Ichthyosis Focus

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

Volume 27, No. 4 *A Quarterly Journal for Friends of F.I.R.S.T.* *Winter 2009*

F.I.R.S.T. Announces the Regional Support Network

The Ichthyosis Support Network (ISN) will now be known as the *Regional Support Network (RSN).* The Foundation is excited to be making positive changes that will impact our members and strengthen our current support network, through communication with caring and compassionate volunteers. The Regional Support Network will be divided into eight regions in the United States, one region in Canada, and one International region. Each region will be led by a Regional Coordinator and supported by Regional Volunteers. The benefit of regionalizing the Support Network is for individuals to communicate with others in close proximity to one another and to form a stronger connection. In addition to communicating by phone, email, or in person, the Foundation will be hosting biennial regional meetings with the assistance of the Regional Coordinator. These meetings will be held during odd years, alternating with the Family Conference.

The structure of the Regional Support Network is very similar to the ISN. If a call is received at the F.I.R.S.T. office by someone seeking a connection, that caller will be matched with the Regional Volunteer within his/her geographic region. Understanding the rarity of ichthyosis, the office will connect callers and volunteers by disease type within the region; and then by social profiles such as age, gender, marital status, ages of children, etc.

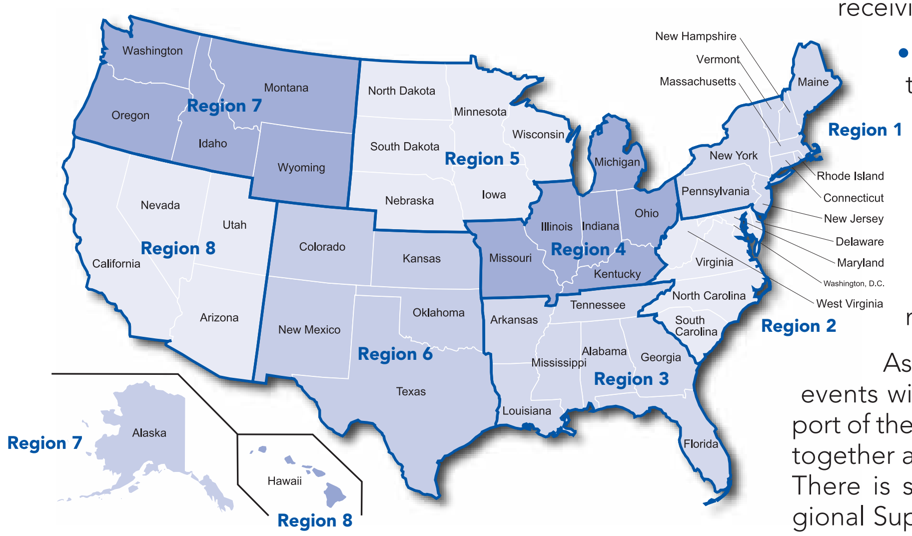
Please help strengthen the Regional Support Network and become a Regional Volunteer. If you are interested in serving as a Regional Volunteer, please read and sign the job description and complete the volunteer application found on pages 11 and 12. Mail both documents to the national office. Once your application is received, a Regional Volunteer Support Manual will be mailed to you.

As a Regional Volunteer, you will be asked to:

- Contact members who are interested in receiving support.
- Keep a log of individuals contacted.
- Actively participate or organize awareness or grassroots events.
- Attend biennial regional meetings.
- Attend quarterly conference call meetings hosted by the Foundation

As a region, grassroots and awareness events will be stronger by gaining the support of the members within the region to work together and support and assist one another. There is strength in numbers, and our Regional Support Network will prove this statement true.

If you would like to be contacted by a Regional Volunteer, please contact the national office. If you have questions or if you would like additional details about the Regional Support Network, contact Moureen Wenik, Program Director by email at mwenik@scalyskin.org or by phone at 1.800.545.3286.



Inside Ichthyosis Focus

Vol. 27, No. 4 Winter 2009

Ichthyosis Focus is published quarterly
by the Foundation for Ichthyosis
& Related Skin Types.

Requests to reprint information
contained in the 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 F.I.R.S.T.,
A spiral fracture of the left tibia – a broken leg. It didn't sound good, but I had no idea how much pain it would bring.

Maggie, my 8-1/2 year old daughter with CIE, broke her leg at the end of September. I told the orthopedic doctor about her condition and had him consult with our pediatrician and pediatric dermatologist. They put her in a splint (full-leg) and sent us home to wait until the swelling period was over so they could cast her. She was miserable and in a lot of pain. From the time we got home that day, she complained about her heel hurting. She ended up in the hospital the next day and stayed a week for pain management – getting casted under anesthesia with the underside of the leg as one piece and the topside of the leg as another piece, in case she had skin issues. She came home in a full-leg non-walking cast with a wheelchair after physical and occupational therapy. She didn't sleep more than two hours at a time and was always saying she was in pain. We saw the doctor weekly, often multiple times in one week.

After four or five weeks, they finally looked at the leg and saw she had an ulcer on her heel under the cast. They cut the cast to a 1/2 leg hoping to remove the pressure. A week later they made the cast removable so we could soak her leg - that was a Thursday. She soaked 2-3 hours a day Friday-Monday, and on Tuesday I took her to the pediatrician. With the soaking, we were able to get all the skin off that had built up (because of her ichthyosis), and they were able to see her wound. The doctor almost fell over. The wound was so deep. That was what was causing all of her pain. They sent us immediately to the bone doc and from there to a prosthetic store to get a foam boot instead of the cast. She came home and slept through the night for the first time in six weeks.

At Thanksgiving she started physical therapy and using a walker. Today she's still in physical therapy and has the wheelchair for distance (like shopping at the mall) and the walker for places outside the house. At our house and in her classroom she is able to get around by herself

I'd recommend to anyone who has ichthyosis and who needs to be casted to keep in mind if you have pain, it could be the cast rubbing on skin. The effect may be much different on an affected individual.

Sincerely,
Janet McCoy
Lititz, PA

Correspondence Corner *continued on Page 5*

Global Rare Disease Day Set for February 28th

The Foundation for Ichthyosis & Related Skin Types will participate in a global Rare Disease Day on February 28, 2009. As a Rare Disease Day Partner, we will join hundreds of other patient organizations, government agencies, medical societies and companies in focusing attention on rare diseases on that day.

This will be the Second Annual Rare Disease Day. The first was observed in Europe last year and was organized by EURORDIS, the European Rare Disease Organization, and the national alliances of rare disease patient organizations in each country.

This year, EURORDIS invited NORD, the National Organization for Rare Disorders, to organize a similar observance in the United States. Activities are also being planned in some other countries. The ultimate goal is to have a global Rare Disease Day on the last day of February each year.

The theme is that rare diseases are a public health issue, affecting millions of people around the world. The hope is that Rare Disease Day will increase awareness of rare diseases, the special challenges encountered by those affected, and the need for research to develop safe, effective treatments or cures.

As a Rare Disease Day Partner, F.I.R.S.T has agreed to help publicize and promote Rare Disease Day.

Partners and their members are encouraged to work with their media contacts, post videos and messages online, share human interest patient stories, and nominate researchers to a Rare Disease Hall of Fame. Pins and bracelets with the Rare Disease Day logo will be available soon at cost to the members of Partner organizations.

In addition, all Partners and their members have been invited to write to their state governors to request that February 28, 2009, be designated Rare Disease Day in the state. (A sample letter and resolution are posted on the NORD Rare Disease Day web page.)

For more information on these and other activities:

U.S. Rare Disease Day page on the NORD website: www.rarediseases.org

Global Rare Disease Day website: www.rarediseaseday.org.

Grassroots Fundraising

If you would like information on holding a grassroots fundraiser, please contact the Foundation office at (215)619-0670 or or e-mail us at info@scalyskin.org.

Portia Cina Makes a Difference

Joining the Cinas at breakfast are Lynne and Harry Alba

Portia Cina may be only 16 months old, but Pancakes with Santa, the event the Roseland Municipal Youth Guidance Council sponsored to honor Portia, proves she isn't too young to bring awareness about ichthyosis. The event raised over $800.00 with the proceeds donated to F.I.R.S.T. Young children and families attended the breakfast for pancakes, and most importantly a visit with Santa. Portia was surrounded by family, friends, and community members who came out on a cold Sunday morning to share in this event. F.I.R.S.T. members Harry and Lynne Alba also attended this holiday event. Lynne met Jolie Cina, Portia's mother, at the 2008 Family Conference and has been great support for the Cinas ever since. With the national office only a few hours away, Moureen Wenik, F.I.R.S.T. Program Director, accepted Jolie's invitation to meet the many friends and family of the Cinas. Another guest of the breakfast proves how talking to others can increase awareness. During a business trip in November, mom Jolie met New Jersey State Senator Richard Cody, the senator in her district. Through conversation she learned about his compassion for those with skin disorders. She decided to follow up on her chance meeting and invited the Senator to the breakfast. To her surprise, he accepted the invitation and joined the festivities. Congratulations to the Cina family for a successful event!

Enjoying Breakfast with Santa are (from left): Sean, Portia, and Jolie Cina, New Jersey State Senator Cody with Santa, and Moe Wenik, F.I.R.S.T. Program Director.

Chicago Area Scrapbookers Crop for F.I.R.S.T.

Foundation member Jennifer See is a busy mom with 4 children, 3 of whom are affected. Scrapbooking is a hobby that lets her be creative but does not mandate weekly attendance, as an art class or music group would. She can pull it out as time permits. This usually means planning on going to a crop while her husband watches the kids on a Friday or Saturday evening. A crop is a session held in someone's home or in a craft store where they give you a place to work on projects and socialize and eat for a small entrance fee.

Having been an avid scrapbooker for 4 years, Jennifer came up with an idea while at her local scrapbooking store (Archiver's) about doing a charity crop. The district manager at Archiver's agreed to donate the space (for a birthday party or women's group event, they usually charge $50 for renting the space) and provided a hostess. Fresh from our Family Conference in Chicago, Jennifer contacted all of the members that she knew from the conference roster in the Chicago area. Samantha Gonzales and Kathy Kouba stepped up to the plate and organized events at other local Archiver's Stores. With a total of 8 volunteers, they were instrumental in getting the food, beverages and some raffle prizes donated. The group made some posters and some contact cards and posted them at the store, churches, schools, etc.

With 20 attendees, over $1,100.00 was raised for F.I.R.S.T.! Congratulations to Jennifer and her group for all of their success.

Dress Down Day in honor of Emma Klima

When the employees of Braden Sutphin Ink Company were asked to dress down at work in support of F.I.R.S.T., they responded enthusiastically. Sharon Enting, grandmother of Emma Klima, who is affected with EHK, asked her company to sponsor a dress-down day. The employees could dress casually that day if they made a donation to F.I.R.S.T. Not only did the employees donate, but the Braden Sutphin Ink Company matched the donations, raising a total of $380.00. Many thanks to Braden Sutphin and Sharon.

Pumpkin Painting Event Successful

Michelle Iott once again ran a very successful pumpkin painting event for F.I.R.S.T., raising over $1,300.00 The pumpkins, donated by Iott's Greenhouse, were painted by children, while their parents shopped the tasty treats at the bake sale. This wonderful event has become an annual tradition.

The Foundation is very thankful to all of our wonderful members for their hard work.
Grassroots fundraisers are a great way not only to raise money for F.I.R.S.T,
but also to raise awareness about ichthyosis in your community.

2009 Testimonial Dinner Honoree Named

The Foundation for Ichthyosis and Related Skin Types is holding their 3rd Annual Testimonial dinner on April 17, 2009 at the Alpharetta Marriott. This year Michael W. Briggs will be honored for his unprecedented support of F.I.R.S.T. Mike became involved with the Foundation after the birth of his grandson, Adam, who is affected with Epidermolytic Hyperkeratosis (EHK). Mike has been a true pioneer since Adam was born. Armed with the passion to find a cure for his grandson, Mike provided the flame to ignite F.I.R.S.T.'s own in-house research program. Now in its fourth year, F.I.R.S.T. has been soliciting, receiving, and funding research grant proposals to find better treatments and cures for the different forms of ichthyosis. Although Mike is humbled by this honor, his mission is to help raise money to support the important work of our foundation.

Correspondence Corner continued from Page 2

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

I went online to order the PDS cream I have been using on my son's feet, and it says now that it's only "physician dispensed" and I can't purchase it on their website. Do you know how I can get it without having to order it through my dermatologist?

Thanks
Shelley Trojanowski
Hillside, IL

Editors Note: NeoStrata is still making the PDS Cream available at a 50% discount to F.I.R.S.T. members. Note that the product is now NEOSTRATA Problem Dry Skin Cream (rather than NeoCeuticals). Neostrata has improved the formula and removed the odor. Here is how our members can order:

(1) Go to www.neostrata.com

(2) Scroll down to the box that says "NeoStrata M.D. Online Store." Where it says "Please enter your Physician Account Number below," put in the following code: FFM99998

(3) This will take you to The NeoStrata Company Online Store. Scroll down to the bottom of the left hand side to "Neostrata Professional Skincare. Click here to learn more." Click there.

(4) This brings you to a page of featured NeoStrata products, including the Problem Dry Skin Cream. The price shown is the full price ($30). When you "add to cart," the 50% discount is applied, bringing the member price to $15.

Sorry that this is a bit complicated! They are hoping to have it simplified in the near future.

Correspondence Corner *continued on Page 10*

SET YOUR SIGHTS ON DISNEY FOR 2010 CONFERENCE

The date and location have been set for our 2010 Family Conference scheduled for June 25-27.

F.I.R.S.T. is headed to the Regal Sun Resort on Disney property in Lake Buena Vista, FL. Room rates will range from $99 to $129, depending on your choice of view. Discount tickets to all the major theme parks will also be made available to all attendees. For those guests with heat intolerance issues, you can be issued a special pass from the Guest Services department of each theme park to bypass or make special arrangements while waiting in lines for attractions.

So start saving your pennies and put **June 25-27, 2010** on your calendar. We hope to see you there! Our 2008 conference in Chicago was the best attended in our 28 year history, with 400 people in attendance. We anticipate that next summer's conference will be even better. More details will follow in upcoming newsletters and on F.I.R.S.T.'s website at www.scalyskin.org.

Spotlight On

Following are excerpts of an article featuring the Dunkin family that was printed in the The Kokomo Perspective by Lisa Fipps in December.

Raising Butterflies

By Lisa Fipps

Selia

Look closely at a butterfly's wings and you'll see that they are covered in scales, just like Cora and Selia Dunkin. The two, now 5 and 3, were born with a rare genetic disorder: Lamellar Ichthyosis. Cora and Selia produce too many skin cells and/or their bodies can't shed them quickly enough, leaving a scaly buildup.

Whereas many people refer to them as fish scales (the root of the word ichthyosis comes from the Greek word for fish), the Dunkins and others dealing with the disorder prefer to liken the scales to those found on butterflies. "A butterfly has scales, but you don't see them unless you look closely," said Mark Dunkin, Cora's and Selia's dad. "So the whole concept behind butterflies being a symbol for ichthyosis is that the children with it, the people with it, are beautiful creatures, but if you look at them closely, yes, you will see the flaws." "But they're still beautiful creatures," said Cora's and Selia's mom, Suzanne Dunkin.

Cora and Selia Dunkin are like butterflies in one other way. Each girl was a collodion baby, born encased in shiny, tight, skin membrane; picture a butterfly emerging from a clear, shiny chrysalis.

When Cora was born a collodion baby, that was the first time the Dunkins knew she was different.

"Dr. Steven Hott delivered Cora, and he and the nurses knew right away that something was wrong," said Suzanne. "It looked like she was wrapped in Saran Wrap."

"I followed Cora down to the nursery, and I saw Dr. Hott looking through medical books to figure it out because he had absolutely no idea what was wrong," Mark said.

"It was very scary, the fear of the unknown," Suzanne said.

Later that day, Dr. Jack Higgins happened to see Cora in the nursery. He instantly knew she had ichthyosis. He'd seen a collodion baby one other time in his 30-year career. Dr. Higgins called Riley Hospital, and a doctor there told St. Joseph Hospital staffers how to care for Cora until she could be transferred to the facility in Indianapolis. Cora's skin had to stay lubricated, and she needed a humidifier, in essence, as she lay in her isolette.

Once the Dunkins had the diagnosis, Suzanne called her friend who is a genetic counselor, Melissa Wesson, and she was able to tell the Dunkins all about ichthyosis.

"It's an autosomal recessive disorder," Suzanne said. "So both of us had to have the TGM1 gene. Mark and I are carriers, but we just didn't know it."

Although ichthyosis can be passed down from parents, according to the Mayo Clinic, "In some rare cases, the genetic mutation occurs spontaneously in the affected generation."

"We didn't know it, but each time I was pregnant we had a 1 in 4 chance that we would have a child with Lamellar Ichthyosis," Suzanne said.

Raising Butterflies *continued on Page 7*

Raising Butterflies continued from Page 6

Before Cora, Suzanne had given birth to Gabrielle, now 10, and Kendall, now 7. Neither has ichthyosis.

When Cora was 2 and Suzanne got pregnant again, the doctors offered to do testing to see if the baby, Selia, had ichthyosis.

"We thought, 'Why?'" Suzanne said of testing the fetus. "We already know how to handle it."

Later in life, the four girls will have to decide if they want to be tested for the TGM1 gene, the Dunkins said.

Caring for ichthyosis is very labor-intensive. It means spending hours bathing to loosen the scales, scrubbing the skin in an effort to shed some of the scales, and putting on creams to help moisturize and exfoliate. Someone with darker pigment has darker scales. Mark and Suzanne said that because Cora has dark hair and eyes her scales are more noticeable than Selia's. Dealing with the scales on the scalp is difficult, the Dunkins said. It helps to cover the scalp in mineral oil, wrap Saran Wrap around it, and cover it with a hat for a few hours to loosen the scales. Then it's time to wash the hair and comb it. The problem is that often the comb will catch on scales that aren't loose enough to come off, causing pain.

Severe scaling on the scalp can lead to patchy hair loss. Suzanne said many adults with it end up wearing wigs. Cora and Selia go to the eye doctor every three months to deal with dry eyes and skin buildup in the eyes. The tight skin makes it difficult for them to shut their eyes sometimes. Mark and Suzanne put Vaseline around their daughters' eyes at night so they close their eyes more easily.

Still, they often sleep with open eyes. "It's pretty creepy, really," Mark said. "You walk in and you think, 'Are they looking at me or are they asleep?' " he said and laughed.

The two sisters also see an otolaryngologist, who removes the excess skin built up in their ears. It can cause hearing problems. Both girls have speech problems that their parents attribute to their not being able to hear sounds well because of the ichthyosis. Cora and Selia, along with their older sisters Gabrielle and Kendall, attend a private, Christian school, Redeemer Lutheran School, where Suzanne teaches. "There, people accept them as who they are," Mark said. "Out in the real world, it's totally different." People stare. People point. People laugh. "Honestly, it makes me more uncomfortable than it does any of them," Mark said of his wife and four daughters. "To me, that's my child they're staring at, making fun of, and I wish that they would come up to me and say, 'What's wrong with your child?' I would answer every question imaginable if they would just come up and ask me. It's not the kids who are the worst offenders. It's the adults. I can understand kids being curious and not knowing. It's a fact of life, I guess. I guess I get mad. I don't get physically mad at them, but inside I get mad because I guess I wouldn't do that. Since I feel that I wouldn't do that, they shouldn't do that. Then again, I may be taking it the wrong way and it's an opportunity for me to come out and say, 'Hey, this is my child, and this is what she has.' We get comments all the time from people. God love them. They'll say, 'Oh, she's really sunburned, isn't she? Don't you think she's been out in the sun too long?' Then I have to explain, no, that's not what it is, and we have to talk about it. It makes me mad."

"It doesn't make me mad," Suzanne said. "If people stare, I just kind of smile, then if they ask, I just answer them. If they don't ask, then we just go on. I just try not to make a big deal out of it."

The older Dunkin girls who don't have ichthyosis, Gabrielle and Kendall, struggle, too, because they don't know what to say or do when people stare or make rude comments about their sisters.

"That's where the sisters kind of have issues a little bit because they feel like they have to defend them," Suzanne said. "People ask questions and look, probably look more than ask, and the sisters are starting to notice that a little bit more, the older they get, and that makes them a little uncomfortable. Gabrielle, she knows she should defend her sisters, but she's not quite sure how to handle it. You can't blame her.

It's hard for a grownup to know how to handle something like that." But 5-year-old Cora is always willing to speak up when people stare or laugh. "I tell them God made me this way," Cora said. "And I like it because my skin is different than everybody else's that I see — and I get to take longer baths."


Cora

Executive Director's Report

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

As another year is upon us, it is exciting to see how much we have achieved. With one year accomplished toward our four-year strategic plan, I am proud to report that we are on track and progressing with success. As you have read in this issue, plans to regionalize our support network are underway and regional meetings are planned for this summer and fall. We have also completed our search for a new Constituent Relationship Management system to better track and stay in touch with our members, donors, and friends of F.I.R.S.T.

Following the recommendations in our Diversified Development Strategy, F.I.R.S.T. is currently interviewing candidates to join our staff in the newly-created position of Development Director. We have also made some changes to current staff positions and shifted job responsibilities. In our spring issue, I plan to announce our newest staff members and these exciting changes.

With the beginning of a new year, there have been several changes to our Board of Directors. At the end of 2008, both Beth Gray and Dan Siegel, Esq. rotated off the board. They both served three consecutive three-year terms, which is the maximum allowed in accordance with our by-laws. Both Beth and Dan have made significant contributions to F.I.R.S.T. and they will be missed as board members. However, we are fortunate that Dan will remain F.I.R.S.T.'s legal counsel. Even though they are not official board members any longer, they promised to remain active with F.I.R.S.T., both as members and donors.

F.I.R.S.T. is proud to announce the addition of four newly-elected board members: 1) Mark Dunkin, father of two affected daughters; 2) Moise Levy, MD, a pediatric dermatologist; 3) William Rizzo, MD, a pediatrician; and, 4) Brian See, Esq., who is personally affected and has three affected children. These new board members bring a wealth of knowledge and expertise to F.I.R.S.T., and, most importantly, they bring a passion for wanting to advance F.I.R.S.T.'s mission.

On tap in the upcoming months is the annual Medical & Scientific Advisory Board meeting at the American Academy of Dermatology meeting in San Francisco in March, the 2009 Testimonial Dinner honoring Mr. Michael Briggs in April, and our four regional conferences. We are also busy preparing for the third annual Phantom Tea national fund raiser. I hope more members will be joining our efforts this year. This fund raiser has been very successful, raising more than $65,000 since its inception.

In closing, I am excited to announce that the location for the 2010 family conference has been selected as Disney World, Florida. We can't wait to make this a fun-filled conference with lots of extra-curricular family activities.

Sincerely,

Jean

Jean R. Pickford
Executive Director

Dear Doctor . . .

Following are questions asked at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Roundtable discussion of Skin Biology and Diseases in 2008

Answers provided by Keith Choate, M.D., Ph.D.
Yale University School of Medicine, New Haven, CT

1. **What have been the top advances in skin biology and skin disease research within the past five years?**

   Genetics: continued identification of genes for rare and common genodermatoses has permitted understanding the pathophysiology of many diseases. With the advent of high throughput genome sequencing, it is possible that we will be able to identify the genetic basis of rare diseases in which families are too small to permit traditional linkage based approaches.

   Stem Cell Biology: the explosion of work in stem cell biology both within the skin and in other tissues raises the possibility that we may be able to develop new therapies via stem cell genetic orpharmacologic modification.

2. **What are promising areas of science in skin biology and diseases?**

   Genomics - next generation sequencing, identification of rare alleles with large effect in rare and common genetic skin diseases.

   Cell biology - high throughput pharmacogenomics - the ability to directly assay the effects of libraries of chemicals on the genetic pathways relevant to skin disease pathophysiology.

3. **What are the most pressing scientific needs?**

   A. Ensuring that the NIH budget grows. Reduced NIH funding over the last 5 years has led directly to the loss of many promising young researchers.

   B. Funding clinician-scientists. Clinicians who actively care for patients with genodermatoses are best poised to understand the pathophysiology of these diseases and to ask relevant scientific questions.

4. **What are the greatest challenges, other than workforce issues, to research progress? What are the potential options for overcoming these challenges?**

   Establishment and maintenance of standardized patient registries. The registries for many disorders are fractured and underfunded. If the NIH were to establish a registry office with standardized protocols for recruiting patients and banking relevant clinical samples for current and future research, cost and complexity of projects would be reduced and all disease communities would benefit - both those with large numbers of individuals and those with very few. A centralized clinical database could be generated and interested scientists could apply to work with patient data sets.

5. **What gaps in training have delayed progress in critical areas of skin biology and diseases research?**

   Clinical training in dermatology is focused on the development of a clinical knowledge base and skill set directed solely toward patient care. While T32 grants permit self-identified physician-scientists to pursue further training in skin biology, we are not engaging clinicians who could do basic and clinical research relevant to genetic skin disease. This relates directly to the structure of Dermatology training programs and would require a new pathway to encourage skin-disease relevant research.

6. **What innovative, creative approaches are needed to transform the understanding of health disparities in skin biology and diseases?**

   The most effective research comes from collaboration of people across disciplines. If the NIH were to sponsor translational research meetings organized by invitation only and which brought together skin disease advocacy groups, basic science researchers, and clinicians, it may be possible to generate new research directives for NIAMS.

Correspondence Corner continued from Page 5

Dear F.I.R.S.T. Staff and Members,

I wanted to know if you have a suggestion for an alternative lotion for Epilyt. The manufacturer no longer makes it and it has worked beautifully for my 4 children, ranging from ages 20 to 7. Any help would be appreciated. Please e-mail me at 9isfine@comcast.net.

Sincerely,
Beverly Martin

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

The least expensive place I've found to purchase jojoba oil is "Trader Joes" here in CA (www.traderjoes.com). They are a retail place but they usually offer better deals. My 4 oz bottle was $6.99 at Trader Joes. Otherwise, I located Purcell Jojoba International on the web (www.purcelljojoba.com), a wholesale place that sells in bulk to the cosmetics industry, and Desert Essence (www.desertessence.com), which offers a whole line of organic skin care products.

Interestingly enough, jojoba oil was used by the Native Americans and can be used for treatment of the scalp, finger nails, and other areas.

Some people may want to combine its use with other skin lotions as well. I've been using "Dermal Therapy's Alpha Hydroxy Lotion" for years, but there is some question about the continual absorption of some of its ingredients like "lactic acid" and "urea." I've found the Environmental Working Group's web site very useful for learning about potential risks of ingredients that are used in skin and hair products. F.I.R.S.T. members can check out their web site at www.cosmeticsdatabase.com. Jojoba oil appears to be completely natural, plant-based, and chemical free.

Best,
Dana

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

Hi, my name is Pete MacKean. I am 43 and live in England. I have suffered with ichthyosis all my life, and like a large number of us felt like I was the only one with it.

As a youngster I was told many things, from my Ichthyosis Vulgaris (IV) was stress related and would go away with age, to there is no cure at all so just live with it or move to a hotter climate. My skin for most of my life has been scaly all over my arms and legs, chest, stomach back and shoulders, varying from thick brown scabby scales to light silvery. It really knocks your self-confidence, and for years, I hated bathing apart from sea bathing, and learnt my own way of dealing with it. I couldn't use soaps but experimented with all types of lotions, most being the oily greasy types.

I remembered seeing a documentary about someone with a similar skin condition in St. Thomas's Hospital London and asked my GP to refer me. I saw Professor Griffiths (now retired), the top skin specialist in the UK at that time. After various tests and biopsy I was offered treatment in the form of Acitretin (Neotigason) a fairly new retinoid drug then, a vitamin A supplement.

I had been taking acitretin for some fifteen to twenty years. After about the third year, there was some improvement, with my skin clearing during the summer and worsening over the winter. As the years passed, aches and pains were becoming too much to deal with. Now, the Acitretin doesn't appear to be working. I have been suffering from extreme tiredness, muscular and joint pains, backache and headaches that last all day. Anti-inflammatories have not been very helpful.

These symptoms have caused me to change jobs in order to find something less physically demanding.

Around March of last year, I was watching a program in the UK, called Casualty 1907, which showed a young boy with ichthyosis. After the show, there was a mention of an ichthyosis web site, so I googled it. I've looked up ichthyosis and my medication on the net before and found nothing worthwhile. I came across a posting made by a young lady claiming she had found a cure for her dry skin. As I read more I became more interested and thought it has to be worth pursuing. With some more research I found it. It is Alpha Hydroxy Lotion made by Dermal Therapy of Canada and supplied in UK by Advanced Care Products of Ipswich, available over the net. It contains 10% lactic acid for exfoliation and 10% urea to sooth itchiness.

I ordered a bottle immediately, and by early April I stopped taking the acitretin and began using the lotion. WOW, amazing stuff, after four days, what an incredible difference. I was practically cleared up. My skin totally hydrated, soft and feeling so natural and more importantly, it looks fantastic. My regime now is I take a daily morning shower, not too hot, have a good soak of 20 minutes using no soap, use something natural with low PH. I wash down using exfoliating gloves available from most chemists, don't rub too hard to prevent itchiness. After shower I dry my head, under arms and between legs, I leave the rest of my skin mostly wet to aid the spreading of the Alpha Hydroxy lotion and smear it all over, even my scalp. It dries in about 10 minutes leaving no greasy smelly residue, perfect as you can dress without feeling sticky. With daily treatment my skin is terrific and maintaining it becomes easier. I definitely recommend it to everyone. I understand it can be used with most skin disorders. Try it.

Correspondence Corner *continued on Page 13*

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Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.)
Regional Support Network

REGIONAL VOLUNTEER (RV)
JOB DESCRIPTION

REGIONAL VOLUNTEER QUALIFICATIONS:

- Must be 18 years of age and older.
- Be a member in good standing with F.I.R.S.T. and have personal experience with ichthyosis.
- Be emotionally stable and mature, and must also hold all communications with callers confidential.
- Have excellent communication skills and objectivity.
- Understand that he/she is not qualified to give any medical advice.

REQUIREMENTS and COMMITMENTS:

- Able to follow the policies and procedures established by F.I.R.S.T.
- Able to maintain written records of contacts with callers and file reports with the Regional Network Coordinator.
- Must be willing to be “matched” with callers and make/accept phone calls/emails.
- Attend quarterly conference call meetings hosted by the Foundation.
- Actively participate in or organize awareness or grassroots events.
- Attend biennial regional meeting (held opposite years of the Foundation’s Family Conference).

RESPONSIBILITIES:

- To establish the reason for the member’s inquiry and to explore the member’s expectations.
- To act as a resource referral.
- To provide psychosocial support.
- To be an active listener.
- To support the member with understanding and empathy.
- To be accepting of the caller’s feelings, ideas or values.

RESOURCES:

- F.I.R.S.T.’s Program Director
- Regional Coordinator

____
Regional Volunteer Name

____
Regional Volunteer Signature

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

Regional Support Network
Volunteer Application

Volunteer Contact Information

(please print clearly)

Name: ____

Address: ____

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

Phone (Day): ____________________ Phone (Night): ____________________

Cell Phone: ____________________ Email: ____________________

Please Check:

I have read the Regional Volunteer Job Description and understand my responsibilities and role in the Regional Support Network. ☐Yes ☐ No

I give permission to F.I.R.S.T. to release my name, contact information and type of ichthyosis to other members who are interested in being contacted by me. ☐Yes ☐ No

I give permission to F.I.R.S.T. to publish my name, contact information and type of ichthyosis in the Regional Support Network contact listing which is distributed to all Regional Volunteers. ☐Yes ☐ No

Volunteer Family Information

This section must be completed with name, age, and type of ichthyosis (if appropriate) of family members.
This will help the office when connecting you to a family within the region.

First Name	**Last Name**	**Age**	**Affected by Ichthyosis**
____________	________________	_____	☐ Yes ☐ No
____________	________________	_____	☐ Yes ☐ No
____________	________________	_____	☐ Yes ☐ No
____________	________________	_____	☐ Yes ☐ No
____________	________________	_____	☐ Yes ☐ No
____________	________________	_____	☐ Yes ☐ No

Please indicate which type of ichthyosis affects your family: ____________________

Are you willing to make long distance calls? ☐ Yes ☐ No

What is the best time for you to accept phone calls? ____________________

Do you speak a second language? ☐ Yes ☐ No

If yes, what language or languages can you speak? ____________________

Foundation for Ichthyosis & Related Skin Types
1364 Welsh Road G2 • North Wales, PA 19454 • Ph (215) 619-0670 • (800) 545-3286 • Fax (215) 619-0780
Web Address: www.scalyskin.org • Email: info@scalyskin.org

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News on the Hill

News on the Hill is a column to keep members current with the legislation in Washington, DC. This column is written by Angela Godby, Assistant Vice Chancellor for Federal Relations for the University of Texas System. She is affected with Lamellar/CIE.

NIH Set To Receive Funding Boost

After years of stagnant growth, the National Institutes of Health (NIH) could see additional funding in 2009. One of the first actions of the new 111th Congress has been working on a so-called economic stimulus package to jump-start the economy. The stimulus plan encompasses a wide variety of funding from Medicaid funding to education infrastructure grants to transportation infrastructure grants. As of press time, congressional leaders are considering a stimulus package which includes an additional $3.5 billion in NIH funding.

The majority of the proposed NIH funding, $2 billion, will be used to fund more research grant applications. Currently, NIH is able to fund less than 20% of all applications received. This has stymied biomedical research into skin diseases including ichthyosis. Moreover, it has threatened the pipeline of new scientists and doctors interested in the field of biomedical research.

Late last year, FIRST joined nearly 200 patient groups, scientific societies, research organizations and companies in a letter to President Obama calling for at least $1.2 billion in additional funding in the stimulus package. The groups also called on the President to appoint a permanent NIH director "who understands the complexity and breadth of NIH's mission and who can help deploy scientific research investments wisely for maximum economic and health benefit."

Slow Start for Obama Administration's Health Agenda

During his campaign, President Obama set universal healthcare reform as a key priority for his administration. Current events appear to have sidetracked that priority, however. In November, President Obama nominated former Senator Tom Daschle as Secretary of Health and Human Services (HHS) and named him the Director of a new White House Office on Health Care Reform. After the revelation of tax payment problems, Senator Daschle withdrew his name from consideration for the post. As of press time, President Obama has not yet named another nominee.

Daschle's departure coupled with early legislative victories, including reauthorization of the Children's Health Insurance Program, have temporarily slid universal health reform further down the priority list. House and Senate committees will be developing health reform measures over the coming year. President Obama's health agenda includes efforts to increase access to quality, affordable healthcare as well as strengthen the NIH and invest in critical biomedical research.

Other key HHS openings at the National Institutes of Health and the Centers for Disease Control and Prevention remain open as of press time. NIH Director Elias Zerhouni departed the NIH in October. A leading candidate for the job is Dr. Francis Collins, former Director of the National Human Genome Research Institute at NIH and leader of NIH's effort to map the entire human genome.

Correspondence Corner continued from Page 10

Late September is usually a bad time of year for me, as the weather turns cold and miserable in UK and my skin usually becomes very uncomfortable, but not now. I have finished two bottles and just ordered two more. I have had some dryness return on my legs and forearms but after a good soak in the bath its gone again, but it doesn't stop me from wearing shorts or short sleeve tops now, I look so much better, a real confidence boost.

I'm now interested in getting the word spread to everyone who suffers with ichthyosis to look at the web sites and to try out the Alpha Hydroxy lotion. The UK site is the Ichthyosis Support Group based in Reading with around 500 members, see www.ichthyosis.org.uk. The best site is www.ichthyosis.com, with over 2400 members, it has changed my life. There are many useful postings on the bulletin board. The moderator, Les Avakian, is a wealth of information and has informed me of many patients who have suffered with problems similar to mine. Also look at the F.I.R.S.T. site, www.scalyskin.org. This site will also keep you updated on all the latest news and scientific breakthroughs.

An interesting side note, I'm now being tested by a rheumatologist for Gluten intolerance which may be the cause of my aches, pains and tiredness. The nurse taking the blood sample said she too had dry skin, only on her legs, but it looked very similar to mine. I told her she has ichthyosis and I recommended the lotion. She was amazed; she never bothered to find out as she was embarrassed by it. Thanks to the ichthyosis.com site I no longer feel alone and I aim to spread the word as best I can to help other sufferers.

Thank you,

Pete MacKean

News & Notes

TIME TO TALK ABOUT CAM:
Health Care Providers and Patients Need To Ask and Tell

The National Center for Complementary and Alternative Medicine (NCCAM), part of the National Institutes of Health (NIH), has launched Time to Talk, an educational campaign to encourage patients — particularly those ages 50 or older — and their healthcare providers to openly discuss the use of complementary and alternative medicine (CAM). CAM is a group of diverse medical and healthcare systems, practices, and products that are not presently considered to be part of conventional medicine, such as herbal supplements, meditation, naturopathy, and acupuncture.

According to a national consumer survey conducted by NCCAM and AARP, almost two-thirds of people age 50 or older are using some form of CAM, yet less than one-third of these CAM users talk about it with their providers. The NCCAM/AARP survey revealed some reasons why this doctor-patient dialogue about CAM does not occur. The most common reasons survey respondents cited were

— That the physician never asked

— They did not know they should discuss CAM

— There was not enough time during the office visit.

More than one-half of respondents who had talked about CAM with their physician said they (not their physician) initiated the CAM discussion. The telephone survey was administered to a nationally representative group of 1,559 people age 50 or older.

The Time to Talk campaign is aimed at addressing the need for this dialogue to help ensure safe, coordinated care among all conventional and CAM therapies. Talking not only allows integrated care, it also minimizes risks of interactions with a patient's conventional treatments. When patients tell their providers about their CAM use, they can more effectively manage their health. When providers ask their patients about CAM use, they can ensure that they are fully informed and can help patients make wise healthcare decisions.

"As frequent users of CAM, people 50 and older need to understand the importance of discussing CAM use with their providers to ensure coordinated, safe care. Simply put, it's time to talk," said Josephine P. Briggs, M.D., NCCAM Director. "Giving your healthcare providers a full picture of what you do to manage your health helps you stay in control."

NCCAM's Time to Talk campaign encourages patients to tell their providers about CAM use and providers to ask about it by offering tools and resources — such as wallet cards, posters, and tip sheets — all of which are available for free on the NCCAM Web site nccam.nih.gov or can be ordered from NCCAM's information Clearinghouse (1-888-644-6226). As the Federal government's lead agency for scientific research on CAM, NCCAM is committed to educating both consumers and healthcare providers about the importance of discussing CAM and providing evidence-based information to help with healthcare decision making.

PATIENT TIPS FOR DISCUSSING CAM WITH PROVIDERS

— When completing patient history forms, be sure to include all therapies and treatments you use. Make a list in advance.

— Tell your healthcare providers about all therapies or treatments — including over-the-counter and prescription medicines, as well as herbal and dietary supplements.

— Take control. Don't wait for your providers to ask about your CAM use.

— If you are considering a new CAM therapy, ask your healthcare providers about its safety, effectiveness, and possible interactions with medicines (both prescription and over-the-counter).

PROVIDER TIPS FOR DISCUSSING CAM WITH PATIENTS

— Include a question about CAM use on medical history forms.

— Ask your patients to bring a list of all therapies they use, including prescription, over-the-counter, herbal therapies, and other CAM practices.

— Have your medical staff initiate the conversation.

For more information on Time to Talk, to order or download materials, or to read the full NCCAM/AARP report on CAM use communication, please visit nccam.nih.gov/timetotalk/.

The National Center for Complementary and Alternative Medicine's mission is to explore complementary and alternative medical practices in the context of rigorous science, train CAM researchers, and disseminate authoritative information to the public and professionals. For additional information, call NCCAM's Clearinghouse toll-free at 1-888-644-6226, or visit nccam.nih.gov.

The National Institutes of Health (NIH) — The Nation's Medical Research Agency — includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical, and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

Funds Available for F.I.R.S.T. Members

Jane Bukaty Membership Assistance Fund
F.I.R.S.T. recognizes that living with ichthyosis is not only a medical issue, but a financial one as well. Maintaining the daily regimen of treatments required can become very expensive. Many insurance companies will not provide coverage for the many creams and lotions required to maintain a patient's skin.

This is your opportunity to receive financial assistance for your Ichthyosis treatment.
The following criteria must be met by the applicant in order to be eligible for JBMAF aid.

- The applicant must complete a membership application.
- The applicant is required to submit a letter indicating his/her need for funding.
- The letter must include the amount of funding requested, the specific product/treatment for which funds are required and a demonstration of the financial need for this product/treatment.

Awards will generally not exceed $100.00. Applications will be awarded two times per year as determined by the Support Network & Member Assistance Committee. Applicants will be eligible to receive one award every two years.

Applications for cycle #16 are currently being accepted, with grants being awarded in June. Applications are available by contacting the national office at 800.545.3286 or info@scalyskin.org Once completed, the application requests can be emailed to the national office or mailed to the attention of the Jane Bukaty Membership Assistance Fund at:
1364 Welsh Road, Suite G2
North Wales, PA 19454.

F.I.R.S.T. Receives 2009 Gold Triangle Award

The American Academy of Dermatology's Gold Triangle Awards recognize and honor media, industry, health community organizations, public service and individual efforts that further understanding of dermatologic issues and encourage healthy behaviors in the care of the skin, hair and nails.

This year, F.I.R.S.T. will receive the Gold Triangle Award for the outstanding success of our national family conference. For the past 27 years, F.I.R.S.T. has been hosting a biennial family conference for our members; affected patients and their families. The conference is a life-changing experience, affording many individuals the opportunity to meet others who look, feel and experience the same issues.

F.I.R.S.T. organizes the services of internationally recognized dermatologists and other healthcare professionals to provide patients with reliable skin care treatments, emotional support and advances in medical research. Formal discussion groups and private screening appointments with leading expert physicians provide a wealth of information that can dramatically alter someone's life. For some members, the conference may be the first time they have direct access to a knowledgeable dermatologist who could provide accurate and experienced medical advice.

The Gold Triangle Award will be presented in San Franciso during the 2009 Annual AAD Meeting in March.

Awareness Creates a Secret Connection

Many times the thought of organizing a grassroots fundraiser or awareness event can be an overwhelming and daunting task, but it doesn't have to be. There are many ways to impact others, without ever knowing that you have. Here is the story the staff recently learned in the national office.

Throughout the past year, multiple donations were received by a generous donor. It was noted that this donor was neither personally affected, nor had a family member affected. A simple phone call to investigate the source of that generosity revealed the motivation of the donations.

The secret connection was made about a year ago, when a F.I.R.S.T. member was hosting an awareness campaign. The campaign consisted of a table with literature, a poster, a donation jar, and the drive to create awareness throughout the community. The donor was so moved by the member, that a donation was made that day and continued throughout the year.

The Foundation is very grateful for the secret connection, and hopes that others will be encouraged by this story. An awareness effort doesn't have to be large and extravagant; it needs to be driven by the heart and with passion to inspire others.

Camp Discovery 2009

The American Academy of Dermatology (Academy) is proud to offer four camping sessions this year for young people with chronic skin conditions, who are between the ages of 8 and 16. Under the expert care of dermatologists and nurses, Camp Discovery gives campers the opportunity to spend a week with other young people with skin conditions, while participating in everything from swimming and fishing to horseback riding to lots of camp games and activities. All campers must be referred by their dermatologist.

There is no fee to attend this very special camp. Full scholarships, including transportation, are provided by the Academy through generous donations from its members, outside organizations, and individuals.

2009 Dates:

- July 5 – 10, Camp Knutson - Teen Camp in Crosslake, Minnesota (ages 15 – 16)
- July 11 – 17, Camp Knutson - Junior Camp in Crosslake, Minnesota (ages 10 – 14)
- August 9 – 14, Camp Dermadillo, Burton, Texas (ages 9 – 16)
- August 15 – 22, Camp Horizon, Millville, Pennsylvania (ages 8 – 13)

For more information about attending or volunteering please visit their web site at www.campdiscovery.org or contact Janine Mueller at (847)240-1737 or jmueller@aad.org.

CAMP DISCOVERY

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

Foundation for Ichthyosis & Related Skin Types
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