

Ichthyosis FOCUS



Volume 26, No. 3

A Quarterly Journal for Friends of F.I.R.S.T.

Fall 2007

Projects Funded in Year Two of Foundation Research Grant Program

The second year of the Foundation's Research Grant Program was met with a total of ten worthy research projects in the categories of Lamellar/Congenital Ichthyosiform Erythroderma (CIE) and Ichthyosis-related research. We are overwhelmingly grateful for the involvement of Dr. Leonard Milstone, Research Review Committee Chairman and Drs. Phil Fleckman and William Rizzo, who all worked tirelessly to evaluate each project. The Research Review Committee's caliber of knowledge and dedication to the ichthyosis community is commendable. Outside reviewers, comprised of scientists and physicians, volunteered their time and talents to assist the committee in review. The decision to fund two of these projects was approved by the Board of Directors.



Dr. Heiko Traupe, at University Hospital, Muenster, Germany, has been selected to receive \$75,000 for his project titled, "Liposomal packing of recombinant transglutaminase-I as an essential step toward enzyme replacement therapy of transglutaminase-I deficient lamellar ichthyosis." Dr Traupe's objective of the project states that "enzyme replacement therapy has greatly benefited genetic skin diseases such as Fabry disease and holds great promise for transglutaminase-I (TGase-I) deficient lamellar ichthyosis (LI) and for other genetic types of LI. The current therapeutic situation for LI is deplorable. We

want to change this by developing an enzyme replacement therapy for TGase-I deficient LI. The general idea is to develop a cream containing the missing enzyme. In previous work, we have already cloned two different cDNA constructs of TGase-I carrying a C-terminal hexahistidine-tag for purification. We are able to express the recombinant proteins in insect cells using the baculovirus expression system. A major obstacle is that the enzyme — once liberated from the cream — because of its intracellular membrane-bound localization needs to be taken up by the keratinocytes to reach its proper place. We want to develop a lipid-based formulation for recombinant transglutaminase-I to show that the enzyme is indeed taken up by the keratinocytes and still has specific activity." The project's relevance to the mission of the Foundation for Ichthyosis & Related Skin Types is that: "The project wants to advance the field of development of a causative treatment for transglutaminase-I deficient lamellar ichthyosis by showing that it is possible for keratinocytes to take up even large proteins such as transglutaminase-I once they have been packed into cationic liposomes. This will be an important milestone in the development of an enzyme substitution therapy for this disease."

Continued on page 15

Hey Kids, Camp is Like a Whole New World!

By Hunter Steinitz

Whenever I go to Camp Horizon I'm never alone. I'm surrounded by people who know exactly what I'm going through. You never feel like you're left out and you never are! Camp gives you a chance to have a week without all the staring, pointing, and being made fun of. You feel like you're one of a group. Whenever camp comes around, I always know that I can have a relaxed week and have fun. It's so great!

Sometimes, when I'm at home, I feel lonely and don't have anyone to talk to or hang out with. A lot of kids at school tease me and don't accept me for who I am because my skin is different. I'm 13 and in middle school in the 7th grade. I'm the only kid around with red, dry, flaky skin. My family tries to help but I still feel like I'm all alone. I don't feel like that at Camp Horizon. Almost everyone there has some kind of skin problem so I'm not "different" there. I get to be me and just be a regular kid. I really look forward to going to camp every year.

Continued on page 16

Teeing Off for Ichthyosis

Members of F.I.R.S.T. hosted golf tournaments and raised over \$23,000 and awareness about ichthyosis. See story on page 3.

Inside Ichthyosis Focus

- 2008 Family Conference Information, page 7
- Phantom Tea Raises \$32,000, page 16
- Meet Esther Kimani from Nairobi Kenya, page 4

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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.

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Grassroots Fundraising

During Ichthyosis Awareness Week, September 30 to October 7, 2007, many of you worked hard to bring awareness about ichthyosis to your communities while raising funds for F.I.R.S.T. Here are some of the great ideas F.I.R.S.T. members had! If you hosted a special event, contact the office with your story.

Emma's Jeans Day

Ichthyosis Awareness Week was a great time for Lisa Klima of Cleveland, Ohio, to organize "Emma's Jeans Day." This was a special day for employees at Lisa's office to wear jeans to work. This fund raising event raised over \$800.00 before the company match! Emma is 4 years old and is affected with EHK.




Friends Make Bracelets
Hi. My name is Amanda. I am 11 years old. My cousin Brian has Harlequin Ichthyosis. I decided to make bracelets out of pretty string (friendship bracelets) and raise money for F.I.R.S.T.. I let people pick their own colors so each bracelet is special. My friend Ashley, also 11 years old, helped me raise all the money I am going to donate. We called all our family members, asked all of our neighbors and sold to our friends at school. My parents told me whatever I earned they would match the amount. I am very happy to make this donation on behalf of my cousin, Brian. He is amazing!

Sincerely,

Amanda

Beading for a Cure

Kim Mayone, of Portland, Maine, raised over \$300.00 with the second annual Caravan Beads Night. Kim has 3 children and her youngest son, Evan, age 2, is affected with EHK, so Kim needs a fundraiser that is "easy and doesn't require a lot of time and effort." Kim loves this event because of the simplicity of it as well as the positive support she receives from Caravan Beads, who generously donated 30% of all sales to F.I.R.S.T. The store opened exclusively for this fund raiser allowing her the opportunity to have 40 friends and family in attendance. For those that could not make the evening to bead, they were able to purchase gift cards, which would be applied to her event. Kim says to make your fund raiser work it is important "to pick something you like to do". Caravan Beads also posted this event on their website and sent an email blast to all the customers on their email list. The support she receives makes this event one Kim will be doing year after year.



Evan admiring beads

Continued on page 11

Teeing Off for Ichthyosis

Josh and Amie Jo DeGarmo of Napa, CA, hosted another successful grassroots fundraiser to benefit the Foundation. Nestled in the hills of Napa Valley, this year's golf tournament was held at the Napa Country Club on July 9, 2007. The couple raised over \$20,000 with raffles, hole sponsors, and corporate sponsors.

This is the second year hosting a golf tournament for the DeGarmos and, according to Josh, "was much easier the second time around." With the outpouring of support received by family and friends, it is obvious how loved and respected the DeGarmo family is in the Napa Valley. Richard and Lois DeGarmo, Josh's parents, were on hand to help with the event while



Carson and Josh DeGarmo

spending time enjoying the beautiful day. The DeGarmos have two boys, Jaydn and Carson, both are affected with lamellar ichthyosis. Way to go Josh and Amie Jo!



The beautiful Napa Valley!



Taking a break to pose for the camera!
Josh DeGarmo, Jacob Ray, Amie Jo DeGarmo,
Richard DeGarmo, Elizabeth Nicponski
and Jaydn DeGarmo.

Driving for a Cure

On Sunday, August 19, 2007, Chris and Michelle Dugan, aunt and uncle to five-year-old Mattingly Dugan, hosted a golf tournament. The event was held at the Brockport County Club in Brockport, NY. The Dugans raised over \$3,000 at their first time fundraiser! Mattingly is very lucky to have such a loving and supportive aunt and uncle, not to mention how lucky mom, Louanna, is to have a brother like Chris and sister-in-law like Michelle.



Rodney & Louanna holding a sign
honoring Mattingly

If you are considering hosting a golf tournament and would like a copy of our Golf Tournament Fund Raising Guide, contact the office at info@scalyskin.org or call 800.545.3286.

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Spotlight On

MY STORY: LIVING WITH ICHTHYOSIS

By Esther Kimani

My name is Esther Kimani and I come from Nairobi, Kenya, East Africa. I am 31 years old and a committed Christian. I have Epidermolytic Hyperkeratosis (Bullous Congenital Ichthyosiform Erythroderma). I developed the condition when I was a few months old. Neither my parents nor the doctors understood what was wrong with me. My parents and siblings do not have my condition. We guess the ichthyosis came from a spontaneous mutation of a gene.

As I grew older, my condition continued, and I continued to be taken to different hospitals and to see different doctors. It was a very painful experience for me in my childhood and especially to my parents, who could not understand what this condition was. They tried all they could to provide me with the best treatments. Blisters would break on my whole body and it was very painful. It also was painful for my family to watch me go through the trauma and pain of this condition. I would be admitted in the hospital for months. I could not do anything for myself. I had to be bathed and fed and I missed a lot of schooling. I was absent for weeks in those few years of my childhood. I did not understand what was happening to me and was confused.

The cold days were extremely hard for my condition. At that time, blisters would erupt. I had the most painful blisters and would be house bound. The hot seasons were also unbearable and would make me very itchy. I would itch until my skin would peel off. I just needed someone or something to help me to stop the itch until my teenage years. Those were the especially hard times for me. In high school, I would also miss classes because of the painful blisters, but my condition was starting to get adaptable. All this time the doctors would not diagnose my condition.

Many said the condition would disappear as I grew up, but many did not have the right diagnoses. They thought it was a general skin condition. They prescribed lotions and creams, which did not really work nor improve my condition. I also tried herbal medication, Chinese medication, homeopathy medication, but none seemed to work.

After high school, when I went to college, I met a person who sponsored me to go to Scotland for medical attention in 1996. That's when I met a dermatologist who did a biopsy on my arm and gave my condition a name. That's when I knew the name as Epidermolytic Hyperkeratosis. He told me it was a genetic condition and there was no cure and they are still doing the research for the cure.

I suffered from depression in my high school years and stress in my college years. I always had low self esteem, but in time I have become a confident woman. Now I am happy, intelligent,

sociable, and I enjoy life to the fullest.

I came back home in 1998. It was extremely hard for me and my family when I was told that the condition was genetic, because we had a lot of expectations for a cure.

In time, I had gotten used to my condition, and now it has gotten a bit better because I don't itch or have blisters anymore. I survive on Vaseline and lotion to hydrate my skin. I am not on any medication; I stopped taking medication a long time ago. My Christian faith has been my anchor because the Lord gives me the strength when I feel down.



My friends and family are all very supportive, and I have never felt discriminated, although I occasionally meet people who give me the stares, but I understand because they are not informed of my different looking skin. Whenever possible, I try to explain to them about my condition. Many are relieved and happy to know that it is normal and not contagious.

I decided to learn more about my condition. Here in Kenya not many dermatologists know about ichthyosis or have met patients with ichthyosis.

Very few know about it so there is virtually no support here where affected patients can get help. That's when I realized I had to do something. So this year, 2007, I got interested in knowing more about ichthyosis, and I started visiting different websites about skin conditions.

I learned about F.I.R.S.T. and I had to say it was an eye opener for me because they had a lot of help for patients like me. Since I had never met any other patient with my condition in Kenya, I thought it would be a good idea if I started a support group here. That's when I wrote an email asking for help, and I was surprised to receive a very kind email from Moureen Wenik. She is a very helpful and a kind lady. She encouraged me a lot. She started sending me posters and brochures, which were very helpful to read and to know actually there are other people like me suffering from my condition from different countries.

I really felt at home at F.I.R.S.T.; I was in the dark most of my life, and my parents too, about my condition. But since I started communicating with F.I.R.S.T. and the many materials sent to me, I now have all the facts at my fingertips and I understand myself better. F.I.R.S.T. helped me to cope and feel loved and know that I share the same feelings with other sufferers. That's why I want to support and create awareness about ichthyosis in Kenya so that we can sit and share our innermost feelings. I am single, but I still believe God will bring me a man who will love and cherish me with my condition so I live my life in full.

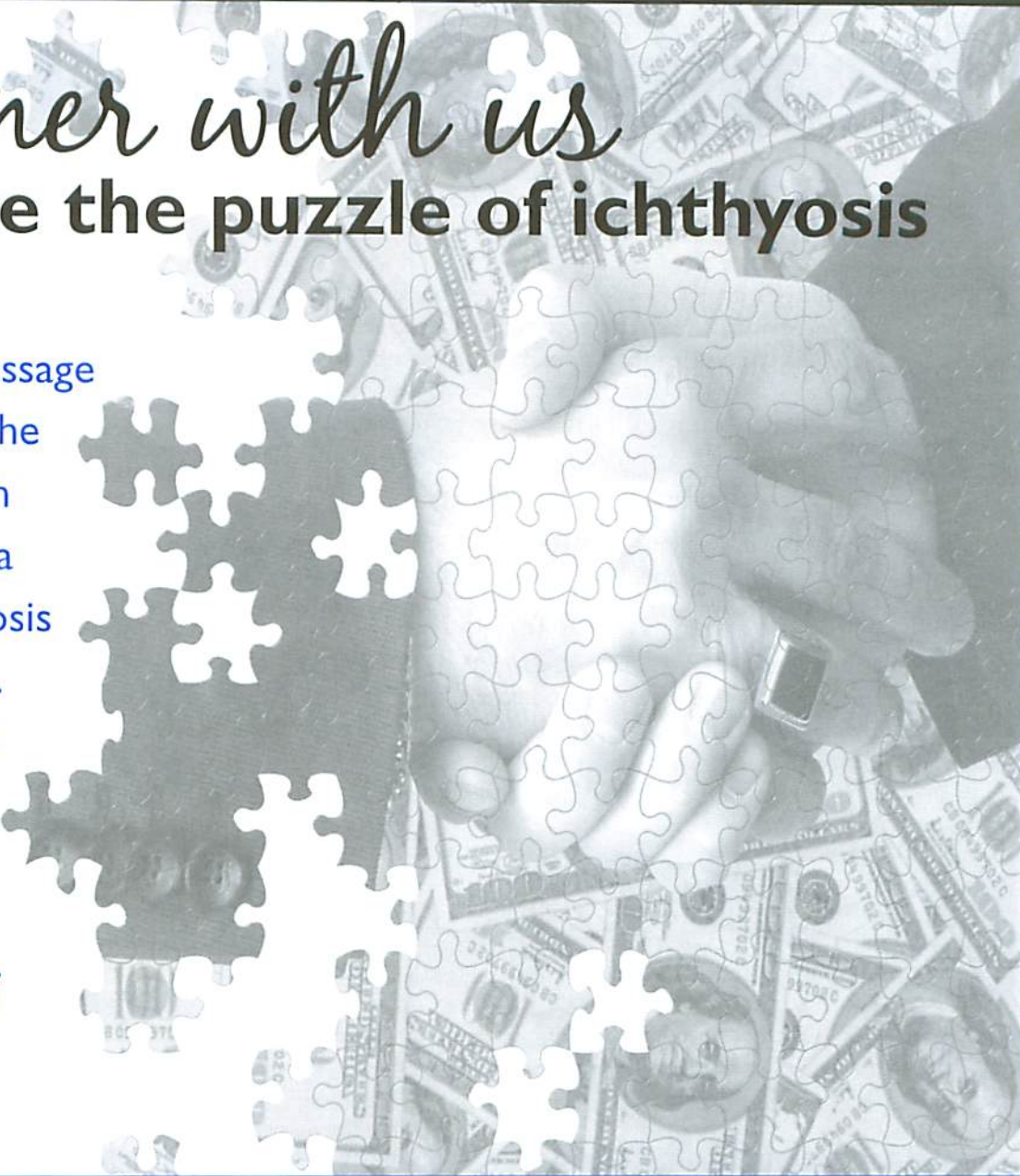
F.I.R.S.T. has really made me smile again and given me a spirit of helping others. Thank you F.I.R.S.T. I appreciate you for your dedication and commitment to help all affected by ichthyosis and look forward to attending the family conference one day.

God Bless.

Esther Kimani

Partner with us To solve the puzzle of ichthyosis

Getting our message out and doing the kind of research needed to find a cure for ichthyosis takes money ... Hopefully, your generous contribution could help us solve a piece of the puzzle.



Send your much appreciated donation to:

Foundation for Ichthyosis and Related Skin Types

1364 Welsh Road • Suite G2

North Wales, PA 19454



Yes, here is my donation to support the Foundation's Research Fund

Name _____

Address _____

City _____ State _____ Postal Code _____

Province _____ Country _____

Email _____

Please make checks payable to F.I.R.S.T. and send to national office.

Thank You

Executive Director's Report

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



From time to time over the past several years, I have polled our membership to survey the "wants" and "needs" that you would like to see the Foundation provide to you and your families. By an overwhelming majority, the item that continually rises to the top of the list is more research. And, as you have seen, the Foundation's leaders listened to our membership and created a flourishing research program. To date, we have funded six quality grants in a wide range of research areas. Through the research grant process over the past two years, it has become quite evident that there are ample interest and scientists who want to investigate the ichthyoses. Now, the biggest challenge we face is being able to keep up with the fund raising to be able to provide the research dollars.

Please consider making a donation to our Research Fund. For those of you who have donated already this year, I personally want to say thank you. Remember, every little bit helps. Donations of \$20 or \$30 can really add up. You can go online at www.scalyskin.org to make your gift, call the office directly, or mail a check to the office address.

In November, our Board of Directors will be meeting in Philadelphia for our bi-ennial face-to-face meeting. At this retreat weekend meeting, we will be reviewing and approving our next five-year strategic plan, which sets goals and objectives for the future. The retreat is always a wonderful opportunity for our board members to interact with one another. Whether the board member is an affected adult, a close relative to an affected persons or a medical professional, the passion is the same for everyone....helping individuals and families affected by ichthyosis.

Gary Mills and Peyton Weary, MD, will be leaving the Board of Directors this year. I want to extend a public thank you to both of them for their commitment to F.I.R.S.T. Gary is the father of two affected children, and Peyton, a dermatologist, is the father to an affected daughter. Along with his wife, Janet, they both have been involved with the Foundation since its inception more than 26 years ago. Both Gary and Peyton have seen the Foundation grow during their board terms and remain steadfast in their commitment to help wherever needed.

The office staff saw a recent change as well. Bonnie Thompson left the Foundation in August, opening the door for our new Administrative Assistant, Lisa Breuning, to join our team. Lisa comes to the Foundation with strong experience from another local nonprofit organization; we are very lucky to have her.

Our staff is very busy preparing for the 2008 Testimonial Dinner honoring Drs. Eugene VanScott and Ruey Yu in San Antonio on February 1. Dr. VanScott and Dr. Yu graciously accepted the Foundation's request to recognize them for their years of service to patients with ichthyosis. In addition to dedicating their careers to ichthyosis-related research, they are also the co-founders of The NeoStrata Company, makers of the NeoCeuticals product line. You can look forward to hearing more about the fund raising dinner in an upcoming issue.



Welcome Lisa

We are also working hard on the 2008 Family Conference in Chicago next summer. I highly encourage you to attend. Next summer's conference is going to be the best one yet. I hope to see many new faces in Chicago. See pages 7-14 for more information.

With best regards,

Jean R. Pickford
Executive Director





Educate, Inspire, & Connect

2008 National Family Conference
Friday, June 27—Sunday, June 29, 2008
Chicago Marriott O'Hare
Chicago, Illinois

Join us for another life-changing experience. The conference features the latest medical and research updates, a better understanding of how to manage your ichthyosis, and, most importantly, a wealth of support from other individuals and families.

Come be educated, inspired, and connected!

Workshops & Events at a glance....

Friday, June 27

7:00am—9:00 am Registration/Breakfast
 9:00am—5:00 pm Clinical Screening Appointments
 9:15—11:45 am General Session
 11:45—1:15 pm Lunch
 1:15—5:30 pm Child Care Camp (ages 1—10)
 1:15—5:30 pm Tween Camp (ages 11—13)
 1:15—5:30 pm Teen Camp (ages 14—17)
 1:15—3:00 pm Adult Workshops I
 3:00—3:15 pm Refreshment Break
 3:15—5:30 pm Adult Workshops II
 5:30 pm On Your Own

Saturday, June 28

7:00am—9:00 am Breakfast
 9:00—11:45 am Child Care Camp (ages 1—10)
 9:00—10:30 am Product Demo (adults/teens/tweens)
 10:30—5:30 pm Offsite Field Trip (teens/tweens)
 10:45—11:45 am Research Update
 11:45—1:15 pm Lunch
 1:15—5:30 pm Child Care Camp (ages 1—10)
 1:15—3:00 pm Adult Workshops III
 3:00—3:15 pm Refreshment Break
 3:15—5:30 pm Adult Workshops IV
 6:30—8:00 pm Dinner
 8:00—11:00pm Dance Party/Talent Revue

Bonus Event!

*Experience Downtown Chicago
 by Night!*

Thursday Evening, June 26

Harry Caray's world famous Italian steakhouse in downtown Chicago is hosting a charity fund raiser on behalf of F.I.R.S.T. Plan to arrive early!
 See details on next page.

Sunday, June 29

7—9 am Breakfast
 9:00—11:45 am Child Care Camp (ages 1—10)
 9:00—11:45 am Tween Camp (ages 11—13)
 9:00—11:45 am Teen Camp (ages 14—17)
 9:00—10:15 am Adult Workshops V
 10:30—11:45 am Adult Workshops VI
 11:45—12:15 pm Closing Remarks
 12:30—2:00 pm Farewell Lunch

CONFERENCE REGISTRATION FORM

Volunteering

Please check if you would be willing to volunteer with:

- Assembling Gift Bags on Thursday, June 26
- Helping at the Registration Table
- Helping at F.I.R.S.T.'s Kiosk Table
- Assisting with Teen/Tweens & Field Trip
- Organizing a Texas Hold 'Em Game
- Assist in managing the F.I.R.S.T. Idols Talent Revue

Name: _____

Phone: _____

Email: _____

F.I.R.S.T. Idols Talent Sign-Up (Ages 5-18)

Child's Name: _____

Age: _____ Grade: _____ Hometown: _____

Type/Description of Act: _____

Performances will take place on Saturday evening at 8:00 pm. A compact disk player and microphone will be provided. You must bring your own music, costume, props, etc. All performances will be limited to a maximum of 2 minutes.

Photo and Video Permission Release

I hereby give my permission to F.I.R.S.T. to use and distribute (including but not limited to use in newsletters, guides, documentaries, appeals, website, and reports at their discretion) any photos or video tapes taken at the 2008 Family Conference in which I or my family may be a part.

Signature: _____

Date: _____

Payment

Registration Fees

Number of Adults (Ages 14 and up) _____ x \$165.00 USD \$ _____

Number of Children (Ages 5-13) _____ x \$115.00 USD \$ _____

No registration fee for children 4 and under (all names must be listed under registration)

Child Care

Number for Child Care (Ages 1-10) _____ x \$15.00 USD \$ _____

I have enclosed a donation to support the conference scholarship fund. \$ _____

Method of Payment

_____ Make checks payable to F.I.R.S.T. in US Funds.

_____ Credit Card Payments: Visa, Mastercard or American Express

Credit Card # _____ Expiration Date _____

\$

Authorized Signature: _____

In consideration of the acceptance of this registration entry, I/we, the undersigned, assume full responsibility for any injury or accident which may occur while I/we am/are attending this conference. I/we hereby release and hold harmless the sponsors, promoters, and all other persons and entities associated with this event from any and all personal injury or damage, whether it be caused by the negligence of the sponsors, promoters or other persons or entity. Applications for minors will be accepted only if signed by a parent or guardian.

Name _____ Date _____

For Office Use Only

Date Posted _____

Check Amex Visa Mastercard Paypal

Authorization # _____ Amount _____

CONFERENCE REGISTRATION FORM

Contact Information

(please print clearly)

Name: _____

Address: _____

City: _____ State: _____ Zip: _____ Country: _____

Phone (Day): _____ Phone (Night): _____

Cell Phone: _____ Email: _____

I give permission to F.I.R.S.T. to publish my name, contact information, and type of ichthyosis in the conference roster, which will be distributed to all attendees.

Registrant Information

This section must be completed with registrant's complete name, age, and type of ichthyosis (if appropriate). There are four tracks of programs: Adult (age 18+), Teen (ages 14-17), Tween (ages 11-13), and Child (ages 1-10). Based upon ages provided, each registrant will be assigned to the appropriate program.

First Name	Last Name	Age	Will Need Child Care*	Affected by Ichthyosis
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>

Please indicate which type of ichthyosis affects your family: _____

*The Foundation has hired a professional child care company to entertain and supervise children, ages 1-10, while parents/guardians are participating in the adult program. There is a nominal, one-time fee of \$15 per child to guarantee placement in the program and to hire the appropriate number of caregivers for the safety of your children.

Clinical Screening

Meet with expert dermatologists who are extremely knowledgeable about ichthyosis to answer any questions or concerns that you may have. These 15-minute appointments will take place throughout the day on Friday, June 27, from 9:00 am-5:30 pm. You will receive an email prior to the conference with your appointment time. *Please note:* There may be physician residents in-training observing during your appointment. This will help educate future leaders in dermatology about ichthyosis.

Name of person for appointment	Age	Male/Female	Type of Ichthyosis
_____	_____	_____	_____
_____	_____	_____	_____

Has your ichthyosis been medically confirmed by a dermatologist? Yes or No

CONFERENCE INFORMATION & HIGHLIGHTS

Registration: To register for the conference, complete the Conference Registration Form and submit payment to the national office by June 6. Registrations will not be accepted without a completed Registration Form and payment. *Please note:* Registration does not include your hotel room. Accommodations at the Chicago Marriott O'Hare must be made separately.

Cancellations & Refunds: Cancellations received prior to June 6 will be refunded less a \$25 per person administrative fee. No refunds issued after June 6.

Hotel Accommodations: The discounted room rate negotiated with the hotel is \$104.00 per night, flat occupancy. This rate is available from June 24 through July 6. All attendees must make their own reservations at the Chicago Marriott O'Hare by calling toll-free at 800.228.9290 or 773.693.4444. To ensure you receive the discounted conference room rate, you must identify our group name of "Foundation for Ichthyosis & Related Skin Types." Reservations must be received on or before June 5, 2008. All reservations must be accompanied by a first night room deposit guaranteed with a major credit card.

Air & Hotel Transportation: O'Hare International (ORD) and Midway (MDW) are the two major airports in Chicago. There is a free shuttle service from the O'Hare International Airport to the hotel, located one level below baggage claim at door #2. The shuttle runs every 15–20 minutes between 5:00 am and 12:00 midnight.

Air Charity Network: You may be eligible for free transportation using the Air Charity Network, formerly the Angel Flight America Program. If you live within 1000 miles of Chicago, Illinois, Air Charity Network will fly a family in a 4-seater or 6-seater plane to and from the conference at no cost. Contact the National Patient Travel Center at 888.675.1405 and refer to the 2008 Foundation for Ichthyosis Family Conference Special Lift Program.

Driving Directions to Hotel: Contact the Chicago Marriott O'Hare at 773.693.4444 or visit their website at www.marriott.com and click on Chicago Marriott O'Hare. Their address is 8535 West Higgins Road, Chicago, IL 60631. There is a fee for parking.

Public Transportation: Chicago's "L" train system has many convenient stops. The "blue line" services the airport and hotel. For more information, visit <http://www.transitchicago.com/maps/rail/rail.html>.

Clinical Screening: All affected individuals and their families have the opportunity to meet with leading expert physicians for a free, private 15-minute consultation on Friday, June 27. Participation is voluntary. Sign-up is required prior to the conference. If you are interested, you must complete the Clinical Screening section on the Conference Registration Form.

Dress Code: Conference attire is casual, including Saturday evening's dinner/dance.

Meals: Additional meals added this year!!! The conference registration fee includes a continental breakfast and lunch on Friday, June 27; breakfast, lunch and dinner on Saturday, June 28; and breakfast and lunch on Sunday, June 29. All registrants are on their own for dinner on Friday evening.

F.I.R.S.T. Idols Talent Revue: This revue, which is open to children ages 5 to 18, is new to the conference. It promises to be a popular and heartwarming event for children to showcase their talents to our audience. The Talent Revue will take place on Saturday evening, June 28, at 8:00 pm in the Nikko Room at the Hawaiian Dance Party. If you want to participate, complete the F.I.R.S.T. Idols Talent Revue section on the registration form.

Experience Downtown Chicago by Night: Charity Benefit at Harry Caray's - Thursday June 26: Harry Caray's world famous Italian steakhouse in downtown Chicago is hosting a charity benefit to raise money for F.I.R.S.T. Open to the public, it is expected to gather a large crowd of local Chicagoans. It will feature a live auction, dinner buffet, cocktails, local celebrity entertainment, and comedians. Conference attendees are invited to attend at a reduced admission price of \$20 per adult. This fee includes dinner buffet, beverages, and transportation to and from the hotel. Keep in mind, the entertainment may not be suitable for families with young children. Transportation will be provided, leaving the hotel at 6:30 pm and returning from Harry Caray's at 10:00 pm.

If you are interested in attending, you must register online at our website (www.scalyskin.org) or complete the registration form available in the newsletter. If you have any questions, please contact Frank Osowski, F.I.R.S.T. member, at frankieo@harrycarays.com.

F.I.R.S.T. is grateful to be the recipient of the funds raised from this event. Please note that this event is not sponsored by the Foundation and is wholly independent of other conference-related events.

1st Annual Phantom Tea Raises \$32,000!

Late last winter, the office decided to try a unique, national fund raiser with our membership. We asked 1600 member families to mail personalized "tea packages" to their family and friends. This invitation asked for a small donation while enjoying a cup of tea and celebrating those affected with ichthyosis.

Eighty-four families responded to say they would help. We quickly went to work and assembled over 2000 tea packages and distributed them to our participating families. Once they received the packages, their job was to address and mail them to their family and friends. Within days, return envelopes started to arrive at the office. The success of our first annual Phantom Tea fund raiser was nothing short of amazing! Not only did this national event raise money for the Foundation, it also created awareness among members' family and friends because each invitation included a descriptive paragraph about ichthyosis.

Here's some of the feedback we heard from our participating families:

"I have always wanted to help out but I could never fit it in my busy schedule. This was so easy to do. The invitations were already made and mailed to me. I just used my Christmas card list and bought a few stamps."

"Many of my neighbors sent in generous donations. It was nice to know that they cared. You'd be surprised what will happen if you just ask."

"Sending out this invitation is much easier for me than asking my family personally. This way they could choose to do whatever they wanted and there was no pressure."

You will be receiving an invitation to participate in our 2nd annual Phantom Tea fund raiser this February. Just think... we raised \$32,000 with only 84 families participating. Imagine the possibilities if all our members took an hour out of their time to send out a few invitations. The potential is endless. We hope to count on your support next year. As always, please call the office if you have any questions at 800.545.3286.



Grassroots Continued from page 2

Country Music Takes the Stage to Benefit Ichthyosis

Autumn Sproull, 13, of Montgomery, Texas, had a great time at the benefit for the Foundation for Ichthyosis and Related Skin Types. The benefit, which was held on September 30, drew hundreds of people and raised over \$10,000.



Tut's Bar and Grill in Conroe, TX, generously donated space for this event. Entertainment for the day included



Scooter Brown, Josh Ward, Amy Hughes, Eric Brendan, and Lance Aldrich. April Sproull, Autumn's Mom, worked for months in advance to secure entertainers, sponsors, door prizes, and raffles

prizes. April's strong community ties encouraged individuals to donate food and time to help make this benefit the success that it was!

Newspaper Features F.I.R.S.T. Family

Betty Ann and husband Paul Foulks, of Midway, TN., were featured in their local newspaper, the Greenville Sun. The story featured their daughter, Carlie, who is affected with Netherton Syndrome, and how it has impacted their family telling



where they found support. Betty Ann and Paul did a great job of creating awareness about ichthyosis in their community. The newspaper

has over 15,000 papers in circulation; think about how many people have been made aware of ichthyosis in just one day! To read their full story, copy the link: <http://www.greenvillesun.com/index.php?template=news.view.subscriber&table=news&newsid=143950>

Awareness and Grassroots fundraisers can be done anytime that is right for you and your community. To learn how you can host a successful event, contact our office at www.scalyskin.org or call 800.545.3286 to receive the Awareness and Fundraising Guide.



**Experience the friendliness and generosity
of the Windy City**



Charity Benefit at Harry Caray's
Thursday, June 26
7:00–10:00 pm

Your Name: _____
Address: _____
City: _____ State: _____ Zip: _____
Phone: _____
Email: _____

For office use only:

Amount: _____
Date Posted: _____
Authorization#: _____

Number of Adults Attending _____ x \$20.00 USD \$ _____
(Registration fee includes light buffet, beverages and transportation)

Please list names: _____

Method of Payment

Make checks payable to F.I.R.S.T. in US Funds.
 Credit Card: Visa, Mastercard or AMEX
Credit Card # _____
Expiration Date _____
Authorized Signature: _____

Bus transportation will depart the hotel lobby at 6:30 pm and return from Harry Caray's at 10:00 pm.
Pre-registration and payment are required.

2008 Family Conference Scholarship Fund Guidelines & Criteria
(Funded by the Jean Giroux Charitable Trust)

A scholarship fund is available for families to apply for financial assistance to attend the Chicago conference. The Family Conference Scholarship Fund, funded by the Jean Giroux Charitable Trust, will provide funds for registration, travel and accommodations. Funding is limited; all applications will be evaluated based on scholarship guidelines.

Scholarships Available

- Scholarships are available for registration fees for two people, with one person being affected.
- Scholarships are available for one hotel room for three nights.
- Scholarships are available for transportation for two people, with one person being affected (includes travel from the airport to the hotel).

Eligibility for Applicants

- Each applicant must have a membership application on file at the national office. You can download a membership application form on our website at www.scalyskin.org or contact our office.
- Based upon availability of funds, priority will be given to applicants who clearly demonstrate a need for financial assistance based upon income and family circumstances.
- All applications will be strictly confidential.
- Each applicant must commit to volunteer at the conference for a period of time and attend all conference workshops.

Disbursement of Funds

- The award recipients will be reimbursed at the conference, either on the last day or mailed to them immediately after the event.
- The award recipients must bring receipts for reimbursement; no costs will be reimbursed without written proof.

Application

- **Completed applications must be submitted by February 1, 2008.** They can be faxed to 215.619.0780 or mailed to 1364 Welsh Road, G2, North Wales, PA 19454, Attn: Family Conference Scholarship Fund.
- Applications must be submitted with:
 1. Confirmation of hotel reservation (if applying for hotel costs)
 2. Confirmation of transportation arrangements (if applying for travel reimbursement)
 3. Copy of most recent IRS Form 1040

All applications will be strictly confidential.

2008 Family Conference Scholarship Application

Application Deadline: February 1, 2008



Name _____

Address _____

City _____ State _____ Postal Code _____

Province _____ Country _____

Home Phone _____ Work Phone _____

Cell Phone _____ Email _____

How many people will be attending the conference? _____

Name: _____ Age _____ Type of Ichthyosis: _____

Name: _____ Age _____ Type of Ichthyosis: _____

Name: _____ Age _____ Type of Ichthyosis: _____

Name: _____ Age _____ Type of Ichthyosis: _____

Have you attended a family conference before? Yes No

If yes, how many conferences and when? _____

Why do you need a scholarship to attend?

Request for Funding

Registration Fees for _____ adult(s) at \$150 and/or _____ child(ren) at \$115.

Hotel Accommodations for _____ nights (up to three nights will be reimbursed).

Travel (please include transportation to and from hotel)

Train \$_____ Plane \$_____ Automobile \$_____ Other \$_____

Monthly family combined income: \$ _____

(Please include a copy of your most recent IRS Form 1040)

Monthly family combined expense: \$ _____

* All dollar amounts must be included in order to evaluate your application.

Please tell us in your own words why you would like to attend and what you expect to learn from the Family Conference? (Use additional paper or reverse if necessary.)

Please feel free to include any additional information that you would like to share with us:

I acknowledge that:

- All receipts for approved funding must be submitted at the conference registration for funds to be reimbursed at the conclusion of the conference.
- I am required to volunteer for a few hours at the conference and attend all workshops.
- The information I provided on my application, as well as my financial information, is accurate and truthful.

Signature of Applicant: _____ Date: _____

F.I.R.S.T. and its officials reserve the right to disqualify any application that is incomplete. Please be sure to check all appropriate boxes. Applications received after February 1 will not be considered.

Thank you for your confidential information.

News & Notes

First World Conference on Ichthyosis

by Dr. Matthias Schmuth

From August 31 to September 2, the First World Conference on Ichthyosis was held in Muenster, Germany. Organizers of the meeting included the Network for Ichthyosis and Related Keratinization Disorders (NIRK), GENESKIN, a European Union-funded research network for rare genetic skin disease, and the German patient support group "Selbsthilfe Ichthyose." Researchers from Africa, Europe, Israel, Japan, and the United States attended the meeting. Patients and members of various European patient support groups actively participated by giving very resourceful lectures on therapeutic pearls and appropriate disease management. An entire session covered current treatments and included a presentation on the "TOMESA experience," an inpatient facility in Bad Salzschlirf, Germany dedicated to the treatment of disorders of cornification.

The current state of experimental therapies in the laboratory was discussed including gene therapy for Sjögren-Larsson disease, enzyme replacement therapy for lamellar ichthyosis, oligonucleotide therapy for epidermolytic hyperkeratosis, and also cell based therapies for epidermolysis bullosa. Albeit promising, all of these attempts are still in the laboratory stage. The majority of the talks, however, were focused on advances in the molecular understanding of the ichthyoses to understand how individual gene mutations cause the disease. There was a panel discussion on how to simplify disease classification of the ichthyoses while at the same time accounting for the increasing diversity of mutations and phenotypes that are being reported from all over the world.



This meeting was an excellent opportunity for international exchange of research and patient groups. It is very encouraging to see how much activity there is. The abstract book of this excellent meeting can be requested from brigitte.willis@ukmuenster.de.

Dr. Matthias Schmuth practices Dermatology at University of California in San Francisco, California, and is a member of The foundation's Medical & Scientific Advisory Board.

Applications available for 2008 Shade Structure Grant Program

Does your local playground have shade for families visiting the facility? Is your child's school yard adequately

shaded for recess or lunch play? Does your son or daughter's sports field provide sufficient shade for spectators? Having shade in areas of play is very important to children with ichthyosis and related skin types. The American Academy of Dermatology's (Academy) Shade Structure Program provides \$8,000 grants for the purchase of a permanent shade structure designed to provide shade and ultraviolet (UV) ray protection for outdoor areas. The Shade Structure Program is open to non-profit organizations or educational institutions that serve children and teenagers, ages 18 and younger. To be considered for funding, applicants must complete an application that demonstrates a commitment to sun safety and is accompanied by a letter of support from an Academy member dermatologist. To download an application, visit: www.aad.org/public/News. If you have questions about the Shade Structure Program or the items required for submission, please contact Jennifer Allyn by email at jallyn@aad.org or phone at 847.240.1730. The deadline for grant applications is Wednesday, March 5, 2008.

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Projects Funded in Year Two

Continued from page 1

Suephy C. Chen, MD, MS, Principal Investigator along with Co-Investigator Mary K. Spraker, MD, at Emory University in Atlanta, GA, have been selected to receive \$50,000 for their project titled "The Economic Burden of Cutaneous Disease in Ichthyosis Patients and Families." This project relates to the mission of the Foundation and the interests of our members because: "Information about the economic impact of disease is important to elucidate as the allocation of both research and medical care resources may be influenced by such data. Therefore, we believe our research will help F.I.R.S.T. continue to meet its central mission, offering information, education and support services to its far-flung membership of persons affected with ichthyosis and their families."

Drs. Chen and Spraker aim to evaluate the economic impact of cutaneous disease in ichthyosis by: 1) performing a rigorous cost analysis from both societal and individual perspectives, as enumerated through microcosting; 2) assessing how individual cost of ichthyosis care relates to individual QOL outcome measurements; and 3) comparing the overall economic impact and QOL of this population to other patient populations. While there are at least 20 different types of ichthyosis, they will mainly focus their study on the following four main types: ichthyosis vulgaris, epidermolytic hyperkeratosis, lamellar ichthyosis, and X-linked ichthyosis. They will correlate disease impact with ichthyosis subtype and/or disease severity.

The Foundation thanks all of the generous donations that many of you have contributed over the past years. The donations are crucial for investigators to continue their important research work in the area of ichthyosis.

Hey Kids...

Continued from page 1

There's so much great stuff to do at Camp Horizon; so much to choose from it's hard to make up your mind on what to do! There is a big camp fire the first night with a band and (you guessed it!) s'mores. Camp also has arts & crafts, crazy hat day, swimming, fishing, paddleboats, concerts, a talent show (you can be silly), and pie day (yum!). The food is great too. There's an optional night of camping in a tent instead of sleeping in your cabin. There's an obstacle course, a tree house, and a climbing wall. I had a *hard time* on the climbing wall at first but, with help, I finally conquered it! Everyone there is so nice and helpful; they want us to have a great time.

One of my favorite things is gambling night. We don't use money but it's a blast. Another favorite of mine is archery. Last year I beat the instructor. We had a contest this year and I beat him again! It was so much fun! The last couple years we've gone to Knoebel's amusement park for a day. They have some really great roller coasters there. I love roller coasters! Sometimes a local motorcycle group comes to camp and takes us for rides on their motorcycles or, sometimes, we get to ride horses. One of the funniest things that happens is the pranks that get played. One year, someone flew Dr. Howard Pride's (camp director) underwear on the top of the flag pole. It was hilarious!

If you get worried about being away from Mom and Dad, don't worry. There are doctors, nurses, and counselors there that can help out with any medical stuff you need to do. I was 8 years old the first time I went to camp. I was nervous about what it was going to be like and about being away from Mom and Dad for a week. It was the first time I was away from home except for sleepovers. Everyone welcomed me when I got there and they were so nice. Right away, I felt like I was at home even though I hardly knew anyone there. You share a cabin with a bunch of kids and counselors. Once I graduate, I want to come back as a counselor.

There was a new kid at camp this year. He wasn't interested in coming before. My mom talked to his mom (you know how that goes) who told him about all the stuff we get to do and how much fun it is. He decided he wanted to try it and he came to camp. I'm so glad he did. I got to make a new friend and he had a blast! If you've never been to camp you "gotta" try it! Just once! I'll bet you'll keep coming back.

I hope to see you there next year! Yeah toast!

Hunter Steinitz - I have Harlequin Ichthyosis



To receive more information on the Camp Discovery program, go to www.aad.org and click on "Parents & Kids."



F.I.R.S.T.

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