugh. Yes, I said laugh. Laughter is a good medicine and we already have learned that it helps us cope.
15. Talk about your feelings. Feelings of fear, sadness and anger are just a few of the feelings that are quite normal in these times and they need an outlet
16. Look to friends and family for a source of comfort. Now is the time to talk to all those people you meant to call and then got busy and forgot.
17. If your feelings are immobilizing you, get professional help. It is not a sin. It doesn’t mean you are crazy. It just means that we are living through extraordinary times.
18. Appreciate the “ now.” Learn to enjoy all the positive things in your life.

September 11, 2001 is a day like most of us have never witnessed before. We cannot let those cowardly terrorists win. We will Meet the Challenge.

For questions or comments, Audrey may be reached at 248-626-6960, e-mail: shrinkA@aol.com, or at her web page www. chronicillness. com

Audrey Kron is a medical psychotherapist, marriage counselor, and author of *Ask Audrey*, and *Meeting the Challenge: Living with Chronic Illness*.

Executive Director's Report

Dear Friends & Members of F.I.R.S.T.:

During these past few months, our lives have been affected by the tragic terrorist attacks on our country. It has made many reflect on how dearly we cherish our family and friends. Some of you may have known someone who was a victim of these horrible events, while others may have relatives or friends who have left the safety of their home to fight for our country. On behalf of the board and staff, I would like to extend my condolences and encouragement for brighter times ahead.

Beginning in January, the foundation will see a change in board leadership. Donna Rice, F.I.R.S.T.'s president for the past five years, will be stepping down from this position. Laura Phillips will take over at the helm and continue the great work Donna has achieved. Donna's dedication and service to the foundation has been truly exceptional. Thankfully, Donna will remain an active board member and we can be assured of her continued commitment.

Some of you may have met our new president, Laura, at a family conference or chatted with her online at ichthyosis.com, her own personal website. Feel free to continue to tap her valuable resources. Also joining our Executive Committee as Secretary is Tiffany Karst. Tiffany has been a very active board member for the past five years. Both Laura and Tiffany come to us with a wealth of experience, enthusiasm and fresh ideas. I look forward to working with them in the upcoming year. I know they will make many positive contributions to advance the mission of F.I.R.S.T.

We are in the final stages of establishing a Strategic Plan for the next three to five years. Our Strategic Planning Committee has been working hard for over a year and their commitment to this project has been untiring. When this plan is finalized, it will map out the direction F.I.R.S.T. will take in the future regarding many important issues. F.I.R.S.T. has been growing in membership and financial stability in recent years. This plan is critical to determine the best way to serve the needs of our members and the ichthyosis community. On November 3, the Board of Directors met in Philadelphia for our annual board retreat. The main objective of this meeting was to review future goals of F.I.R.S.T. and discuss our philosophy to support these goals. In the next few issues of the newsletter, I will be explaining our Strategic Plan in more detail.

The 2002 Family Conference will be here before you know it. Scheduled dates are July 5-7, 2002 in Seattle, Washington. The past two conferences were held on the east coast so I expect to see an increase in attendance, so make your reservations early. The conferences are very important to families affected by ichthyosis. Affected adults and children can meet others who have ichthyosis. It will provide you with an opportunity to speak and personally meet with physicians who specialize in ichthyosis and its treatment. Plus much more! I strongly encourage you to come to Seattle this summer. If you are still unsure, our staff can connect you with other families who have attended conferences in the past. You can talk with someone F.I.R.S.T.-hand about the benefits of this unique gathering.

You should have recently received our annual holiday card and appeal envelope. If you have not done so yet, please consider making a donation to F.I.R.S.T. No matter if your gift is large or small, please send what you can. Every donation brings us closer to finding effective treatments and a cure. Because of members like you, F.I.R.S.T. is growing stronger everyday.

Sincerely,

Jean

Jean Pickford

PS - F.I.R.S.T. can distribute the Focus newsletter online. If you would like to receive it electronically, please let me know by checking the box on your holiday appeal envelope and providing your email address. You may also contact me directly at jpickford@scalyskin.org.

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

It has been an honor and a pleasure to serve FIRST as president of the board the past 5 years. I have enjoyed this period of service which has provided me with many enriching experiences.

I am equally honored to remain on the board for another term and look forward to the growth that will undoubtedly occur under the leadership of Laura Philips, our new president. Laura has been both CFO and Secretary of the board and in spite of the many demands upon her time; the welfare of FIRST has always been her prime concern. Her record of accomplishments in her profession, as a Certified Public Accountant, as well as her volunteer service to FIRST ensures us that this foundation will go forward to greater achievements.

FIRST is also fortunate to welcome Tiffany Karst as Secretary. Tiffany is a social worker at the University of Kansas Medical Center and is serving her second term on the board. She has been a tireless grassroots fundraiser for many years.

Please join me in welcoming Laura and Tiffany and thanking them for their commitment to the mission of this organization.

Sincerely,

Donna Rice

From One Dad to Another

Kathleen Mary Smith was born on October 13, 1984, arriving a few weeks earlier than expected. As any parents, my wife, Jackie, and I just wanted a healthy baby. When Katie arrived I could see right away that something was wrong; not only by the way she looked but by the doctor's and nurses' reactions. The doctor told the nurse to call the ICU and in a flash Katie was in an incubator and we were both on our way to the unit.

I was told to wait in an office for the doctor. After waiting for what felt like a lifetime, I got restless and happened to look at a book on the desk. It was opened to a page that had ichthyosis on it, with several pictures of children and adults with the disease. I could not comprehend what I was looking at. I was thinking will little Katie live, and if she does, how is she going to get through life with this skin that looks so unbelievable? I went to find a nurse and insisted she let me see Katie. Katie looked like she had been pulled from a fire; her skin was almost purple and looked so sore. She was encased from head to toe in skin. All I could do is wait for the doctor.

Dr. Joseph Alper examined Katie and told me that she probably had lamellar ichthyosis. I told him what I had seen in the book and he did what he could to comfort me. Then I had to tell Jackie what Katie had and what the prognosis was. I tried to prepare her for what she was about to see. The first thing Jackie said when she saw and held Katie was, "She is so beautiful." Thinking about that moment in time still gives me chills because I have never witnessed so much love and strength as I did that day. Jackie has never looked back and has been a source of strength for Katie and our whole family.

One of our concerns was how our daughter Shannon would react to her new baby sister. But all Shannon cared about was that she had a new little sister. She liked helping with Katie's care, especially her baths. Shannon was like her little nurse and loved being a big sister. Her attitude never changed over the years and is still a great big sister. We are truly blessed with both our girls.

Dr. Alper treated Katie up until his retirement last year. The support we had from him was so important. There are so many questions about what to do, and how, and why. Dr. Alper always gave us hope. And it's hope that keeps you going so you can be the best parents you can be.

Fathers are protective of their children. For children with something like ichthyosis many people are rude, mean and just plain ignorant. I have chosen to confront someone who is rude, or points or stares, so hopefully the next time they see someone different they will think twice about their behavior. I know a lot of people will disagree with my way of dealing with these situations, but I find that it gives Katie a large part of her self-confidence. I never avoid something because of someone's indifference or ignorance. I want my daughter to go and do anything she desires. If your child feels you avoid situations or places because of their ichthyosis you lower their self-worth. The most terrible thing that could happen is that your child knows that you are embarrassed by them. Can you think of a more devastating feeling for a child? Everyone has to deal with their own life in their own way, but I really feel that if your pride and love for your child is shown and known to them privately and publicly, true confidence will fill their hearts and minds.

We attended the F.I.R.S.T. Family conference in Philadelphia last year. It was our first time attending a conference and our first opportunity to meet others with ichthyosis. The conference was a emotional and heart warming experience. Katie connected with other girls her age and became fast friends with one in particular. They both flew out to the Teen Camp in Minnesota this summer. Katie is anxious to get her driver's license soon. If anything scare me as a father now, this does.

I wanted to share my thoughts and if this is of any help to anyone, I'm glad I did.

From just another Dad,
Ted Smith
South Attleboro, MA

News & Notes

State Children's Health Insurance Medical Insurance for Children of Working Families

Did you know that your state, and every state in the union, has a health insurance program for infants, children and teens? If you work but still can't afford health insurance for your children, your family may be eligible for free or low cost health insurance through the State Children's Health Insurance Program. For little or no cost, this insurance pays for doctor visits, prescription medicines, hospitalizations and much more. Most states cover the cost of dental care, eye care, and medical equipment.

Guidelines and eligibility vary from state to state, but in most states uninsured children, 18 years old and younger, whose families earn up to $34,100 a year (for a family of four) are eligible. The name of the insurance is different from state to state, but all 50 states offer a state children's health insurance program, as well as the District of Columbia and the U.S. territories of American Samoa, Commonwealth of Northern Mariana Islands, Guam, Puerto Rico, and the U.S. Virgin Islands. Children's health insurance programs are not welfare programs. They are designed to help working and low-income families provide health insurance for their children. Depending on your income and the state you live in, it may be possible for your entire family to receive health insurance.

To find out more about the State Children's Health Insurance Programs where you live go to www.insurekidsnow.gov and click on Your State's Program. Or call 1-877-KIDS-NOW (1-877-543-7669), or call Maureen in the F.I.R.S.T. office, 1-800-545-3286.

Resurrected Priority: Stem Cells

Reprinted from NORD, December 2001

Last summer, President Bush made a major speech to the nation announcing his decision in the fetal stem cell debate. The President said that federal funds could not be used to extract stem cells from fertilized embryos if the stem cells were extracted after the date of his speech. However, research on stem cell lines that existed before his speech would be allowed.

The ethical debate about stem cells virtually disappeared after September 11, but during the week of November 26 it was resurrected when a small Massachusetts biotechnology firm, Advanced Cell Technology, announced that it had cloned human embryos for the purpose of providing sources of stem cells for therapeutic uses. The announcement triggered an intense political debate calling for immediate enactment of a prohibition against cloning. The House passed the legislation several months ago, but the Senate has not yet acted on the bill.

The New York Times, however, says the human cloning experiment was a failure, not a success, because none of the cells lived more than a few days. Furthermore, the therapeutic use of stem cells is still theoretical; scientists have not yet proven that stem cells will help animals, no less humans. But the announcement by Advanced Cell Technology has triggered an intense political reaction that may further stifle this promising field of investigation because Congress is now aware that the private sector may not observe the same ethical boundaries that publicly-funded researchers are compelled to follow.

Bloomingdale GA – Regional Meeting

October 13th marked F.I.R.S.T.'s 2nd Regional Meeting. Patrice Russell, a long-time member of F.I.R.S.T., hosted the daylong event in Bloomingdale, Georgia. Nineteen local F.I.RS.T. members gathered for a day of sharing and learning. Special thanks to Dr. Mary Spraker of the Emory University School of Medicine Department of Dermatology, and member of F.I.R.S.T.'s Medical Advisory Board, who attended the conference to provide medical information about ichthyosis to the attendees.

The day began with a morning reception and registration. Dr. Spraker discussed various aspects of ichthyosis, including treatment methods, research and new genetic findings. After a down-home southern barbeque lunch, participants participated in a question and answer session with Dr. Spraker, as well as an open discussion. The nine children in attendance had the chance to participate in activities including pony rides, T-shirt painting, and a puppet show.

Thanks to everyone who participated to help make this Regional Meeting a success, especially Patrice Russell for coordinating the event and to Dr. Spraker for taking a day out of her busy schedule to speak at the meeting.

Randy LaBarbera and Merritt Andrews

Patrice and Randy Russell

Greg Studdard and Mary Spraker, MD

ASK THE READERS: What Do You Do?

We have developed **ASK THE READERS:** What Do You Do? to share this valuable information with others. Each issue will ask a question of our readers and we will print your answers. If you have any advice you would like to share, please take a moment and send in your comments.

When your child gets a scrape or cut, what do you do about a band-aid that just won't stick?

We try to avoid adhesive bandages altogether, since they tear the skin when they are removed. (My daughter has EHK.) Instead, we use a telfa gauze pad to cover the wound and then wrap a soft gauze bandage around the limb (or whatever is injured) taping the soft gauze to itself, not the skin.

It is very important to notify hospital personnel in the emergency room or before surgery that adhesive bandages should not be used. Especially avoid the sticky adhesive bandages that are used to attach heart monitors, secure IV's, or to dress surgical wounds. The skin will definitely tear away, sometimes complicating the reason that brought you to the hospital in the first place.

Betsey B. Freed, Santa Barbara, CA

My daughter is 5 years old and gets scrapes and also cracks on the bottom of her feet from dryness. She has lamellar ichthyosis. We have found that the only bandage that works on her skin is *Nexcare First Aid Waterproof Bandages* by the 3M Company. They are made of latex. We buy the cute tattoo ones; they are clear and highly flexible. They stick to her skin even after getting wet and applying cream! I swear by these bandages.

They can be purchased at any drug store. We buy them at Wal-Mart. I even wrote 3M to tell them how wonderful these bandages are and they offered me a free box! I thought that was great!

Jenny McMillan, Chicago, IL

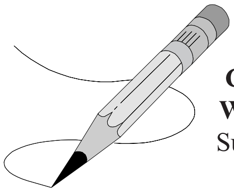
Cover the cut with a gauze square coated with a little ointment or Vaseline. Use stretch cotton gauze to wrap over the gauze square and hold it in place. Secure the end of the stretch gauze with tape.

Raymond Reed, Jr., Delanco, NJ

Here's our next question:

How have you and your child's school personnel partnered together to provide adequate time and resources for the care of their ichthyosis?

Send us your comments. We will print the responses in the next newsletter. Here's how to contact us:



E-mail: info@scalyskin.org
Fax: 215.631.1413
Call: 800.545.3286
Write: 650 N. Cannon Avenue,
Suite 17, Lansdale, PA 19446

Ichthyosis Research

continued from page 1

Considerable work has also gone into analyzing the safety of gene modification strategies as well as what happens to the human immune system if it is suddenly exposed to the product of a new gene that it has never met before. All of these are major considerations when it comes to the design of successful gene therapy approaches. The science may still be in the laboratory, but further "mouse models" are already emerging and, statutory regulation permitting, human trials are now a more realistic proposition than they have been for some time.

So, the progress to report is that researchers now have a much better handle on the causes of most forms of ichthyosis and that we should now anticipate further reports of gene therapy studies. Most of these will represent minor advances, taking the science forward step-by-step and learning more about how newly transferred genes behave, but gradually we will get closer and closer towards those studies that have a major impact on ichthyosis sufferers and their families.

John McGrath
Professor of Molecular Dermatology
St. John's Institute of Dermatology
St. Thomas' Hospital, London, England

"In general, the goal in taking care of ichthyosis is to hydrate (moisturize) the skin, hold in the moisture, and keep scale thickness to a minimum."*

**Foundation for Ichthyosis & Related Skin Types, http://www.scalyskin.org*

Aquaphor® Healing Ointment helps heal dry skin associated with ichthyosis. Its unique petrolatum-based formulation combines a moist environment with the benefits of a semi-occlusive barrier that allows skin to breathe and absorb fluids.

Aquaphor is ideal for daily use because it is hypoallergenic, non-comedogenic, fragrance and preservative-free. Aquaphor Healing Ointment is safe enough for even the most sensitive skin.

Special Offer

For Readers of this F.I.R.S.T. Newsletter

MANUFACTURER'S COUPON | EXPIRES 12/31/01

Save $2.00 on any Aquaphor® Product

(NO TRIAL SIZES)

Consumer: Coupon good on the purchase of any Aquaphor® Product, no trial sizes. Limit one coupon per item purchased. Any other use constitutes fraud. Not good with any other special offer. Consumer must pay sales tax.
Retailer: You are authorized to act as our agent to redeem this coupon and we shall reimburse you at face value plus 8¢ handling in accordance with our redemption policy. Cash value 1/100¢. Copies available upon request. Offer void if copied and where prohibited, taxed or otherwise restricted. Mail to: Beiersdorf Inc, PO Box 880504, El Paso, TX 88588-0504. Good only in USA.

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5 72140 33082 3 (8101)0 10658 1201

ISN Education & Training Coping and Crisis Information

Part 3 — Signs and Symptoms of Depression

Everyone feels blue, or down, now and then in response to life's disappointments or to unusual challenges. But when certain feelings persist and keep you from functioning normally they may be signs of depression. If, during your conversations, the person you are supporting reports any of the following symptoms, you may want to encourage them to talk to a health professional.

- Persistent feelings of anxiety, sadness or emptiness.
- Loss of interest in things they once enjoyed.
- Insomnia, oversleeping, early morning awakening.
- Significant changes in appetite or body weight.
- Overwhelming fatigue.
- Restlessness, irritability.
- Difficulty concentrating, remembering, or making decisions.
- Persistent physical symptoms that don't respond to treatment such as headaches, digestive symptoms like nausea or diarrhea, or chronic pain.
- Feelings of guilt, hopelessness, worthlessness, helplessness.

If the caller reports that any of these symptoms are keeping them from functioning normally, encourage them to contact their family doctor or a mental health professional. The sooner depression is treated the sooner recovery, and normal functioning, can begin.

A New Service at F.I.R.S.T.: Honor and Memorial Cards

Tired of going to the card store and spending lots of money? Here's a great way to send out honor or memorial cards to your family and friends while supporting the foundation. F.I.R.S.T. has created two very special cards, one for memorial acknowledgements and the other to honor someone's life event (i.e. birthday, engagement, marriage, religious milestone, new home, etc.). It's simple and easy to do and provides a thoughtful way to recognize your family and friends. Here's how to send a card:

Complete the form below and return it to the F.I.R.S.T. office at 650 N. Cannon Avenue, Suite 17, Lansdale, PA 19446 with your check or credit card information. Order a packet of six cards and envelopes, three of each kind. Keep your cards on hand and use them as needed.

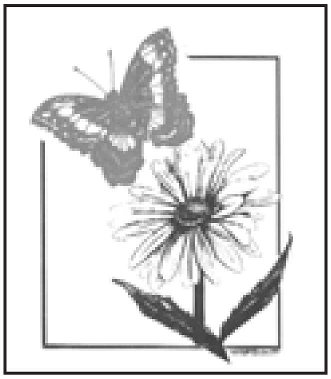
You may also contact the office via email, phone or mail with the necessary information including the type of occasion, name & address of recipient and name & address of sender. We'll send the card for you! Your card will be sent on the very same day we receive your request. Special thanks to Merritt Andrews, age 31, affected with lamellar ichthyosis. Merritt donated the artwork for these beautiful cards. Thank you for supporting the important work of the Foundation for Ichthyosis & Related Skin Types, Inc.

A donation has been made
in honor of
____

to the

Foundation for Ichthyosis
& Related Skin Tuypes

by
____
____
____



A donation has been made
in memory of
____

to the

Foundation for Ichthyosis
& Related Skin Tuypes

by
____
____
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☐ Please send me _______ packet(s) of six cards @ $25.00 each. Total $________

☐ Please send me _______ individual memorial cards @ $5.00 each. Total $________

☐ Please send me _______ individual honor cards @ $5.00 each. Total $________

Name ____

Address ____

City ______________________________ State __________ Zip __________

Phone ____

Payment Method: ___ check ___ credit card Account # ______________________ Expiration Date ________

(Visa, Mastercard and American Express)

What's New, What's Hot & What Works…

My 30 year old son suffers from Congenital Ichthyosiform Erythroderma (CIE). We have treated him for the last 30 years with Retin A, which as you know is very expensive. A few months ago I was using ammonia to clean something, so I put on some latex gloves to protect my hands. When I took off the gloves a large amount of dead skin was inside the gloves. At first I didn't think that much about it, but then I began wondering if there was an application for my son's condition.

A few days later I went to local dive shop and bought him a diving suit (wet suit). He puts it on, after either wetting the inside of the t or his body with water, d keeps it on for 20 to 30 nutes. It works much better than the Retin A for exfoliating dead skin. After taking the suit off he bathes and applies Aquaphor for moisturizing. Using the suit this way has allowed him to cut way back on the Retin A. His skin is better and I have saved many times the cost of the suit. (I bought the cheapest one I could find, $100. to $120.)

Maybe this idea would be applicable to someone else.

Sincerely,
Arnold Zimmerman
Gainesville, FL

I have found with little babies the diaper makes a difference in their skin. Pampers brand works wonderfully and are the only ones my daughter can wear that don't irritate her skin.

A tip for clothes washing, use *All Free & Clear*.

Diana Lynn Walton
Shreveport, LA

Product Listing

F.I.R.S.T. has a listing of over 50 products and/or companies that may help in your skin care. This list contains suggested products and their active ingredients, manufacturer names, phone numbers and stores where they are sold. The product listing is not intended to be exhaustive or all-inclusive and F.I.R.S.T. does not endorse or recommend any of these products. We have compiled this list as a service to our members. F.I.R.S.T. encourages you to consult with your dermatologist for treatment advice. If you would like a copy of this product listing, log on to our website www.scalyskin.org and click on the "members only" section. You will need a password to enter this section, so contact the national office for this information at info@scalyskin.org or 800-545-3286.

The Ichthyosis Registry Needs You!!

The National Registry for Ichthyosis and Related Disorders needs you to reach their goal of enrolling every person in the U.S. with ichthyosis (with the exception of ichthyosis vulgaris). The registry is funded by the National Institutes of Health to promote research into the diagnosis and treatment of the ichthyosis. The bigger the registry is, the more they can do to promote understanding about the ichthyosis, and that leads to better treatment.

What can enrolling in the registry do for you?

- The registry can confirm or clarify your diagnosis. You can share that information with your doctor.
- Depending on the form of ichthyosis you have, you may be eligible to be tested for a genetic diagnosis, and genetic counseling regarding that diagnosis. The specific genetic mutations for several forms of ichthyosis have been identified.
- As a Registry enrollee, you can choose to be notified about research studies related to your particular form of ichthyosis. You can then choose to contact the investigator or not – there is no obligation to participate. Your information will be kept completely confidential.

Even if you are not interested in participating in research projects, sharing your diagnosis and how it affects you with the Registry helps create a valuable resource for those researchers who are interested in studying and treating people with ichthyosis and related disorders. The Registry uses the information that you share with them to educate dermatologists and researchers about the Registry and its resources by: presenting information at scientific meetings; publishing notices in medical journals; and providing a doctor's forum on the Registry website for doctors to ask questions about ichthyosis. Enrolling is quick, easy and private; your name and personal information are never shared. To enroll now, contact Geoff Hamill, Registry Coordinator, at 1-800-595-1265, or email him at info@skinregistry.org, or visit the website at www.skinregistry.org. Not sure you want to do this or need more information, call Maureen in the Foundation office, 1-800-545-3286.

Let's See What Our Members Have Been Up To...

F.I.R.S.T members **Melissa and Doug Osterloth**, from Wauwatosa, WI, hosted a fundraiser on October 13 to educate their community about ichthyosis, and raise funds for F.I.R.S.T. Both friends and neighbors lent support, helping the Osterloths raise over $1000.00 in raffle sales and selling over $2000.00 of Tupperware, of which F.I.R.S.T. receives a percentage. These totals far exceed their original goal of $300.00. Melissa and Doug are planning to make this fundraiser an annual event.

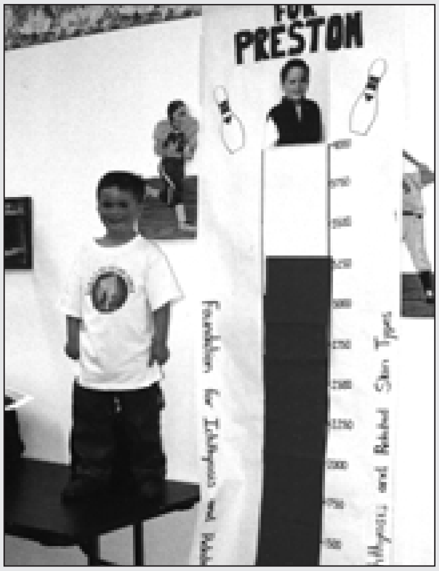
The Osterloths have been members of F.I.R.S.T. since 1999. Their two-year-old daughter, Tatum, has lamellar ichthyosis. F.I.R.S.T. extends their thanks and gratitude to the Osterloth family for their hard work, and to their community for its support.

Easton B. Smith, a long time member of F.I.R.S.T., celebrated his 70th birthday this fall. Ever generous and mindful of the Foundation, he requested that friends and family members make a donation in his name to F.I.R.S.T. Easton is surely loved by his community; donations in honor of his birthday totaled over $800.00. All proceeds will go to ichthyosis research. Thank you Easton and friends for your dedication to F.I.R.S.T.!

Preston Maurer and his family hosted a bowl-a-thon during Ichthyosis Awareness Week (September 30 to October 7) to raise awareness about ichthyosis and funds for F.I.R.S.T. The event turned into a community-wide project and F.I.R.S.T. was the recipient of a very large donation.

The Maurer's had been discussing the idea of hosting a fundraiser for F.I.R.S.T. ever since attending the family conference in Philadelphia during the summer of 2000. They made plans to organize a bowl-a-thon and were hopeful, with the help of family and friends, to raise $1000.00. They never imagined the response they were to receive. Total donations for the bowl-a-thon exceeded $3800.00. An added bonus, a car wash was held by some senior high school students of Redwood Valley High School and their parents. The car wash raised $500.00 which was matched by the AAL.

The Maurer's were truly overwhelmed by the generosity of family, friends, and especially strangers. Their hearts were touched by their community's desire to reach out and help those with special needs. "We were truly amazed at the response, and information we were able to share with our community about ichthyosis." Preston, age 4, was born with Congenital Ichthyosiform Erythroderma (CIE).



Shelby Riggs was featured on the front page of the Boulder City News and was featured in the Las Vegas Tribune in advance of Ichthyosis Awareness Week. Shelby is the daughter of Lori Florian, one of our Ichthyosis Support Network Coordinators. The article detailed Shelby's ichthyosis, CIE, and mentioned the dates for Ichthyosis Awareness Week. Lori and Shelby also organized a carwash fundraiser at their local McDonald's on October 13 to bring attention to ichthyosis and raise funds for F.I.R.S.T.

Entertainment Books are for sale once again this year. These books can be purchased for $25.00 and contain coupons to local businesses in your area. Books are available for all states in the country. The books became available as of August 24th. For each book purchased, F.I.R.S.T. will receive a $5.00. Contact Kelly Strother at the national office at info@scalyskin.org or call 800.545.3286.

Dr. Peyton Weary, F.I.R.S.T. Board of Directors member, recently was awarded the 2001 Community Service Award by the Medical Society of Virginia. This award recognizes a Virginia physician for outstanding initiative, meritorious service, and leadership in the area of community service. The Medical Society of Virginia believes that "the giving of one's self to the community is an integral part of the commitment a physician makes to the practice of medicine."

Dr. Weary, a former President of the American Academy of Dermatology has supported the Foundation for Ichthyosis & Related Skin Types for many years and was a founder of the Coalition of Patient Advocates for Skin Disease Research.

On September 29, 2001, **Rodney Hoover** hosted the Tour of the Flinthills Benefit Ride to kick off Ichthyosis Awareness Week. Prior to the ride Rodney gave an informational talk on ichthyosis and F.I.R.S.T. to the Manhattan Optimist Club in Manhattan, Kansas.

That Saturday morning, Rodney and his brother-in-law Reggie left Flush, Kansas on a 62-mile bike ride across the Flinthills of Pottawatomie County, Kansas. Their first stop was the Rock Creek Historical Society Museum in Westermoreland. They toured the facilities and saw much of the county's wonderful heritage. From there they headed to Blaine for a quick rest. Seven and a half hours after they began, Rodney and Reggie completed their journey in St. George.

Rodney and Reggie raised over $650.00 for the foundation, and had a very enjoyable bike ride through the countryside.

Heading North to Alaska

The day after the Family Conference, F.I.R.S.T. members are invited to participate in a seven-night cruise through the scenic waters of Alaska. The "Inside Passage Classic Alaska 7 Night Cruise" will take place from July 8 - 15, 2002, aboard Holland America Line's ms Volendam. The seven-night cruise will journey from Vancouver, through the forested cliffs and snow-capped mountains of the Inside Passage, to the capital city of Juneau, and the former goldrush town of Skagway. The cruise also goes through Glacier Bay and Ketchikan, also known as the "City of Totems."

Holland America is offering F.I.R.S.T. members discounted rates, which are available through February 28, 2002. F.I.R.S.T. members who need to make reservations or more information should contact Scott White at Convention Cruises Northwest, 1.800.275.9198, or scott@csnwseattle.com.

Prices based on double occupancy
Cancellation Protection Plan (optional): Additional
Port Charges & Taxes (additional): $183.65
Seattle to Vancouver Motorcoach Transfer (optional): $90.00

A $350.00 per person deposit, plus the cancellation fee waiver if accepted, is due in the Convention Services Northwest office one week after reservation is made.

The discounted rates are valid until February 28, 2002. The ship has the right to increase rates at that time. A deposit will guarantee your rate.

Proof of citizenship, either a valid passport OR certified copy of your birth certificate and picture ID is required.

	Brochure Price	F.I.R.S.T. Rate	Savings
Outside Category*			
B Minisuite	$4106.00	$2463.60	$1642.40
F Large	$3146.00	$1887.60	$1258.40
H Large	$2906.00	$1743.60	$1162.40
Inside Category*			
I Large	$2573.00	$1543.80	$1029.20
K Large	$2466.00	$1479.60	$986.40
M Large	$2360.00	$1416.00	$944.00

*Additional categories are available.

Airline Transportation to Seattle

F.I.R.S.T. has made agreements with several major airlines offering discount tickets to the 2002 Family Conference. US Airways, Delta Airlines, and Northwest/KLM/Continental are all offering special round trip discounts to F.I.R.S.T. members traveling to next year's conference.

US Airways

Offering discounted round trip flights from June 30, 2002 to July 12, 2001.

- 7% off following all rules and restrictions
- 10% off with 60 day advance reservations/ticketing required

To obtain these discounts, call US Airways' Group and Meeting Reservation office at 877.874.7687, and refer to Gold File Number 38632202. Certain rules and restrictions apply. Additional discounts are available. Call US Airways from 8:00 a.m. to 9:30 p.m., EST.

Delta Airlines

As an "Official Airline" of the 2002 conference, Delta will be offering discounted round trip tickets from July 2, 2002 to July 10, 2002.

Discounts include:

- 5% discount off US Domestic published fares
- 10% discount for tickets purchased 60 days in advance

Call Delta Meeting Network Reservations at 1.800.241.6760, Monday - Sunday, 8:00 a.m. to 11:00 p.m., EST. Refer to file number 182733A. Additional discounts are also available. Certain rules and restrictions apply.

Northwest/KLM/Continental

A preferred airline of the 2002 conference, discounted tickets are being offered from July 2, 2002 to July 10, 2002.

Discounts include:

- 5% off applicable published fares
- 10% off applicable published fares for tickets purchased 60 days in advance.

Call the Meeting Services Reservations Desk at 1.800.328.1111, Monday - Friday, 7:30 am to 7:30 pm (CT). Refer to WorldFile Number NMWE6. Additional discounts are also available. Certain rules and restrictions apply.

Angel Flight America Program

Through the National Patient Travel Center, you may be eligible for free airfare using the Angel Flight America Program. If you live within 1000 miles of Seattle, Angel Flight will fly a family in a 4-seater or 6-seater small plane to the conference at no cost. Contact the National Patient Travel Center at 888.675.1405 and refer to the 2002 F.I.R.S.T. Family Conference Special Lift Program. If you live outside the 1000 mile limit, they suggest using www.expedia.com or www.orbitz.com to search for the cheapest tickets and order online.

2002 Conference Program

A Family Affair: Caring, Sharing & Support

(subject to change)

ADULTS

(AGES 18 AND UNDER)

Saturday

Opening Remarks
State of the Foundation
Ichthyosis Registry & Related Disorders

Breakouts:

Ask the Doc's, Pediatric Concerns
Ask the Doc's, Adult Concerns
Importance of Family

Clinical Screening

Mom's Discussion
Dad's Discussion
Women's Discussion
Men's Discussion

Sunday

What's New in Research

Breakouts:

ISN Sign-Up & Training
Treatment Options
How to Support Your Kids Through a Medical Procedure
Info Sharing/Helpful Hints

Closing Motivational Speaker

CHILDREN

(AGES 8 AND UNDER)

Saturday & Sunday

Free Child Care and Activities provided by Professional Child Care Providers

CLINICAL SCREENING

A Clinical Screening will be available to all affected individuals. Physicians who specialize in ichthyosis will be available for one-on-one consultation. Screening appointments can be made on Friday, July 5 at the registration table.

TEENS

(AGES 13 – 17)

Saturday

Opening Remarks
State of the Foundation
Ichthyosis Registry & Related Disorders

Healthy Choices in a Fast Food World

Career Panel Discussion

Teen Talk/Doctor Talk

Sunday

What's New in Research

Coping with Social Challenges

Simple Strategies for Personal Safety

Closing Motivational Speaker

TWEENS

(AGES 9 – 12)

Saturday

Opening Remarks
State of the Foundation
Ichthyosis Registry & Related Disorders

Creative Outlets for Personal Expression

Healthy Choices in a Fast Food World

Tween Talk/Doctor Talk

Sunday

What's New in Research

Simple Strategies for Personal Safety

Coping with Social Challenges

Closing Motivational Speaker

Raffle Items Needed

If you work for a company or know someone in business who would be willing to donate an item in support of our raffle, please let Jean know at the office. Items such as a DVD player, trips, electronics, jewelry, housewares, gift certificates, etc. would be greatly appreciated. All donations are fully tax-deductible to the extent allowed by law. Call the office at 800.545.3286 or email at info@scalyskin.org.

Room Reservations

Call 800.643.5479 to make your room reservations. F.I.R.S.T.'s discounted price is $89.00 + applicable taxes per room, flat occupancy. Be sure to mention this group rate is reserved under Foundation for Ichthyosis. The deadline for room reservations is June 13, 2002. This rate is available from June 30 to July 9, 2002 if you are planning an extended stay.

Seattle Tour

F.I.R.S.T. is organizing an optional social tour around Seattle on Sunday, July 7, after the conference is over. Coaches will take our group for a 3-hour tour of Seattle and its famous sights. There will be a small fee for this tour, which will be available in the next issue. See the Registration Form for details and payment information.

Talent Show

On Saturday evening, the conference committee would like to host a Talent Show. If you have something you would like to perform for the audience, please contact Jean at the office. Here's your chance to show off your talent. Whether you can dance, sing, play a musical instrument, tell a good joke, juggle or whatever, we want to hear from you. Don't be shy!

Airport Shuttle

There is a free shuttle from the Seattle-Tacoma Airport to the Seattle Marriott Sea-Tac. The shuttle runs every fifteen minutes and pick-up is on the third floor parking structure. Stop at the information desk in the airport for more details.

2002 Family Conference Registration Form

Name: ______________________________

Address: ______________________________

City: ____________________ State: __________ Zip: __________ Country: ________

Phone (day): ______________ (evening): ______________ Email: ______________

Early Bird Registration Fees by **March 15, 2002**
Adults (age 18 & over) - $70.00
Child (age 17 & under) - $35.00
Registration fees will increase after March 15, 2002
so register early!

- *Please make all checks payable to F.I.R.S.T.*
- *F.I.R.S.T. also accepts Mastercard, Visa and American Express. Please provide type of card, account number, expiration date and billing address for credit card.*

Name ☐ Adult 18 & over ☐ Teen age 13-17 ☐ Tween age 9-12 ☐ Childcare age 8 & under Age Type of ichthyosis

______________________________ __________ ______________

Name ☐ Adult ☐ Teen ☐ Tween ☐ Childcaree Age Type of ichthyosis

______________________________ __________ ______________

Name ☐ Adult ☐ Teen ☐ Tween ☐ Childcare Age Type of ichthyosis

______________________________ __________ ______________

Name ☐ Adult ☐ Teen ☐ Tween ☐ Childcare Age Type of ichthyosis

______________________________ __________ ______________

Name ☐ Adult ☐ Teen ☐ Tween ☐ Childcare Age Type of ichthyosis

______________________________ __________ ______________

☐ Yes, F.I.R.S.T. may include our name and contact information in a conference roster to be distributed to conference attendees.

☐ Yes, F.I.R.S.T. may include the type of ichthyosis that affects our family on our nametags.

☐ Yes, I (we) will attend the 3-hour bus tour of Seattle on Sunday, July 7 after the conference. The bus will leave the hotel lobby at 2:00 p.m. and return around 5:00 p.m. Each ticket is $10.00 per person. Your seat will be reserved when payment is received.

Number of adults (18 & older) ______________ x $70 per person = ______________

Number of children: (1 through 17)* ______________ x $35 per person = ______________

Number of individuals attending Seattle Tour ______________ x $10 per person = ______________

Grand Total = ______________

- *Please return registration fees with complete form to Jean Pickford, F.I.R.S.T., 650 N. Cannon Avenue, Suite 17, Lansdale, PA 19446. Kindly make checks payable to F.I.R.S.T. in US funds.*
- *Cancellations will be honored with full refunds until Advance Registration Date of Wednesday, June 7, 2002.*

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

CLINICAL RESEARCH STUDY — TREATMENT OF ICHTHYOSIS VULGARIS

Volunteers are currently being sought for a research study using a cream for the treatment of Ichthyosis vulgaris (moderate to severe dry scaling skin).

To qualify, participants must:

- Be a healthy male or female at least 18 years of age
- Have moderate to severe dry, scaling skin on both lower legs

All study visits, procedures and study cream will be provided at no cost to you. Participants will receive payment for their participation.

Below is a list of US dermatologists who are conducting this study. If you have Ichthyosis vulgaris and are interested in participating in this study, please call the site nearest you. Michelle Chambers, MD

Michelle Chambers, MD 1275 Olentangy River Road, Suite 202 Columbus, OH 43212 614-294-3854	John DiGiovanna, MD JBS-1, 593 Eddy Street Providence, RI 02903 401-444-7853	Frank Dunlap, MD 7042 East Broadway Tucson, AZ 85710 520-885-6793	Drore Eisen, MD 7691 Five Mile Road, Suite 312 Cincinnati, OH 45230 513-232-3376
Charles Fixler, MD 7720 Montgomery Road Cincinnati, OH 45236 513-984-6887	J. John Goodman, MD 2051 45th Street, #200 West Palm Beach, FL 33407 561-845-1030	Regina Hamlin, MD 6079 North Fresno Street, Suite 101 Fresno, CA 93710 559-432-8018	DermResearch, Inc. 8140 North Mopac, Bldg 3, Suite 120 Austin, TX 78759 512-349-0500
Steven Kempers, MD 7205 University Avenue NE Fridley, MN 55432 763-571-4200	Antoinette Mangione, MD 9880 Bustleton Avenue, Suite 203 Philadelphia, PA 19115 215-671-0277	Joseph Muccini, MD 12401 Olive Boulevard, Suite 103 St. Louis, MO 63141 314-344-3096	Christopher Nelson, MD 6677 13th Avenue North, Suite 3B St. Petersburg, FL 33710 727-345-2399
Elyse Rafal, MD 2500-22 Route 347, Suite 82 Stony Brook, NY 11790 631-689-1900	Ronald Savin, MD 134 Park Street New Haven, CT 06511 203-865-6143	Harry Sharata, MD 4200 University Avenue, Suite 2030 Madison, WI 53705 608-238-5577	Joel Shavin, MD 2383 Pate Street Snellville, GA 30078 770-972-2241
Eileen Smith, MD 55 West Tietan Street Walla Walla, WA 99362 509-525-3720	Daniel Stewart, MD 43900 Garfield Road, Suite 106 Clinton Township, MI 48038 810-286-7325	Leonard Swinyer, MD 3920 South 1100 East, Suite 310 Salt Lake City, UT 84124 801-269-0135	Marvin Tankel, MD 10 Peninsula Boulevard Lynbrook, NY 11563 516-599-4242

Please help us to minimize our printing costs. Call us at 1-800-545-3286 if you do not wish to receive any future issues of *Ichthyosis Focus.* **Help F.I.R.S.T. reduce its postage costs – would you be willing to accept the Focus Newsletter via e-mail? Let us know.**

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Lansdale, PA 19446

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