Ichthyosis Focus

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

Vol. 25, No. 2 — *A Quarterly Journal for Friends of F.I.R.S.T.* — Summer 2006

Obstacles to Translation

The Foundation for Ichthyosis and other skin disease patient advocacy groups supported and attended an *Obstacles to Translation Conference* in early March. The *Obstacles to Translation Conference,* held at the Mission Bay Campus of the University of California, San Francisco (UCSF), on March 1 and 2, 2006, addressed the obstacles that have prevented the skin disease community from translating known information about the genetic basis and physiological pathways of inherited skin diseases into successful therapies.

The conference, organized by Dr. Ervin Epstein, Jr., UCSF, Dr. Leonard Milstone, Yale University, and Dr. Barbara Gilchrest, Boston University, brought together representatives from academic science, biotech and pharmaceutical companies, venture capital groups, the government, and patient advocacy groups to identify the barriers to translation and to emphasize strategies to surmount them. The program was divided into eight sessions, each focused around major topics important to the development of molecularly targeted drugs for inherited skin diseases. The topics included the drug development process, financial issues, targeting DNA, and the regulatory process, among others.

Two days of detailed presentations and intensive discussion ended with all the participants dividing into breakout groups. The breakout groups were each given a specific obstacle to discuss and were charged with returning to the group at large with a short list of possible solutions to the specific problem. Four obstacles were identified for discussion: obstacles to drug discovery, obstacles to translation of promising therapies, obstacles to various institutional cultures (academic, corporate, health delivery, government institutions, etc.), and obstacles to raising money.

Several interesting and varied suggestions came out of the discussion groups; we will report in more detail on those in a future issue of the Focus. But, in short, the outcome of this conference offered good news and bad news for the Foundation and other patient advocacy groups.

The good news is:

There are many brilliant and dedicated minds working on rare inherited skin disorders.

Researchers are making progress in knowledge of these diseases and are sharing that knowledge with each other.

The Federal government, specifically the NIH (National Institutes of Health) and the Office of Orphan Drug Development within the Food and Drug Administration, has several initiatives in place to help academic scientists move their research efforts forward.

Many people are thinking about translational research.

The bad news is:

It takes a great deal of time and money to for an academic scientist to reach the point where he or she can identify a promising drug or targeted therapy.

It takes significant time and money to move a promising drug or targeted therapy through the drug development process.

Biotech and pharmaceutical companies and venture capitalists are not interested in helping unless the drug or therapy has a large potential market value.

So where do the Foundation and other patient advocacy groups go from here? The consensus is that we need to:

Keep raising money for research, because there is no promise that anyone else will step in.

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Designate Funds through United Way of America **Or** CFC Combined Federal Campaign **Giving Programs**

See page 3 for details

Ichthyosis Focus

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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 Friends and Members of F.I.R.S.T.:

We are trying to organize an ichthyosis support group in northern California! Meetings would be held bi-monthly around the Stanford University area. We are trying to get an idea of how many people would be interested in attending and what days or times would be best. Please contact Courtney Shell at cshell065@comcast.net, or Lisa Taylor at 650-725-9961 with your opinion or for more information.

Dear Jean Pickford:

I would like to share with you a letter that I wrote to Galderma about one of their products that works for my ichthyosis. I know there are worse cases of ichthyosis out there than what I have to deal with on a daily basis, but this may help someone. Thanks, Karen Beller.

Dear Galderma Product Development:
I have been dealing with a genetic skin disorder called ichthyosis for the last 40 years. My skin is extremely sensitive and cannot tolerate a lot of the lotions and creams that are on the market today. I have to apply large amounts of cream to my entire body daily, after every shower, and periodically throughout the day. I have tried every product imaginable and have found that Cetaphil cream has been a "miracle cream" for me. With the cream, my skin feels soft and the flaking associated with ichthyosis is very controllable. It keeps my skin moist throughout the day and I do not have any adverse reactions to the cream; other products have caused me to break out into rashes, stinging, redness, etc. I purchase my cream from Costco about every four to six weeks, approximately six 20-ounce jars at a time.

It is quite expensive, but it does the trick in controlling my skin problem. Although my daily regimen includes a couple of other products not made by Galderma, I believe that the Cetaphil cream is the key component in my battle with ichthyosis.

Anyway, I just wanted to plead with Galderma to keep making this great product because I do not know how I would control my skin problem without the Cetaphil cream. Fortunately, my 14-month old daughter was not born with the same skin disorder as me, but I apply Cetaphil cream to her skin too; it is so gentle (if it works on my skin, I know it will be gentle for my baby's skin).

Have you done any research with regard to ichthyosis? I am going to forward this email to the Foundation for Ichthyosis to tell them about your product and how it has helped me. Thanks and keep up the good work.

Karen Beller
Malott, WA

Spotlight On...

Karen and Randy LaBarbera

I met Randy 15 years ago, at a singles party that he and a mutual friend of ours were having at his house. I had heard of and seen Randy at church and other social events before this evening. He was noticeably different, red with flaky, dry skin. I didn't think much of it when we all took a walk around the lake at his neighborhood complex and he started talking to me about work, people we both knew, and other nonessential chit chat. I did study his face and wondered about his skin condition; if it hurt, was it hereditary, how it affected his every day life. Later that week, the same mutual friend asked us for a foursome in tennis, where I partnered with Randy. He had a very good athletic ability, and we won. The next day, he surprised me with a cleverly crafted small trophy with a tennis ball on top of a golden cup that read "#1 Tennis Champs." We talked and I noticed he was confident, witty and funny, and didn't seem to remember that he looked different. I finally asked him about his skin condition, what it was called, and if it hurt. The look on his face startled me, because his expression changed to a look of bewilderment mixed with shame. Before this moment, he always carried on as though there were no differences, and I realized then that this was when it hurt, when a person pointed out that there was a difference. Randy openly explained to me his skin condition and the everyday pains he had to take to care for himself. I was thankful for his openness and we became the best of friends. I loved being with Randy but was not prepared when he took my hand and held it and we were suddenly on a date. I remember thinking to myself, "I should pull my hand away and break this off now, because I don't want to hurt him." I never did let go and in April of 1995 we were married. Randy is a loving, wonderful husband and a darned good cook. So many have told me that he was blessed to find me, but in turn I have to reply that it is I that am truly blessed to have him in my life.

Donate through the United Way or Combined Federal Campaign Programs

Donating to the Foundation through the United Way or Combined Federal Campaign is an easy and convenient way to support the important work of the Foundation. A small deduction of $5.00 per paycheck can add up to over $200 per year for the Foundation. It's simple, convenient, and can really make a difference.

The United Way of America is the national organization dedicated to leading the United Way movement in making a measurable impact in every community across America. The United Way movement includes approximately 1,400 community-based United Way organizations. Each is independent, separately incorporated, and governed by local volunteers. The Foundation for Ichthyosis is the recipient of funds from many of the United Way community-based organizations. Through the Donor Choice Program, you can designate all or a portion of your donation to the Foundation. Simply write in "Foundation for Ichthyosis & Related Skin Types" on the Donor Choice Option form and your gift will be sent to our office. Be sure to include our new mailing address and phone number, 1364 Welsh Road, Suite G2, North Wales, PA 19454, 215-619-0670.

The Combined Federal Campaign (CFC) is the annual fund-raising drive conducted by federal employees in their workplace each fall. Federal employees and military personnel raise millions of dollars each year through the CFC to benefit thousands of non-profit charities. The Foundation is the recipient of funds from many CFC organizations throughout the country. The Foundation's CFC code is 0810, which is listed in the charitable organizations directory.

Contact your Human Resources Department to find out how you can support the Foundation using United Way or Combined Federal Campaign.

Obstacles to Translation

continued from page 1

Continue and refine lobbying efforts to encourage expansion of the research in rare diseases, with a possibility of focusing on expanding the FDA Office of Orphan Drug Development.

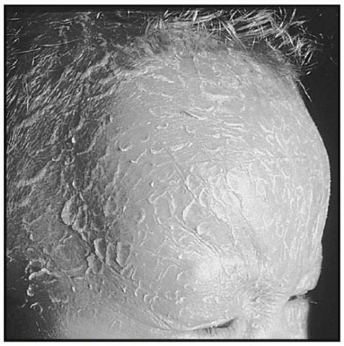
Be prepared to collaborate with other groups to identify promising "demonstration" projects (projects that have promise for more than one disease type) and pool money and resources to promote those projects.

Be prepared to step in to reduce regulatory or financial barriers by advocating for creative solutions, such as a national Institutional Review Board (IRB) for rare disease research. (Currently researchers have to get their own institutions' IRB approval for new or continuing projects, which makes collaboration with other scientists in other institutions and settings difficult.)

We will update you again on the outcomes of the *Obstacles to Translation Conference,* when the final notes from the conference are available. In the meantime, you can read more about the conference here: www.obstacles.medschool.ucsf.edu.

Please watch the Fall 2006 newsletter for more about the Foundation's Research Grant Program.

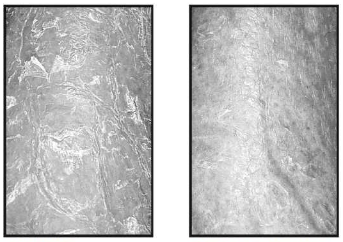
When Timothy* grows up, his parents want him to be ordinary. Just ordinary.



Problem **D**ry **S**kin (PDS) Symptoms
of Lamellar Ichthyosis
BEFORE

AFTER 4 WEEKS

PDS Symptoms of Lamellar Ichthyosis



BEFORE

AFTER 4 WEEKS
(outer, lower leg)

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* Ficticious name. Consult a physician before using on children.

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> ***"Now is the time to think about getting involved in an awareness week activity for this year."***

One week out of the year our members host awareness campaigns and fund raising events to raise money and educate the public about ichthyosis. Ichthyosis Awareness Week will be celebrated officially during October 1-8, 2006. In actuality, Ichthyosis Awareness Week can occur anytime during the year - when you can devote your energy to raising awareness or funds for the Foundation.

Educating your local community can make life a little easier for those who are affected. The simple knowledge that ichthyosis is a genetic skin disease which is not contagious, a bad sunburn, or the result of poor bathing habits can help the public better understand the disease and its symptoms.

Ichthyosis Awareness Week

October 1 through October 8, 2006

Fundraising Ideas:

- Auction
- Bake Sale
- Bingo
- Book Sale
- Candy Sale
- Car Wash
- Dance
- Donations in lieu of birthday gifts
- Dress Down Day at Work or School
- Garage Sale
- Golf Tournament
- Halloween Costume Contest
- Raffle
- Skate-a-thon
- Submit a personal story to local newspaper, radio or TV stations
- Walk-a-thon

How you can help...

The possibilities are endless. Start by contacting your local newspaper to let them know about Ichthyosis Awareness Week. Share your personal story with them, or let them know that you will be hosting a fundraising event.

For those of you who have always wanted to do something to help raise awareness and money for the Foundation, but have little experience...we have the answer. The Foundation staff has created an easy-to-follow manual on how to organize a grassroots fundraiser. Available free of charge to anyone who requests it. The manual contains great information on how to contact your local media and the essential steps to create a successful event, plus much more. Please call the office at 1-800-545-3286 or email us at info@scalyskin.org with your mailing address to receive a copy.

Conference Chatter

2006 National Family Conference

Conference Highlights

Atlanta, Georgia, provided a great location for our 14th bi-annual conference. The hotel's service, friendliness, and amenities, especially the indoor pool, created a warm and welcoming environment for all our visiting families.

In attendance were 124 families, totaling almost 300 members. Fifty-five families (or 45%) were first-timers to a family conference. That's almost half!

Foreign members traveled from as far as Australia, Belgium, Bermuda, Bhutan, Canada, Gaza, and Mexico.

Mary Bellucci with Ugygen Pelden from Bhutan

The teenagers enjoyed bonding with each other and their field trip to the Center for Puppetry and the new Georgia Aquarium was a big hit.

Formal discussion groups were planned for the whole afternoon on Saturday. However, during the entire three-day event, you could find groups of people in all corners of the hotel sharing their experiences.

Donna Clare, a local Georgian and grandma to a young affected girl, did an incredible job of soliciting and gathering prizes for an enormous door prize give-away and raffle. Over 100 gifts were given away to excited winners, which included three kids' bicycles, cooling vests, spray misters, a week stay at a condo in Florida, and a gorgeous gold bracelet.

Each registrant received donated gift bags filled with 23 various lotion samples and coupons, along with a free colorful conference T-shirt.

Volunteers make short work of filling gift bags

The private screening appointments with ten of the leading expert physicians in the country were an invaluable opportunity. For some, this was the first time meeting a knowledgeable dermatologist who could provide accurate and experienced medical advice.

Many members shared practical ideas for treating their skin and products that have proved useful to others.

Parents of young children were able to participate and enjoy the many workshops thanks to Loving Care Family Services, a local child care company hired to care for and entertain the little ones.

The opening general session focusing on the 25-year history of F.I.R.S.T. provided an account of how the Foundation has grown over the years through the eyes of a founding member, Jim Griffin.

One of the biggest highlights was Saturday night's dinner dance. A fun time was had by all, whether you danced with new friends or sat back and watched the kids enjoying themselves. Several teens choreographed their own hip-hop dance routine and showcased their hidden talents. Several teens also amazed us with solo singing performances. Emotions ran high when the DJ closed the evening by playing "That's What Friends Are For" by Dionne Warwick. Family and friends linked arms, hugged and danced together, thanking one another for support, advice, and friendships.

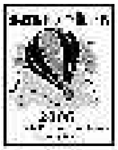
Dave Scholl, F.I.R.S.T.'s president, presented awards to many deserving volunteers and donors, recognizing them for their commitment and generosity to the ichthyosis community.

The stars of the new Teen DVD were honored

Sunday's farewell lunch was a fun way to end the long weekend. It provided the opportunity to say goodbye to old and new friends. Picture-taking and address-sharing were popular activities along with the promise to see everyone again in two years at the next family conference!

Conference Chatter

2006 National Family Conference



Conference Highlights

The following awards were presented at the 2006 National Family Conference

Volunteer of the Year Award

Presented to members whose leadership and heartfelt dedication to the Foundation best exemplify the spirit of giving.

2005
Eustolia Perez
Edinburg, TX

2006
Becky Butler
Rochester, NY

Frances Bernstiel Memorial Award

Presented to member(s) whose outstanding grassroots fundraising efforts help to contribute to the financial strength of the Foundation

Donna & Fred Kober
Las Vegas, NV

Past Board Member Award

Gloria Graham, MD
Tiffany Karst Moore
Leonard Milstone, MD
Laura Phillips
Recognizing nine years of service on the Board of Directors

Distinguished Service Awards

Presented to member(s) for their extraordinary contribution or service to the Foundation by helping us grow in strength, membership, or recognition.

Denise Benedetto
Elizabeth Berry & Cort DeHart
Jim Bode
Jasmyn Bowie
Margaret Frost
Ryan & Annamarie Gonzalez
Shawna Grady
Matt Gray
Michelle & Chad Iott
Dawn Johnson
Lisa Klima
Alyssa Kosmer
Ryan Licursi
Susie Lozevski
Kim Mayone
Jean Meeker
Michelle Myers
Julie Pratt
Bailey Pretak
Macy & Lori Rogers
Tom Seaman
Zebulun Sipper
Katie Smith
Susan Suda
Edie Wohlgang

Special Appreciation Award

Michael Briggs

Corporate Sponsorship

Many thanks to our corporate donors. Their support helps to keep the cost of the conference reasonable for our members. Allergan ** Barrier Therapeutics ** Galderma ** Hill Dermaceuticals ** Johnson & Johnson Consumer Products Co. ** Ortho Neutrogena ** Taro Pharmaceutical

The Foundation wishes to recognize and extend our sincere appreciation to our major Corporate Sponsors for their financial support of the 2006 Family Conference.

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Conference Chatter

2006 National Family Conference

Conference Comments

“I just want to say that my husband and I really enjoyed the conference. This was our first time, since our son is only 10 months old. We plan to go to every one there is in the future! We really learned a lot. I think it was great for my husband to finally talk with others that either have ichthyosis or have children with it. It was so nice to meet everyone, and now we don't feel so alone. Everyone that we met and spoke with was so helpful. For anyone who was not able to make it, I sure hope that you get a chance to go to the next one.”
Shandra from Illinois

“I had the best time at the conference. I learned a lot. The most enjoyable time I had was meeting new people, seeing the kids, realizing that I'm not alone, and being able to make new friends. I came home and told my husband he was going to have to come to the next one, and we are going to bring our boys because they need to see the different types of ichthyosis.”
Kathy from North Carolina

“I have not stopped thinking about the conference since we got home. That 'I'm all alone feeling' has been replaced with a greater sense of family. To the adults and families who have lived with ichthyosis, you are a true inspiration. I look ahead at my daughter's future and am less afraid. Thank you and we can't wait to see all of you again.”
Shannon from Massachusetts

“I agree with what everyone else is saying! It was FANTASTIC meeting everyone that I did, and I had a blast at the farewell dinner. I can't wait to go to the next one…I already told my husband to start saving so he can come, too!”
Courtney from New Jersey

Making new friends and connections

Catching up with old friends

“We truly had a wonderful time at the conference! As a first time mom, I didn't know what to expect and was a little apprehensive going into the conference on Friday. I quickly realized how wonderful everyone was and felt at peace with everything that has been going on with us and our daughter. My attitude has completely changed and I no longer feel scared or alone. The families, children, and moms are so wonderful. To see the strength and courage of everyone is so up-lifting for me! I look forward to being part of FIRST and can't wait until the next conference.”
Jennifer from Florida

“I'd just like to say that my daughter and I had a great time this year. It was good to see old friends and make new ones as well. It is a good feeling to be around people knowing "no questions will be asked.” Yet the irony is we all ask questions. I hope everyone had as much fun as we did.”
Terry from Virginia

“I just want to back up what everyone has been saying about the conference... it's all I can talk about. I had a wonderful time and am so hopeful about my daughter's future (in skin) and really already looking forward to the next conference. Thank you.”
Crystal from Ohio

“Yahoo! What a super time we had! It was so amazing meeting everyone at the conference. My husband and I left feeling that it was SO WORTH it and can't wait another two years for the next conference.”
Sarah from Canada

“I had a lot of fun at the conference. It was great that I got to see old friends again and I had a lot more time this year to make new friends.”
Jennifer from Ohio

Conference Chatter

2006 National Family Conference


Alexis Hill gets crafty.


Hunter Steinitz &
Kacey Leach

Ada & Sophie
DeLeu lend a hand.


Tsering Choden & Jovun Dosanjh


Nancy Hrabal & Barbara
Amos take a break

Shelby Riggs &
Lori Florian

Tiffany Moore
& Jessa Karst


Laura Phillips
& Janet McCoy


Chloe Collins


Kelly Klafter & Edie Wohlgang


Diana & Shauna Grady

Conference Chatter

2006 National Family Conference

Everybody loves the Chicken Dance

The Dads group retires to a more relaxed setting

The conference is a great place to:

Connect with old friends

Make new friends

Raise the roof

The teens rocked the house with their performance

Dance fever!

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University of California
San Francisco

Proud Sponsor
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2006 Testimonial Dinner
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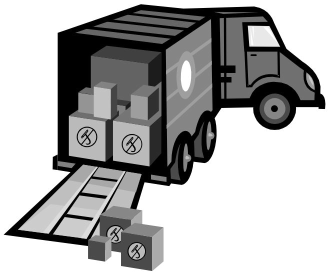
Drs. Mary Williams
& Peter Elias
San Francisco, CA

The National Office is on the Move!!

After two and a half years at our Valley Forge Road address in Lansdale, the national office has moved to larger headquarters to keep up with our incredible growth. Our new office provides larger office space for our many activities and programs. The new address is:

F.I.R.S.T.
1364 Welsh Road, G-2
North Wales, PA 19454

Our toll-free number (800-545-3286), website (www.scalyskin.org) and email (info@scalyskin.org) will remain the same.



Have you moved recently or are planning on moving soon? Please let us know your change of address so you can continue to receive the Focus. Postage for the newsletter does not include forwarding.

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