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

ICHTHYOSIS FOCUS

Vol. 20, No. 2 A Quarterly Journal for Friends of F.I.R.S.T. Summer 2001

Am I at Increased Risk for Skin Cancer Because I Have Ichthyosis?

John J. DiGiovanna, MD

Ichthyosis is a name that we use for a group of conditions with dry, scaly skin. The different types of ichthyosis can have very different manifestations. Some affect the skin mildly while others cause severe thickening, cracking and discomfort. Some are present at birth while others do not develop until adulthood. Most people with ichthyosis do not have other health problems associated with their skin condition. However, there are some types of ichthyosis that are associated with other health problems. What about skin cancer?

Of the many different types of ichthyosis, most are not associated with an increased risk for the development of skin cancer. While the skin may not shed normally, and may also

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Please complete the form on page 15 in order to continue to receive information and materials from F.I.R.S.T.

July 5-7, 2002 - National Family Conference Dates

It's official! The national family conference has been scheduled for Friday, July 5 through Sunday, July 7, 2002 in Seattle, Washington. The hotel that has been selected is the Seattle Marriott Sea-Tac. The hotel is located near the Seattle-Tacoma airport so it will be a free, quick and easy ride if you're traveling by airplane. It is also easy to get to from any major highway.

F.I.R.S.T. is planning a fun and educational weekend. We read your evaluations from last year's conference in Philadelphia and we will be making some exciting changes. We plan to have separate programs for adults, teenagers, "tweens," and children plus more social time to talk with others. Details about each specific program will be published in the fall issue of Focus.

We hope that by letting you know the dates and location more than one year in advance, it will allow more of our members to join us. Start making plans today so you can share in this wonderful and enriching experience.

2001 Research Grant Recipient

Congratulations to Karima Djabali, Ph.D. of Columbia University, as the 2001 recipient of F.I.R.S.T.'s research grant. Dr. Djabali's project on The Genetics of Woolly Hair and Keratoderma (Naxos Disease) will focus on defining the genetic defect for this disease. Naxos Disease is a rare inherited disorder with features including woolly hair, thickened palms and soles (keratoderma) and associated with cardiomyopathy. The hair and skin manifestations lead to severe psychological and social disability, and the cardiac involvement may lead to sudden death at an early age. Two families have been identified with this disease in Israel and found with characteristic hair findings. This information will aid in a clarifying the function of hair proteins and may lead to a better understanding of hair physiology and to the development of novel treatment approaches. You can look forward to hearing more about this project in a future issue of the Focus.

For the past three years, F.I.R.S.T. has funded a grant through the Dermatology Foundation in Evanston, IL. The cost of a basic grant through the Dermatology Foundation recently increased from $10,000 to $20,000. F.I.R.S.T. would like to gratefully acknowledge The NeoStrata Company for its generous donation of $20,000 to help F.I.R.S.T. fund the grant for the 2002 Research Awards. Their commitment to the foundation has always been generous and, once again, they continue to show their support of our work.

Ichthyosis Focus

Vol. 20, No. 2
Summer 2001

Ichthyosis Focus is published quarterly by the Foundation for Ichthyosis & Related Skin Types (F.I.R.S.T.)

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

Dear Jean:

I recently attended the regional conference in Houston. It was very enlightening for my entire family. It was also quite nice to meet such lovely people. Donna Rice suggested that I pass on one of the unique things we use on our skin. We discovered quite accidentally that the skin on our underarms does not proliferate, or crack, when we use a speed stick type deodorant. Any antiperspirant is too drying and thus too painful to use. The deodorants like speed stick (whose first two ingredients are water and propylene glycol) do a great job of keeping our skin intact and moisturized. It has the side benefit of control of the odor associated with the bacteria that can proliferate in our unique skin. The medical speaker at the Houston regional meeting said that the triclosan ingredient is an antimicrobial chemical. In the warmer months, or when we are in a hurry, it can be used on other parts of the body like backs of the knees, fronts of elbows, neck, etc. It works best when applied right out of the shower, post towel drying. We have used many brands (Old Spice, Speed Stick and store brands) and many fragrances. The important thing is that the first two ingredients are propylene glycol and water. I hope that this works for others as well as it has worked for us.

Marianne Egan
Kingwood, TX

P.S. We have Curth Macklin Ichthyosis Hystrix type.

Dear F.I.R.S.T.:

My daughter, myself and my mother have Epidermolytic Hyperkeratosis (EHK). Ever since my daughter was old enough to talk I educated her about this skin problem. When she started school, she requested to be allowed to get up in front of the class, introduce herself, explain her skin problem and answer any questions they may have. It was our belief that if she educated them and answered their questions, it may alleviate their fears and therefore reduce the amount of hateful remarks.

Two years ago my daughter entered junior high and when she requested to address her fellow students, the school said no. I did, however, give them a great deal of information about EHK, including letters from doctors about the issue of odor. A few months ago, my daughter (14) was sent home on two occasions and made to spend the rest of her day in the office on three occasions because the school said the odor was intolerable. It broke my heart. I could see if it were caused from her not wanting to take care of herself, but this is not the case. She bathes daily, washes her clothing every night, puts fragrances in her Vaseline, changed her deodorant, soap and shampoo. She has tried everything imaginable to try and prevent this from happening but to no avail.

It's difficult enough for a teenager entering into this age, especially for a girl with all the pressures that today's society puts on them, but now she has to add this humiliation to it. The school did not read the information I supplied to them so that they would know how to handle this situation appropriately. She was not allowed to go back to school until a meeting was held.

I did contact the local news channels as well as the local newspapers about this. They were very interested in speaking with me. I did not do this to be ugly, but rather in an attempt to educate the public about ichthyosis and to try to come to an agreement that would be satisfactory to all. If they can do this to my daughter then who's to say that next time they won't try to prevent a blind student from attending school because there are stairs to climb and they could get hurt.

The same thing happened to me at her age, but my mother was too frightened to fight the school system. I wasn't. My daughter has learned that she doesn't have to accept this kind of treatment from anyone and she does have rights to an education.

Karen Carey
Fort Smith, AR

Dear F.I.R.S.T. members and friends,

Hi! My name is Michele Menzia and I live in Wasilla, Alaska. I wrote a story a couple of issues ago about having ichthyosis called “The Magic of Mermaids.” While driving to a friend’s house in December and scanning the last F.I.R.S.T. issue, a little article on the back page grabbed my attention. It was about a little girl in Asia with ichthyosis who needed a family. It immediately brought back memories of my own mother who died a year and a half ago. I thought about how she, more than anyone else, could look at me and make me feel good about myself. She would look at me with so much love and with so much pride and was always quick to tell me how much she loved me and how proud she was of me. My mother gave me strength, determination, and so much unconditional love that I realized without her I would probably never have achieved the things I have in my life. It made me so sad that this little girl did not have someone like that in her life right now. I knew then that I wanted to be this little girl’s mother and love her the way my mother loved me.

I called WACAP to get more information. This little girl is just over a year old and was given up because she has ichthyosis. She has been in an orphanage since she was one month old. Her family had lost two children with ichthyosis previously and knew they had to give her up to give her a chance at life and because they could not bear to lose any more children.

I am a single mom, a special education teacher, with two children, ages 12 and 8. My daughter Becca is my birth child. I adopted Cody three years ago when he was 5. They are both very happy, do wonderful in school and are involved in just about everything. I really was not planning to adopt again but Nisha has already stolen my heart. I have already turned in all the paperwork and home study, and am waiting for approval to adopt her. Please keep Nisha and us in your thoughts while we wait for her to join our family.

Sincerely,
Shelly Menzia

Editor’s Note:

If you would like to contact Michele about her adoption effort, you can write to:

Michele Menzia
1825 Caribou LP RD
Wasilla, Alaska 99654

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.

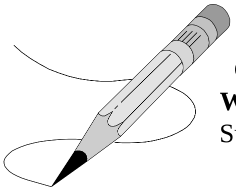
In response to your Spring 2001 question...How do you balance the needs of your affected child(ren) with the needs of your unaffected child(ren)?

My youngest child, Michael, has Netherton Syndrome and we had never seen this before. At first it was very hard to deal with everyone. What we do to make sure that everyone feels equal is when it is time to lotion Michael, we include his sisters (if they want to help). We always make sure that they know what is going on and how we need to treat it. We found it is much easier to deal with as a family than all alone. We don't want to leave everyone else out. Sometimes we get a little crazy with the Crisco and we all end up with it on ourselves. You have to have fun as well as take care of the needs of the person with ichthyosis. Sometimes it is not easy to do...but we just stop, take a deep breath, regroup and start over.
Gerald & Paula W.

Here's our next question:

During hot summer months, how do you keep your body cool?

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



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Fax: 215.631.1413
Call: 800.545.3286
Write: 650 N. Cannon Avenue,
Suite 17, Lansdale, PA 19446

The way I balance the needs of my affected daughter with my unaffected daughter is this....

After bath when I have to put lotion on my affected daughter (Amanda), I also put lotion (cheaper stuff) on my unaffected daughter (Danielle).

If I buy a product to keep my Amanda cool (i.e. mini-fan, spritz bottle) I also buy one for Danielle.

I believe that the attention I give both daughters are equal since I don't make Amanda's condition an issue. While the things I do or buy for Amanda are a necessity and these same things that I do or buy for Danielle are a luxury, they just see it as mommy spending the same amount of attention and money on both of them. **Jean M., Egg Harbor Township, NJ**

I have twins, one with lamellar ichthyosis and one without. I give my son (the one without) extra time with mama. He has his own song I sing with only him at night and I just go that extra mile to make him feel special.
Patrice R., Bloomingdale, GA

I guess I can say that we take each need separately. Since my children are older, they understand the extra time and recognize the special needs. It seems that they love the child so much they just want what is best for him. They understand our time commitment. It is no different than if we had a diabetic child or another need and we had to spend extra time and energy to see that he was best served. **Bette W., Lyle, MN**

I wanted to reply to your question regarding balancing the needs of my son with my other sons needs. I try to encourage my son, David, who does not have EHK to help me with Joshua's care. We apply lotion onto one another's skin every day and night. I try to make it fun for them so they don't feel uncomfortable with each other's needs. Bathing is also another fun time for us to share. I include both of them when Joshua needs to take a long bath or when we have to reduce his scales by scrubbing them. They are both very comfortable with Joshua's disorder and they never feel left out! **Debbie B., Southbridge, MA**

Both of my children are affected, so there is empathy between the two boys.

My older son, 13, can apply his own lotion and medications, while the 8 year old still relies on me to "do his lotion" before dressing for school. My children are also x-linked, which seems to make their affliction less severe.

My bigger problem is trying to help my husband and his family understand the disease.
Leigh D., Hopkinton, MA

Executive Director's Report

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

On March 26, 2001 I traveled to Washington DC to meet other members of the Coalition of Patient Advocates for Skin Disease Research (CPA-SDR). This annual meeting at the capitol is organized to bring together all the small skin disease groups to have a larger and stronger voice at the government level.

I had the privilege of touring the skin biology lab at the National Institute of Health (NIH) and meeting with Dr. Steve Katz, director of the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS).

Dr. Katz explained that last year only 20% of the meritorious grants received at NIAMS were funded. Dr. Katz is hoping that NIAMS will be able to fund over 30% this year. He indicated that the allocation of money is driven by the scientific community and funding is directed to where the opportunities lie.

On March 27, members of the CPA-SDR, the Society of Investigative Dermatology and the American Academy of Dermatology broke into small groups to visit congressmen and senators. Our group, called the NIAMS Coalition, was comprised of medical professionals and representatives of lay-advocacy groups. The primary purpose of our visits was four-fold. The first two purposes were to ask for support to increase the NIH budget by 16.5% and the NIAMS budget by 16.5%. In order to stay on track with the plan to double the NIH budget in five-years, each yearly increase needs to be 15%. Last year's request did not reach the 15% level. This year's increased request of 16.5% (or $3.4 billion) was to compensate for last year's shortfall.

It is very important to support this initiative because the NIH is where most of our important research originates. Research that involves any new discovery for any skin disease is beneficial to all skin diseases. Since skin diseases are so closely related, eventually it will filter across the board and possibly lead to discoveries in ichthyosis. It is critical for fundamental research to be continued as well. Even though we all want our particular disease to be the focus of increased research, it is difficult to study any particular disease if we do not know the basic function of skin cells.

The third purpose of our visit was to ask for support to fund a workshop that will collect accurate data about the cost of skin disease in the country. The last professional study of these costs was performed in 1979 and funding for a workshop would allow these figures to be re-tabulated. Current estimates include: $215 billion for musculoskeletal conditions, $13.8 billion for osteoporosis and related fractures, $82.5 billion for arthritis and $22.3 billion for skin diseases.

The final purpose of our visit was to ask for funding of the Clinical Research Enhancement Act that was passed last year. This act allows for a loan repayment plan for doctors who have just graduated from medical school. Recent estimates indicate that new doctors incur over $95,000 of debt before they graduate. Many of these doctors have young families to support and they choose the higher-paying career path in private practice. This loan repayment plan is intended to encourage more doctors to choose a career path in research.

March 26, 2001, Members of the Coalition of Patient Advocates for Skin Disease Research Annual Visit to National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS). Dr. Stephen I. Katz, Director, NIAMS (2nd row, 4th from left), Dr. Steven Hausman, Deputy Director, NIAMS (top row, 7th from left) and Dr. Alan Moshell, Director of Skin Disease Program, NIAMS 2nd row, last on right)

On behalf of F.I.R.S.T. and our membership, I was very proud to be a part of this effort. The success of our requests has yet to be determined. As of this writing The Bush White House, Senate Republicans and moderate Democrats are still trying to negotiate a FY2002 budget package.

Sincerely yours,

Jean

Jean R. Pickford

> “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

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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.

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Houston Regional Meeting — April 7

Where would the world be without volunteers? Certainly not in Houston, Texas on April 7! Stephanie Concialdi, Dawn Johnson and April Sproull, all F.I.R.S.T. members and mothers of young girls with ichthyosis helped organize and host a regional mini-conference. They all know it's a long time until the next national conference in Seattle and wanted to assist F.I.R.S.T. in providing local members with the personal contact they benefited from in Philadelphia last summer.

An opportunity for the free flow of ideas, skin care tips and emotional support, coupled with up-to-date medical information was the focus of the Houston event. Add a wonderful Spring day, good food, feather boas and a furry friend and you have a pretty good idea of the day's events.

Dr. Moise Levy, chief of pediatric dermatology at Texas Children's Hospital and professor of dermatology and pediatrics at Baylor College of Medicine, spoke to the group, describing the similarities and differences in the various types of ichthyosis. Additionally, Dr. Levy discussed breakthroughs in genetics, current and potential research studies, and resources available to individuals affected by ichthyosis, including molecular diagnosis and appropriate treatments. Dr. Levy and his associate, Dr. Denise Metarie, made themselves available for questions from the audience and individuals.

Conference participants were then offered a unique opportunity when Riley, a 6-year-old Jack Russell Terrier diagnosed with lamellar ichthyosis arrived. (For more information about ichthyosis and dogs, please see page 15.) He was accompanied by Ms. Kendra Tucker, a veterinary assistant at the Comparative Dermatology Lab of Texas A&M's College of Veterinary Medicine. Ms. Tucker showed a video detailing the research currently being conducted by Dr. Robert Dunstan, Riley's owner. Dr. Dunstan's efforts to locate the transglutaminase1 enzyme in Riley drew an interesting parallel to the successful research completed in people with lamellar ichthyosis. The obvious parallel between Riley's condition and care and that of his human counterparts was intriguing and generated discussion, questions and concern from many of the children present. Riley took his celebrity status in stride, but was a little miffed when he was not allowed to eat the Nerf balls. Riley has since received a chewable ball courtesy of F.I.R.S.T.

Discussion groups followed a long lunch and social time. Karaoke was provided for the kids during this time and many of the moms had a hard time deciding whether to talk or watch their kid's perform. Talk won out in the end.

F.I.R.S.T. is fortunate to have the volunteer resources necessary to host an event like the Houston mini-conference and hopes to be able to offer additional regional meetings in other parts of the country.

Visit our website at www.scalyskin.org to learn about upcoming regional conferences.


From left, Emily and Kelsey Chapin, Erica Fedewa and Jordan Johnson


Michele and Bob Cotter


Marianne and William Egan


Dr. Moise Levy


Karen and Cindie Carey

What's New, What's Hot & What Works…

Boston Marathon Fund Raiser

Two friends of Tracie Pretak, Bailey Jones and Kelly Walters ran in the Boston Marathon to raise awareness about ichthyosis and funds for F.I.R.S.T. John Sherry of St. Mary's, PA and Dave Cavalline, from Ridgway, PA ran this 26.2 mile race on April 16 with over 15,600 competitors. John's time was 2:56:42 with an overall finish at 657 and a division finish of 464, in the top 700. Dave's time was 3:23:59 with an overall finish of 3901 and a division finish of 1184, in the top 4000. Both finished in the top 25%! What an amazing accomplishment when most of the top marathon runners in the world compete in this race.

Bailey Jones is a 14-year-old with lamellar ichthyosis. For several years, Tracie, Bailey's mom, and Bailey have been hosting a spiritual concert in their town to help educate others about ichthyosis and to raise funds for F.I.R.S.T. Last year, Kelly Walters, 10, who lives nearby and also has ichthyosis, joined their efforts. Kelly and Bailey became fast friends and today they are planning to do more concerts in other towns in their area.

Thanks to Dave and John, the foundation will be receiving donations that were made in their honor. The local newspapers in their community picked-up the story and many friends, neighbors and well-wishers supported this event.

Send us the Name of your Doctor

The F.I.R.S.T. office continually receives requests for doctor referrals. The national office would like to expand its list of doctors who have experience in treating people with ichthyosis. Please take a moment to mail a note to the office or contact us at 800.545.3286 or info@scalyskin.org with the name of your doctor. F.I.R.S.T. will then contact him/her and ask whether he/she is willing to care for more patients with ichthyosis and receive information about ichthyosis and about our organization. F.I.R.S.T. is interested in physicians located in any part of the country, so don't hesitate to share the name of a doctor that you think could help others.

Indian Website Features a F.I.R.S.T. Member

Amneet Anand, a 7-year-old with Neutral Lipid Storage Disease, and her mother were successful in submitting a story to www.nariworld.com, a website that features information about Indian women, family, men and kids. In Indian Language Sanskrit, Nari means woman. Their story talks about their own personal experience with ichthyosis and also asks for funds to be donated to F.I.R.S.T. If you would like to read about Amneet, log onto www.nariworld.com and click on Archives, scroll to "Human Interest Story" and click on *A Mother's Struggle with Fate.*

Medical Advisory Board Member Receives Award

This year, the Women's Dermatologic Society added Gloria Graham, M.D. to the list of Rose Hirschler Award Recipients. The Rose Hirschler Award is named in honor of Dr. Rose Hirschler, the first known female dermatologist in the United States. This award is presented annually by the Women's Dermatologic Society to physicians who have made significant contributions to medicine and dermatology, and who by their achievements, have served to enhance the role of women in the dermatologic specialty. Congratulations to Dr. Graham!

Film Documentary Entitled 'Kenny'

On May 21, producers, actors, agents and film industry executives gathered together at the Tribeca Screening Room in New York City to watch a film documentary about Ken Krips. Ken has lamellar ichthyosis and his childhood friend, Lisa Regina, wrote, directed and produced this poignant story about Ken's life to raise awareness about ichthyosis. There was also a second screening on May 23 in Pitman, New Jersey at the Broadway Theatre. Many of Ken's family, local business owners and movie extras came to this screening, which was open to the public.

Ken grew up in southern New Jersey with his mother, Arlene and brother, John. Most of the filming took place near his hometown and Mayor Sandra Love of Gloucester Township was a great supporter of this project. Mayor Love authorized the closing of several streets so the crew and actors could film. Two young boys from the local community portrayed Ken in flashback scenes when he was a young boy.

Ken's local community embraced this project and was extremely generous. Many businesses donated food, lodging and other items for the film crew and actors. Bill Balis, owner of Adelphia, a restaurant in Deptford, NJ, also opened his doors and donated an after-party for the screening in New Jersey.

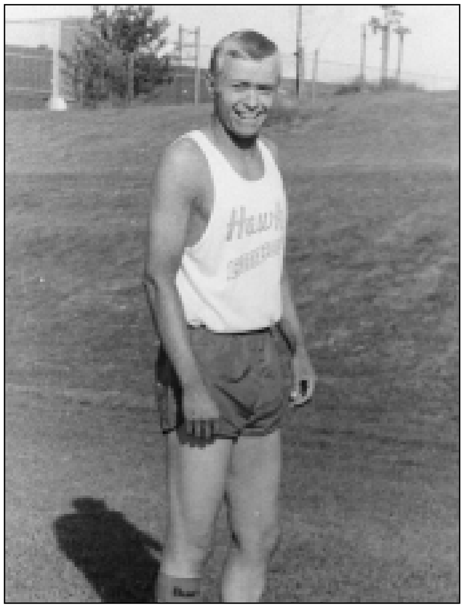
No Sweat

Editors Note: A few months ago, Jim Borden, a member of F.I.R.S.T., contacted us at the office. He asked if we could publicly thank and recognize his college track coach, Joe Owens, in the Ichthyosis Focus. Coach Owens was a teacher and role model for Jim. After coaching him for 2 1/2 years in college, he decided that everyone should know about "the ichthyosis kid" and how Jim overcame his handicap to compete in track. Coach Owens contacted several magazines and the following article was published in Newsweek on May 11, 1970. As a result of this article, Jim was contacted by 11 people who had the same disease and he passed those names on to the foundation to help build its audience. Thank you to Coach Owens and Jim Borden for their efforts to promote ichthyosis awareness. Over the past 30 years, research into skin diseases, including ichthyosis, has made remarkable progress. Defective genes have and continue to be identified and better treatments have become available. This article was reprinted with permission from Newsweek.

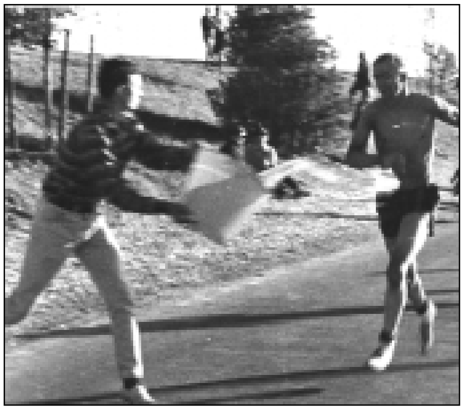
No Sweat

Spectators watching track meets at the State University of New York at New Paltz this spring are startled by a strange ritual during the 1- and 2-mile events. As Jim Borden, a 21-year-old senior from Easton, N.Y., strides along, teammates dispersed at intervals along the track step out from the crowd and, like prop men in TV's "Laugh-In," douse him with buckets of cold water. Jim, track coach Ed Bell explains to curious bystanders, is seriously lacking in sweat glands. The dousing keeps his temperature from reaching danger levels during his physical exertion.

Borden was born with a disease called ichthyosis (from the Greek, "fish disease"). The disorder involves overproduction of keratin, the tough protein that is the major constituent of the skin, hair and nails. As a result, the skin acquires a dry, scaly appearance. Moderate ichthyosis, chiefly affecting the elbows and knees, is not uncommon. But Jim suffers from the much rarer severe form, in which the disease covers nearly his entire body. In such cases, sweat and oil glands are often missing in large numbers. This means that the body cannot readily disperse excess heat through perspiration, as it normally does. And because of the lack of oils, the skin is excessively dry.



Infant: At birth, the skin on Jim's entire body was swollen and inflamed. Because of the danger of infection, the inability to control his body temperature, and a temporary bladder problem, doctors gave the infant only 48 hours to live. Jim survived, however, through constant treatment with antibiotics to ward off bacteria and application of petroleum jelly to relieve the dryness. As he grew up, doctors tried a number of remedies, including the addition of goat's milk and vitamin A to his diet, but to no avail. Jim has had to keep his body smeared with petroleum jelly to relieve the dryness of his skin, and avoid sunlight, which is highly irritating to patients with ichthyosis. But he was unwilling to heed his doctor's warning that, because of his inability to sweat, he shouldn't take part in sports.



During normal activity, the lack of sweat glands poses no major problem for Jim. He gets rid of body heat through the evaporation of moisture in his breath. Dogs, which have sweat glands in only feet and noses, keep cool in much the same way. But for Jim, the act of breathing would not be sufficient to compensate for the increase in body heat during strenuous exercise. "Jimmy tried to go out for wrestling in his freshman years," recalls Joe Owens, New Paltz athletic director, "but there was no way for us to gauge how fast his temperature was rising. It was just too dangerous for him to be pinned under another guy - besides, the temperature in the wrestling room is 78 to 80 degrees, which is good for wrestlers, but not for Jimmy." But the school's physician gave in and permitted Jim to try cross-country running and track. "If you don't let me run," he told Owens, "I'll tear the gym apart brick by brick."

But first Owens had to think of a way to keep Jim cool. One idea, finally rejected, was to supply the runner with a frozen T shirt that would provide a flow of cool water as it thawed. The formation of a bucket brigade proved the most workable solution.

Intense: In cross-country events during the fall, cool, damp weather helped Jim's problem. Still, teammates were stationed along the route to toss water on him as he passed by. And occasionally Jim would veer off course long enough to run through a convenient stream or dive into a nearby pond. Even though the course is up to 5 miles long, Jim didn't suffer any ill effects. In the spring of his sophomore and junior years, Jim ran the half-mile, but he found that the relatively intense burst of speed required was too exhausting and that he had insufficient time over the short course to recover from the shock of the cold water thrown by the bucket brigade.

This year, Jim is running the 1- and 2-mile events-and with better results. He finds the three dousings he gets during the mile, and the seven during the 2-mile run, no hindrance to his performance. "In fact," he points out, "I now hold the 2-mile school record."

ISN Education & Training Coping and Crisis Information

Part 1 — Helping an Angry Caller

The angry caller may shout, be aggressive, or confrontational. Allow the person to express their anger. Try not to be defensive or take it personally; it is your job to help them vent their anger and see some solutions in their conversation:

- Help define the source and purpose of their anger. Ask open ended questions to help them get there (questions that require more than a yes or no answer).
- Help or allow the caller to get specific about what is upsetting them, but point out there may be more than one reason for their anger.
- Reassure them that their feelings are normal and not uncommon.
- Don't focus on blame.
- If they are willing, help them come to solutions about the factors making them angry.
- The caller may want to stay angry rather than be logical. Try to help them understand that long term anger is neither healthy or productive. Remaining angry leaves them 'stuck' where they are, and consumes a lot of physical and emotional energy.
- If the caller starts to attack you personally, try to remain calm and remind them that you can't help them if you are feeling attacked.
- Suggest taking a break if things are getting too out of control. Call another member for support if you need it.
- CALL BACK WHEN YOU SAY YOU WILL.

Resources:
American Academy of Pediatrics
Anger in Children
www.aap.org

American Psychological Association
Brochure - Controlling Anger - Before it Controls You.
750 First Street, NE
Washington, D.C. 20002-4242
202-336-5500
www.apa.org

Don't Sweat the Small Stuff — and It's All Small Stuff.
Richard Carlson

The Power of Positive Thinking.
Norman Vincent Peale

When Anger Hurts:
Quieting the Storm Within.
Matthew McKay & Judith McKay

Ichthyosis Awareness Week – Sept. 30 to Oct. 7, 2001

Mark your calendars! This year's National Ichthyosis Awareness Week is scheduled for September 30 through October 7. The office has already been in contact with several members who are planning events in celebration of this important week. Remember...even the simplest things can help. It's not hard and can be a lot of fun. If you need ideas or advice, call the national office staff. Just think, if all our members participated in some kind of awareness program during this week, we would make an enormous impact.

Spotlight On...

Dylan Slater

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

I was 18 years old when my son Dylan was born on March 30, 1998. When he was born his skin was dark red and shiny and he could hardly open his eyes. He had a lot of hair on his head but it was under all of the extra skin that had built up on his body. He had no eyelashes, eyebrows or hair on his body. It was all covered with skin.Dylan looked different from the other babies in the nursery. When the nurse first brought him to my room she said, “We gave him three baths to try to remove the skin but it is still there. We don’t know what it is.” I was so frightened. It wasn’t until later that evening that I learned from my pediatrician, Dr. P.L. Verma, that he was a collodion baby and had a rare skin disorder called ichthyosis. I am so thankful to have an excellent pediatrician that knew right away what it was. I wouldn’t trade him for the world.

My pediatrician immediately called a specialist in dermatology. Together the doctors ordered blood work and prescribed a salve to apply all over Dylan’s body, to help relieve the tightness of his skin. Even with the salve, Dylan’s skin would sometimes crack open and he would look like he had been burnt with scalding water or some kind of chemical. Some people would stare, others would ask about him, and still others would talk about him behind my back. I usually overheard what they were saying.

My parents immediately had a cool mist humidifier installed on the furnace to keep moisture in the air. We know the humidifier has helped Dylan because it has seemed to help the rest of my family’s skin as well. Our mission was to find out everything we could about this skin disorder. We were on the internet and registered with F.I.R.S.T. and the National Organization for Rare Diseases (NORD). At our first office visit, when Dylan was two weeks old, our doctor suggested we do a biopsy to find out what kind of ichthyosis Dylan had and to see if there was any other condition we were not aware of, like cancer, etc. When the results came back it lead us to believe that Dylan had ichthyosis vulgaris.

The doctors started to treat Dylan for vulgaris but they had never treated a newborn with a skin disorder like this. Even though we felt these doctors were doing the best they could, we decided to find someone who specialized in ichthyosis. We were advised to go to Duke University and we found out about Dr. Neil Prose. Dr. Prose specializes in children’s skin diseases and we also knew Dr. Prose was on the medical advisory board of F.l.R.S.T.

As members of the foundation, we had seen his name in the newsletter. By the time Dr. Prose was able to see Dylan he was a little more than eight months old. We collected all of Dylan’s medical records and took them to Dr. Prose at our first visit. Dr. Prose read the reports, biopsy, etc. and immediately knew he was being treated for the wrong type of ichthyosis. He told us that Dylan had lamellar ichthyosis, not vulgaris. Dr. Prose said he is not the worst case nor the best case he had seen, but that his case would be considered average. We were very disappointed but relieved at the same time. We were finally on the right track, even though we felt we lost eight months of the right treatment and medicine.

We traveled to Duke to see Dr. Prose every four months for a while and now we see him yearly. Dr. Prose has changed his medicine several times. He was on Theraplex cream that seem to work but now he uses Aquaphor with 8% lactic acid, and Theraplex is applied to his feet. Dylan’s skin seems to get better and better. To look at him from a distance you can no longer see anything wrong with him. His face, chest, back and neck are clear, although he still has scales on his legs and ankles and his hands are rough and dry. His feet present a special challenge. They will crack and bleed sometimes due to the dryness and he will walk on the sides of his feet. He loves to go barefooted so it is very hard to treat his feet, because he is too young to understand to keep his shoes on. To combat this, we put his medicine in the cracks on his feet, and then apply an antibiotic and put socks on him. He will only wear them for a while.

We think Dylan is beautiful and he is a very smart little boy. He is in excellent health and has no other health problems. However, he does have trouble playing outside when it is hot because he will overheat very fast. We allow him to play outside for about 15 to 20 minutes at a time and then he comes inside to cool off. We will let him play out early in the mornings or late in the afternoon. Dr. Prose said if we wet his T-shirt down with water and keep a mist bottle around he may be able to stay outside for longer periods of time without overheating.

We work very hard at finding ways around all these set backs. We have lotion sitting around everywhere! He loves to put lotion on his head, in his hair, on his legs and feet so we let him. We bathe him twice a day, sometimes three, for 20 minutes at a time. We have special soap, gloves and sponges we use to try to remove the extra skin. After his bath we wrap him in a towel and put his medicine (Aquaphor with 8% lactic acid) with a moisturizer in it, all over his body. We try to cover as much of his body as we can with clothing to keep the moisture and medicine on him as long as possible. Dylan is only three years old but we worry about the time when he will go to school or want to play sports. We are optimistic that we will find a way around the overheating, etc. We purchased books from F.I.R.S.T. to explain his condition to people, like his babysitter, and we will let his preschool teacher read them, along with his other teachers he will have when he starts school.

My mother works for a charitable organization and she designates a portion of her charitable contributions to F.I.R.S.T. through the United Way campaign. If we could help anyone that has a child or an adult with ichthyosis we would do it. If you have an opportunity to contribute cash, stocks or bonds, or if your workplace has payroll deduction, please remember F.I.R.S.T as one of your charities. The medicine can get very expensive, and we worry about the other children and adults that may not have insurance to help with their medical bills, medicine or special soaps, etc. We hope others can be exposed to the best treatment like Dylan has received from the wonderful doctors in his life.

I also work for a local television station... maybe we can do a story or public service announcement about F.I.R.S.T. You can contact me at Jamie Slater, P.O. Box 13391, Sissonville, WV 25320, call me at (304) 984-1268 or email hslater@wvinter.net or jamiedds@yahoo.com. Thank you to F.I.R.S.T. for the informative newsletter that you mail to me quarterly. It is a big help to me and my family.

Jamie L. Slater

Note from the Editor: Thanks, Jamie, for your informative letter. The readers should know that the mild form of ichthyosis, ichthyosis vulgaris, never appears as a collodian baby. Also, as we can see from your letter, biopsies of the skin of a collodian baby at two weeks of age are generally not helpful in making a diagnosis.

April 30, 2001

Dear F.I.R.S.T. members:

F.I.R.S.T continued making great strides in fiscal year 2000. The Foundation hosted a very well received Family Conference in July 2000 in Philadelphia, Pennsylvania. Over 275 people attended this three-day conference, meeting others with ichthyosis and talking with members of our Medical Advisory Board as well as other expert friends of the Foundation.

In conjunction with the Family Conference, the Foundation hosted its first Continuing Medical Education (CME) program for local physicians to provide up-to-date information on the ichthyoses. The physicians received comprehensive information on the current understanding of the genetics and pathophysiology behind the ichthyoses, as well as practical approaches to the diagnosis, management and treatment of ichthyosis patients. A number of our members with ichthyosis attended the CME program, providing the physicians with an unparalleled opportunity to see several different types of ichthyosis "up close and personal."

F.I.R.S.T. received funding to hire a part-time Program Director through a generous donation from Beiersdorf. The Program Director manages the Ichthyosis Support Network (ISN) as well as other program-related activities. The addition of a third staff member allows the national office to function at a higher level, enables F.I.R.S.T. to re-energize its ISN, and provides better program services to our members.

F.I.R.S.T. also committed to funding another research grant through the Dermatology Foundation. With the help of a kind contribution from NeoStrata, we were able to increase our grant to $20,000. This effort marks another step toward additional research into a cure for ichthyosis.

Other noteworthy accomplishments in fiscal 2000 include the awards of several financial assistance grants from The Jane Bukaty Membership Assistance Fund. This program was newly added in 1999 and is available by application for financial help to F.I.R.S.T.'s members.

All these accomplishments, and yet F.I.R.S.T.'s net assets increased by 41%. This significant increase is the result of several factors. In addition to the generous support of our increasing membership and corporate donors, F.I.R.S.T. received an especially large donation from its long-time benefactor, Dr. Eugene Van Scott. We're also very lucky that we have a highly dedicated and hard-working staff making the most of our national office. This crucial increase in net assets provides F.I.R.S.T. with more options and comes at a particularly important time. The Board of Directors is currently involved in an intense strategic planning process, with the expectation of approving a new strategic plan by the end of 2001.

Continued support from F.I.R.S.T.'s diverse group of steadfast patrons made all these programs and advancements possible. I hope you are as proud of F.I.R.S.T.'s achievements as I am.

Sincerely,

Laura J. Phillips

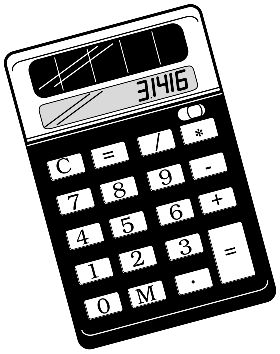
FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC.
STATEMENTS OF FINANCIAL POSITION
SEPTEMBER 30, 2000 AND 1999

ASSETS

	2000	1999
Current assets:		
Cash and cash equivalents	$ 67,053	$ 30,474
Marketable securities	61,461	69,725
Accounts receivable	4,440	
Total current assets	132,954	100,199
Cash, permanently restricted	10,000	10,000
Furniture and equipment, net	17,087	1,545
Other assets	2,492	3,086
	$ 162,533	$ 114,830

LIABILITIES AND NET ASSETS

	2000	1999
Current liabilities:	$ 5,287	
Accounts payable and accrued expenses	4,192	$ 2,047
Accrued payroll and benefits		
	9,479	2,047
Total current liabilities		
Net assets:	135,057	101,210
Unrestricted	7,997	1,573
Temporarily restricted	10,000	10,000
Permanently restricted		
	153,054	112,783
	$ 162,533	$ 114,830



This Statement of Financial Position is taken from the foundation's official audited financial statement as of September 30, 2000. A complete copy of the audited financial statement and the independent auditors' report is available and can be obtained by calling the national office at 215.631.1411.

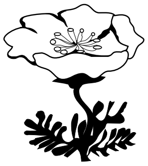
In Loving Memory of Theresa A. Napoli

The following is a copy of a note sent to F.I.R.S.T. by Theresa's mother, Tricia:

This note is to let you know that my sweet daughter, Theresa A. Napoli, died on March 16, 2001. She was 25 years old. She had been hospitalized for 3 weeks for anemia and needed a blood transfusion. She had developed a skin infection that entered her blood stream and was being treated with I.V. antibiotics. While in the hospital, Theresa developed chest pain and "coded." The crash team did get her heart started again, but even with the aid of a ventilator, they couldn't keep her oxygen level up. She died six hours later. I stayed with her until the end.

I have asked that people send donations to F.I.R.S.T. in her memory instead of flowers. Please apply these donations toward research as that was what Theresa had requested. Next month I will be organizing a spaghetti dinner fund raiser at the apartment complex where Theresa lived for five years. All proceeds will be sent to F.I.R.S.T. for research to help find a cure. I plan to continue to try and help find a cure for ichthyosis in any small way I can. I don't want another mother to have to grieve for her 25 year old son or daughter.

Theresa enjoyed going to your conference in Philadelphia last year so much. It was a joy to watch as her face lit up when she met other young adults with the same symptoms as her disease.



F.I.R.S.T. extends its heartfelt sympathy to the Napoli family during this difficult time. Donations in Theresa's memory are gratefully accepted.

Increased Risk for Skin Cancer

continued from page 1

make too much scale, this process does not usually result in skin cancer. However, skin cancer is very common, and the rate of skin cancer worldwide is increasing in epidemic proportions. The number of new skin cancers that occur in the U.S. each year is larger than the number of all other cancers combined. It is estimated that one in seven people in the U.S. will develop skin cancer during their lifetime. Because skin cancer is such a common condition, some people with ichthyosis will also develop it, however ichthyosis, in general, is not a risk factor. It is important to recognize that there are specific, known risk factors for skin cancer. For example, skin type (how the skin reacts to sun exposure) is a risk factor for skin cancer: individuals who burn easily and tan poorly are at increased risk. Other risk factors include a family history of skin cancer, a history of repeated sun or artificial ultraviolet exposures, and blistering sunburns. Large numbers of moles, as well as atypical (irregular shape or color) appearing moles are a risk factor. People who have had one skin cancer are at increased risk for developing additional ones.

There have been a few reports in the medical literature of people with ichthyosis who have developed many skin cancers. However, most people with ichthyosis are not at increased risk. It is difficult to know with so few reports, whether there is a specific rare type of ichthyosis that is associated with an increased risk or whether those few individuals were developing skin cancers because of other known risk factors for skin cancer.

What about other scaly skin conditions? Psoriasis is a very common scaly skin condition, affecting about 2% of the population in the U.S., or about 5-6 million people. While psoriasis is not known to increase the risk for the development of skin cancer, some of the treatments used for psoriasis can increase the risk for skin cancer including topical tar preparations and ultraviolet phototherapy. These treatments are not usually used to treat ichthyosis.

So what's the answer? Well, anyone who has known risk factors for skin cancer, such as easy sunburning, a history of blistering burns, a family history of skin cancer, or many moles should take precautions. Skin cancer is easily treatable and has a very high cure rate when diagnosed early. Dermatologists recommend sun protection, a skin self-examination on a regular basis, and a periodic dermatologic examination. The ABCD's of skin cancer were developed to help people recognize skin lesions, that are likely to be melanoma, the most serious form of skin cancer. The A stands for asymmetry. If you draw a line, which cuts the lesion in half, and one side is different from the other, it is asymmetrical. I think of it as a sign that different parts of the lesion are growing in different ways. B stands for borders. Irregular borders are another sign of a suspicious lesion — once again different parts are growing differently. C is for color. Skin lesions with many colors have a greater risk, and D stands for diameter—larger than 6 millimeters (about 1/4 inch), that is, larger than a pencil eraser. A skin lesion can have all of these and still not be a melanoma, so these are just clues suggesting features to look for that makes a lesion suspicious. The most common forms of skin cancer, basal cell cancer and squamous cell cancer, are clearly triggered by UV light. Basal cell cancers usually look like skin-colored pearly bumps. Squamous cell cancers look like red, scaling bumps or patches. Both of these cancers may bleed easily and show a central ulcer that does not heal. A dermatologist should evaluate anyone with risk factors or worrisome skin lesions.

Sun protection is wise for people with risk factors for skin cancer. While ichthyosis can cause a lot of problems, for most people it does not increase their risk for skin cancer.

UK's Ichthyosis Support Group National Day 2001

The United Kingdom's Ichthyosis Support Group (ISG) held their 2nd National Day at Birmingham Children's Hospital on Saturday, March 24, 2001. Forty families affected by ichthyosis - nearly 200 individuals including adult and children affected by the disease, caregivers, professionals, friends and helpers, attended the event. Families traveled in from all over the UK and from as far away as Malta.

Various lectures were held. Topics included an 'Overview of Ichthyosis' by Dr. Celia Moss of Birmingham Children's Hospital, 'Treatments' by Dr. John Harper of Great Ormond Street Hospital for Children and 'Gene Therapy and Research' by Professor John McGrath of St. Thomas' Hospital. Dr. Mary Judge, Manchester Hospital, led a discussion group for children and Mandy Aldwin, ISG committee, chaired another group for adults affected by ichthyosis. A selection of workshops were held throughout the day, including one on genetics run by Dr. Jenny Morton of Birmingham Women's Hospital. Other topics covered were aromatherapy, benefits advice, behavioral and educational issues.

Six pharmaceutical companies each had a stand providing samples and information about their products. A representative from Changing Faces was also available to provide support and advice for people living with facial disfigurement.

The children were initially kept entertained by a circus 'zebra' before 40 of the children were taken on a half-day excursion to 'Cadbury World.' The children remaining in the hospital were kept amused by an 'army' of friends and 'Mr Right,' a professional entertainer.

After the ISG Fundraiser of the Year was awarded to Mr. Paul Brownless for raising over £3000 while cycling from Lands End to John O'Groats, the day closed with a 'Question and Answer' session chaired by members of the ISG Medical Advisory Board.

The ISG committee would especially like to thank Dr. Celia Moss for providing the venue, for her invaluable guidance with the preparations, and for her participation on the day. Thanks also to all the professionals, friends and helpers who enabled the day to run smoothly and successfully.

The Ichthyosis Support Group also celebrated on this day, as it was recently granted charity status, Registered Charity Number: 1084783. For more information contact:

Email: isg@ichthyosis.co.uk (soon to be changing to .org.uk)

Affected Individuals and Caregivers:
National Contact, Pamelia Catlyn-Ranger
Tel: 020 7461 0356 (after 8pm)

Medics and professionals: Secretary,
Shelly Batt Tel: 01635 253829

Ichthyosis in Dogs

In an edition of Ichthyosis Focus four years ago, there was a short article and a picture of Riley, a Jack Russell Terrier with ichthyosis. The picture was taken when Riley was only 12 weeks old and living in Michigan. Riley is now 5 years old and lives in Texas. He is the mascot of the Comparative Dermatology Laboratory at Texas A&M where one of our major objectives is to help dogs with this disease and to use this knowledge to help humans.

Of all mammalian species, dogs are the most prone to develop ichthyosis. We have recognized ichthyosis in eight different canine breeds all with different forms of the disease. In breeds such as Golden Retrievers, the skin changes are extremely mild, in others, like the form of ichthyosis affecting Riley that resembles lamellar ichthyosis in humans, the scaling is quite severe. Other forms of canine ichthyosis resemble human epidermolytic hyperkeratosis and ichthyosis bullosa of Siemens.

One reason why ichthyosis is much more common in dogs than in humans is that dogs do not randomly select their mates. Rather, owners make this decision, usually choosing to breed two closely related animals (mother to son and father to daughter matings are common). This method of breeding, known as inbreeding, is advantageous because it increases the chance of expressing good genetic traits. Unfortunately, breeding two related dogs also increases the chance of expression of genes that cause disease. Because the major problem with inbreeding is that it tends to increase the chance that two apparently normal dogs who carry a genetic defect (such as ichthyosis) will be selected to mate, the result of which could lead to an affected puppy. Because male dogs thought to have especially good features can be used hundreds of times as sires, if such a dog carries a gene for ichthyosis, the disease can unwittingly be spread throughout a given breed.

Taking care of a dog with a severe form of ichthyosis is like taking care of a child with the disease: retinoids, baths to remove excess cornified material, avoiding skin infections with bacteria and/or yeast and keeping the dog cool.

At the Comparative Dermatology Laboratory, our work is just beginning. We have sequenced the canine transglutaminase 1 gene and are now sequencing the keratin genes keratin 1, 10 and 2e. Hopefully with the next update we can report how similar the different forms of ichthyosis are in dogs and humans.

Robert W. Dunstan & Kelly M. Credille,
Comparative Dermatology Laboratory,
College of Veterinary Medicine, College Station, TX 77843

We Need To Hear From You

In an effort to be more efficient and cost conscious, F.I.R.S.T. will be updating its database records to include mailings only to those members who have an interest in continuing to receive materials and samples from the office. If you have already responded to the first request sent in our membership mailing, we thank you. If not, here's a second opportunity to contact the office. Please complete the information below and send it to the office or contact us at (800)545.3286 or info@scalyskin.org. If you cannot afford to make a donation, that's okay. We still want to hear from you. We would like to keep you on the mailing list. Please take the time to contact us. F.I.R.S.T.'s membership is very important and we don't want to lose touch with you. It will only take a few moments of your time and it will make a big difference. If the office does not receive some form of contact, we will assume that you no longer want to receive mailings from F.I.R.S.T.

Name: ______________________________

Address: ______________________________

City ______________________________ State ________ Zip ______

Day Phone ______________________ Evening Phone ______________________

Email ______________________ Fax ______________________

Name & Age of person(s) affected: ______________________________

Type of ichthyosis ______________________________

☐ Yes, you have my permission to include my contact information in F.I.R.S.T.'s membership directory. Please attach a few words as to why you're a member of F.I.R.S.T. (i.e. my three year old son has X-linked ichthyosis). This information will be included in the membership directory.

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Volunteers Needed: Study on Growth Failure and Ichthyosis

Some infants and children with congenital Ichthyosiform Erythroderma (CIE or Lamellar ichthyosis), Harlequin Ichthyosis, Netherton Syndrome and Epidermolytic Hyperkeratosis have difficulty gaining weight and growing. We are seeking patients with ichthyosis and growth failure for a clinical study to investigate the causes of their growth failure and to determine if skin barrier formulations can improve skin function in these children. These studies will be performed at no cost to the patient and the results of the study will be shared with the patient.

Parents who have a child with ichthyosis and trouble growing or gaining weight and who are interested in learning more about or participating in our studies may contact Dr. Williams or Dr. Heyman at the addresses below:

Contact Mary L Williams, M.D., (email: mlwilliams@orca.ucsf.edu; Phone: (415) 353 7884; FAX (415) 353 7850) or Melvin B. Heyman, M.D. (email: mheyman@peds.ucsf.edu; Phone: (415) 476-5892; FAX (415) 476 1343) in the Departments of Dermatology and Pediatrics, University of California San Francisco.

Cooling Vest Available

A child's used cooling vest has been donated to the office and is available to a member of F.I.R.S.T. The vest was originally given to a boy with lamellar ichthyosis by NASA. The family would like to give someone else the opportunity to use it. The vest would fit a child size 7 or 8. Please contact the national office at 800.545.3286. The vest is available on a first-come first-serve basis.

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. F.I.R.S.T. encourages you to consult with your dermatologist for treatment advice. We have compiled this list as a service to our members. 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.

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.**

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

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