

Ichthyosis Focus



Vol. 24 No. 4

Anniversary 25th Issue

Winter 2006

Foundation Launches Research Grant Program

The Foundation's commitment to research is a major component in our mission. After nearly two years of discussion, planning, and fundraising, the Foundation has officially launched its own Research Grant Program. The new grant program will promote and strengthen investigation into the causes, treatments, and potential cures for ichthyosis.

The Foundation has been supporting research into the ichthyoses, over the past eight years, by providing grant money through the Dermatology Foundation. Under this system, the Dermatology Foundation has been responsible for announcing, receiving, reviewing, and awarding ichthyosis-related research grants using the funds provided by our Foundation. With the adoption of this new program, the Foundation will manage the entire program through the national office. Guided by the Foundation's Research Committee, which is comprised of knowledgeable physicians, scientists, and Foundation leaders, the office will administer and manage the annual grant-funding program.

Surveys of the ichthyosis community, specifically individuals affected with ichthyosis and their families, have indicated that research is their primary area of interest and their top priority for funds donated to the Foundation. In response, the Foundation initiated this program to promote promising avenues of research by investigators who have a new or established interest in ichthyosis.

The genetic basis of most types of the ichthyoses is now known. Recent advances in knowledge about epidermal structure, function, and physiology have provided insights into the pathogenesis of several of the ichthyoses. A variety of new approaches to molecularly-targeted therapy for genetic disease have been developed by the scientific community. The Foundation and its stakeholders are determined to promote the use of this knowledge and to encourage its translation into more effective therapies. The Foundation is particularly interested in supporting new initiatives that will lead to ongoing, self-supporting programs in ichthyosis research. It will also support shorter studies that will provide definitive information within one to two years.

Several very generous donors have requested that their sizable contributions be focused on research into Lamellar Ichthyosis/Congenital Ichthyosiform Erythroderma (CIE) and Epidermolytic Hyperkeratosis (EHK). Because there are many varieties of ichthyosis, it is difficult to study each individual disease. However, all the ichthyoses share the same common feature, abnormal function of the stratum corneum and the build-up of scale on the surface of the skin. Our Medical and Scientific Advisory Board strongly believe that research progress involving these two diseases will benefit all forms of ichthyosis.

The program was officially made public in January with announcements posted on the Foundation's website and in industry journals and organizations, which include the Society of Investigative Dermatology, the Journal for Investigative Dermatology, the Society for Pediatric Dermatology, the

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Register Now!!

2006
National Family Conference
Soaring to New Heights



June 30, July 1 & 2, 2006
Atlanta, Georgia
Deadline for Registration - May 31, 2006
See pages 11-14

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Types

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Correspondence Corner

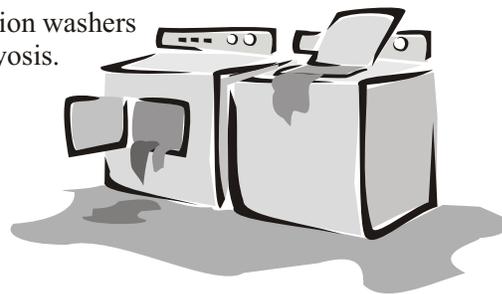
Dear Foundation members and readers of the Ichthyosis Focus:

I recently bought a new washing machine. It is new technology that saves water and energy. Unfortunately, it cannot cope with the petroleum jelly-laden clothes of my son who has ichthyosis. The cream and jelly never thoroughly wash out; instead, it turns into balls of gum that have to be picked out of the wet clothes by hand.

I do not recommend the new Calypso-motion washers for families who have a member with ichthyosis.

Sincerely,

Mary Fitzpatrick
Pasadena, CA



Foundation Resources

Australia / New Zealand
Support Contact List

The Foundation has compiled a support network contact list for our members in Australia and New Zealand. If you are a member of the Foundation, live in that area of the world, and would like to be a part of the support contact list, please contact Maureen in the Foundation office. You must be registered as a member of the Foundation and must also place your name and contact information on the list. The list is shared only with the members participating in the list.

Any member of the Foundation, located anywhere in the world, may make use of the Ichthyosis Support Network at any time. Most of our support network volunteers are located in the U.S., but we are frequently able to connect members with other families elsewhere in the world.

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Texas Members to Raise Money for Lamellar Ichthyosis Research



Two parents of a young daughter affected with lamellar ichthyosis have founded Project Save Our Skin (SOS) in Fort Worth, Texas, to help raise awareness of ichthyosis and money for ichthyosis research. In their efforts to learn more about ichthyosis after their daughter was born, they quickly realized how little information was available in their local area. Only when they discovered the Foundation did they learn that information, resources, and support were readily available to them about this rare genetic disease. Being concerned and loving parents, they were eager for as much information as possible and their quest began to make a difference in their daughter's life.

Armed with this passion, Cort DeHart and his wife, Elizabeth Barry, formed Project SOS, a non-profit organization, and partnered with the Foundation to fund lamellar ichthyosis research. They launched the F.I.R.S.T./PROJECT SOS Lamellar Ichthyosis Research Grant program to encourage and support the investigation into the causes, treatments, and potential cures for lamellar ichthyosis. The Foundation anticipates funding a lamellar ichthyosis research grant this year through the new research program. Project SOS plans

to provide the funding for this year's grant and to continue to provide funding on an annual basis for lamellar ichthyosis research.

Project SOS raises money through several events. Each spring, Project SOS sponsors the Broken Oar Tarpon Invitational, a charity fishing tournament in Key West, Florida. The event is a four-day, guided catch-and-release fly fishing tournament. To participate, each angler must pledge to raise money for Project SOS and lamellar ichthyosis research. Through the generous efforts of the participants and their sponsors, the Broken Oar Tarpon Invitational is the main fundraising event for Project SOS.

Cort's law firm also participates in fundraising for lamellar ichthyosis research. Every year, the law firm of DeHart Crockett, P.C. hosts its own charity event called, *Crawfish in the Park*, for the benefit of Project SOS. The firm hosts a huge crawfish boil in April with live music, children's activities, and all you can eat crawfish. Current and former clients, local attorneys, judges, family, and friends are all invited to help support Project SOS and ichthyosis research. Attendance and donations continue to increase annually.

If you would like information about either event, please send your inquiry to cort@dehartcrockett.com or visit www.projectsos.org.

Foundation Launches Research Grant Program

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American Journal of Human Genetics, and the American Association of Professors of Dermatology. Grant applications are due in April, and grant award announcements will be made at the end of June.

The Foundation will review projects and fund grants in the following three areas:

- Ichthyosis-Related Research (any type)
- Epidermolytic Hyperkeratosis (EHK)
- Lamellar Ichthyosis/ CIE

The projects must focus on three priorities, which have been developed jointly and will be reviewed annually by the Foundation's Board of Directors and Medical & Scientific Advisory Board. The first priority is original investigations leading to improved understanding of the molecular pathogenesis of the various ichthyoses, particularly lamellar

ichthyosis/CIE and EHK. The second priority is novel approaches to the management and treatment of the various ichthyoses, particularly lamellar ichthyosis/CIE and EHK. The third priority will focus on investigations that address the treatment and prevention of secondary complications or quality of life issues for patients with disorders of keratinization. High priority will be given to projects that focus on the translation of known genetic information and established pathogenic pathways into curative therapies or new therapies that promise a significant impact.

This is an exciting time and monumental step forward for the ichthyosis community. Please continue to support the Foundation's appeals for research donations. As you can see, your dollars are being put to good use. If you would like to learn more about this program, visit our website at www.scalyskin.org or contact Maureen Tierney at the national office at 1-800-545-3286.

Grassroots Fund Raising 2005

Monster Dash

Dedicated Foundation member Dawn Johnson hosted her annual *Monster Dash* fundraiser in October 2005. Over 200 supporters gathered on a beautiful Saturday morning at Westwood Elementary School in Friendswood, Texas, for this fun event.



Children participated in a half-mile run, while the adults walked or ran a one-and-a-half mile course or a five-kilometer course. Every participant who completes the course receives a medallion and t-shirt. Participants donate an entry fee and tickets are sold for a large raffle.

Many local businesses donated raffle items, including smoothies for all the participants, airline tickets, and gift certificates.

Jordan Johnson, a first-grader, and her mom, Dawn, have been organizing the *Monster Dash* since 2000 to raise awareness of and money for the Foundation. This



year's proceeds totaled \$6000 in support of the Foundation's programs and services.



It takes months of planning and organizing to create this event. Over the years, Dawn's experience and her commitment to the Foundation continue to be strengthened by the support of her community. The Foundation is extremely grateful for her efforts. If you are interested in copying the *Monster Dash* format and hosting an event in your community, please contact the Foundation office at 1-800-545-3286.



The Johnson Family

Creative Ideas

Several members of the Foundation used some very creative ideas to raise funds in 2005.

Sharon Enting, Emma Klima's grandmother, held a fund-raiser through her employer, Braden Sutphin Ink Company of Cleveland, Ohio. Sharon raised over \$300, which Braden Sutphin matched, bringing the total to over \$600.00.

Member Lisa Klima held a "Dress Down Day" at her place of business and raised over \$300.00 for the Foundation.

Foundation member Julie Pratt came to us with a great idea. Lorraine Daniels, our administrative assistant, designed and printed pretty cards for her brother Allan's wedding, noting that the bride and groom were making a donation to the Foundation in lieu of wedding favors. Allan and his bride made a very generous donation to the Foundation. We thank the new couple for thinking of the Foundation and including us in their special day.

Kim Mayone, member and brand new mother of Evan Paul Mayone, asked those attending her son's christening to make donations to the Foundation in lieu of gifts for the baby. A thoughtful gesture that is very much appreciated by the Foundation.

Macy Rogers, 8 years old, had the guests at her birthday party send donations to the Foundation in lieu of gifts. A very grown up and generous thing for her to do! Mom Lori Rogers gave donations to the Foundation this holiday season in honor of son Ben's middle school teachers, in lieu of the traditional teacher gifts. A great way to honor a favorite teacher or coach!

Michelle & Chad Iott were instrumental in the Car Wash fundraiser held by the National Honor Society of Flandreau High School in South Dakota. This endeavor raised approximately \$300.00 for the Foundation.

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New DVD Available

Living with Ichthyosis: A Teenage Perspective

The Foundation's newest addition to its resource library is finally here! The new 43-minute DVD entitled, "Living with Ichthyosis: A Teenage Perspective," provides an upbeat, positive message for all affected individuals and their families about what it's like to grow up with ichthyosis. This DVD is a balanced, informative, and real-life documentary told by eleven teens, who opened their hearts and shared their thoughts and feelings about living with ichthyosis. The DVD covers many issues, including daily living experiences, dealing with peers, school activities, skin care routines, doctor relationships, future plans, and much more.

The new DVD will be helpful for all audiences: affected teens, pre-teenagers, parents of newborns and toddlers, relatives, teachers, healthcare professionals, or anyone whose life has been touched in some way by ichthyosis.

The Foundation sincerely thanks all the teens and their families for volunteering their time, thoughts, and energy to the DVD. The Foundation also gratefully recognizes the commitment and devotion of Justin Tormey, producer and director of the DVD, and president of ASAP Productions in New Hope, PA. Justin worked countless hours filming and editing the DVD. He knows first-hand how this tool will help everyone in the ichthyosis community, because his only sister is affected with lamellar ichthyosis. The Foundation also thanks Operation Good Neighbor Foundation for their generous grant to underwrite the production costs and other expenses incurred while making the DVD.

To order a copy of the new DVD, please complete the form below and send it in to the office. You can also order one directly by calling the office at 1-800-545-3286 or emailing us at info@scalyskin.org. Each DVD is \$14.95 plus shipping.

DVD Order Form
Living with Ichthyosis: A Teenage Perspective

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ Email: _____

Number of DVDs _____ x \$14.95 = _____ Subtotal
_____ Shipping (\$2.00 standard or \$4.05 priority)
_____ Total Enclosed (check or credit card)

Please make checks payable to F.I.R.S.T. in US Funds or complete credit information below.
The Foundation accepts MasterCard, Visa or American Express (circle one).

Credit Card _____ Exp. _____

Authorized Signature _____

Mail form and payment to F.I.R.S.T., 1601 Valley Forge Road, Lansdale, PA 19446.

Executive Director's Report

Dear Members & Friends of the Foundation,



The beginning of a new year holds promise and excitement for wonderful things to come. That is certainly true for our Foundation this year. There are so many exciting things to share with our members and friends in this report. We will be very busy in 2006!

This year marks the 25th anniversary of the Foundation; twenty-five years of amazing growth and service to individuals and families affected by ichthyosis. Please take a moment to review the timeline on pages 8 and 9. This timeline highlights just a few of the hallmarks during the past twenty-five years. Unfortunately, the newsletter is not big enough to mention every major accomplishment. There is so much that takes place behind the scenes to achieve these milestones. We are the only support organization devoted to the special interests of the ichthyosis community in North

America. With your support, we will continue to serve our members and the friends who contact us daily for help, support, and resources for another twenty-five years.

In addition to celebrating our anniversary, the Foundation is embarking on a new endeavor for the future. Twenty-five years of growth, both financial and professional, has positioned us to launch our own in-house research program. No longer will the Foundation rely on others to promote, administer, and review ichthyosis-related research. Our Board of Directors, Research Committee, and staff believe we will achieve greater results hosting our own program, ultimately translating the results into positive therapies for affected patients. The front cover story explains our new research program in more detail.

The 2006 Family Conference, "*Soaring to New Heights*," is now six months away and registration has begun. You can register online at our website, www.scalyskin.org, and use PayPal to securely pay your registration fees. Or you can complete the registration on pages 13 and 14 and mail your form and payment back to the office. The conference attendance increases every year. We fully expect this year's Atlanta conference to have the highest attendance yet. Imagine more than 350 people in one place who are all affected with ichthyosis, either personally or through a loved one. For these three days, ichthyosis is no longer a rare disease. Everyone knows about it, lives with it, and faces the same challenges as you. I hope to see you there.

In March, Maureen, our Program Director, and I will be traveling to San Francisco for a week packed full of ichthyosis-related activities. Beginning on March 1 and 2, we will be attending "Obstacles to Translation," a conference addressing the obstacles that have prevented researchers from translating the spectacularly successful identification of gene defects in heritable skin disorders into molecularly targeted therapies. The goals of the conference are to identify the barriers to translating known information into successful therapies and to emphasize strategies to overcome them, setting the course for the discovery and development of improved therapies for patients with skin diseases.

Following the conference, the Foundation is hosting a fundraising Testimonial Dinner on Friday, March 3 to honor Drs. Mary Williams and Peter Elias, founders of F.I.R.S.T. Mary and Peter, a husband-and-wife team, have dedicated their professional careers to helping ichthyosis patients and are truly deserving of this honor.

The next day, Saturday, March 4, the Foundation's Medical & Scientific Advisory Board will meet for its annual breakfast meeting to review, discuss and plan strategies for the upcoming year. This year's meeting will be especially interesting as it follows the Obstacles conference and the launching of the Foundation's new research program. Following the breakfast, the Moscone convention hall will open to thousands of dermatologists and pharmaceutical company exhibits for the annual four-day American Academy of Dermatology convention. Maureen and I will each volunteer time at the Coalition of Skin Diseases booth, sharing information about ichthyosis and our Foundation with dermatologists from all over the world.

This past December, I had the opportunity to appear on a live radio program in our local area. The program, entitled "To Your Health with Sherri Putnam," featured a discussion about ichthyosis and the Foundation's programs and services. Board member Terry Tormey, who was responsible for organizing the radio spot, joined me on air. We appeared for nearly an hour on two radio stations, 1490 AM WCB and 1440 AM WNPV, reaching thousands of local residents. We have received calls from community members in response to this airing.



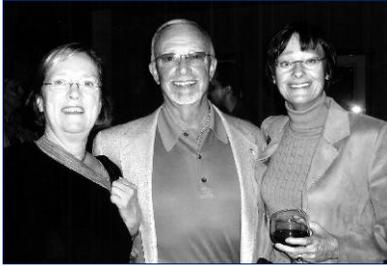
Jean Pickford, Terry Tormey and Sherri Putnam

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Executive Director's Report

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This past November, our Board of Directors met face-to-face in Philadelphia to discuss and review our current state of affairs as well as adopt new strategies for further growth. The meeting was extremely productive, with many exciting plans for the future. The meeting also provides an opportunity for our national board members, who live in many different locations around the country, to get to know each other in a more personal way.



Dr. Mary Williams, Mike Briggs & Laura Phillips



Valerie Scholl, Terry Tormey, Dr. Phil Fleckman & Dave Scholl



John Schoendorf, Dr. Terry Melton & Beth Gray

At the retreat, we voted in one new board member, Sherri Bale, Ph.D., president of GeneDx, Inc., in Gaithersburg, MD. Sherri has been a long-time friend and supporter of the Foundation. She is pleased and honored to be a part of our organization.

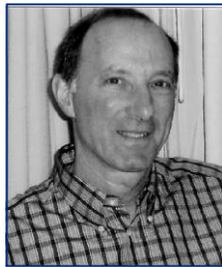
The statement, "All good things must come to an end," has never been so true than at the retreat. We had to say goodbye to four board members, as their terms on the Board had expired. The Foundation's bylaws state that board members can serve up to nine years on the board and these extremely caring, devoted, and generous members have done just that. Gloria Graham, MD, Leonard Milstone, MD, Tiffany (Karst) Moore, and Laura Phillips will be greatly missed. Each of them has contributed greatly to the organization in leadership roles and has been instrumental in helping the Foundation achieve its success. Although they can no longer serve on the board, they will still remain active volunteers within the Foundation. Their vacancies now pave the way for new and fresh leaders to emerge.



Dr. Sherri Bale



Dr. Gloria Graham



Dr. Leonard Milstone



Tiffany Moore



Laura Phillips

Finally, thank you to everyone who contributed to our recent holiday mailing campaign. As you can see, all of the Foundation's accomplishments would not be possible without the generosity of our members, friends, and corporate partners. Every cent counts, so please continue to support our important work.

Warm regards,

Jean R. Pickford
Executive Director

Grassroots Fundraising - Creative Ideas

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Alexej & Susie Lozevski appealed to their friends and family with a personal letter writing campaign. To date, they have raised over \$5,000.

Susan Suda worked with students at Central Middle School in Grafton, ND, to sell silicone bracelets, created and distributed by Becky Butler (Correspondence Corner, Ichthyosis Focus, Spring 2005) for ichthyosis awareness. The students sold nearly 200 bracelets after hearing a presentation by Susan, which included information about ichthyosis, a viewing of the Foundation's video, "Butterflies - The Children of Ichthyosis," and a question and answer session. This project complemented a community volunteerism segment that the seventh and eighth grade students had recently completed in their Life Skills class. In addition to their fundraising efforts, the students incorporated Susan's message of raising awareness by completing a challenge by their instructor to write a letter to a family member or friend who lives outside of Grafton. The students were to explain what they had learned about ichthyosis and share information from an informational handout. Susan also spoke about ichthyosis to a classroom of Early Childhood Development students at a local

senior high vocational school. These students also assisted with the bracelet fundraiser. The efforts of these civic-minded students and their instructors raised \$400 for the Foundation. Their efforts are very much appreciated by Susan and F.I.R.S.T.

Paul and Jean Meeker also bought the silicone bracelets that Becky Butler (Correspondence Corner, Ichthyosis Focus, Spring 2005) designed and distributed for ichthyosis awareness and resold them to family, friends, and coworkers. Their efforts brought in approximately \$100.

The Foundation sincerely thanks all these individuals for giving of their time and imagination. The generosity of all our members helps advance important programs like the new Research Grant Program and family conferences.

If anyone would like more information on Grassroots Fundraising please contact the national office, 1-800-545-3286. We have a 33-page booklet, "The Awareness & Fund Raising Guide," available to assist you.

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Drs. Peter Elias & Mary Williams
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2006 National Family Conference: *Soaring to New Heights!*
June 30, July 1 - 2 ♦ Crown Plaza Ravinia Hotel ♦ Atlanta, Georgia

PROGRAM AT-A-GLANCE

Friday, June 30th

(pre-scheduled clinical screening appointments throughout the day)

12 — 2 pm	Registration
2—4 pm	General Session
4—4:15 pm	Break
4:15—5:30 pm	Workshops I
6—9 pm	Family “Picnic” Social (optional)

Saturday, July 1st

7—9 am	Breakfast Buffet
9—12 pm	Workshops II
12—1:30 pm	Lunch
1:30—3 pm	Disease-Specific Discussions
3—3:15 pm	Break
3:15—5:30 pm	Practical Advice Discussions
6—10 pm	Dinner Social

Sunday, July 2nd

7— 9 am	Breakfast Buffet
9—11:30	Group Support Networking
11:30—12:30 pm	General Session/Conference Wrap-Up
12:30—	Farewell Lunch (Optional)



Registration: To register for the conference, complete the Conference Registration Form and submit payment to the national office by May 31. If you need to cancel prior to the conference, a full refund will be awarded. Registration will not be complete without form and payment.

Meals: Breakfast, lunch, and dinner on Saturday and breakfast on Sunday are included in your registration fee. Friday evening’s dinner and Sunday afternoon’s lunch are optional for each attendee and must be pre-paid with your registration.

Dress Code: Conference attire is casual, including Saturday evening’s dinner.

Clinical Screening: All affected individuals have the opportunity to meet with leading expert physicians in ichthyosis for free, private 10-minute consultations on Friday, June 30. Participation is voluntary. Sign-up is required prior to the conference. If you are interested, you must complete Section V of the Conference Registration Form.

Child Care: A professional child care company will provide services during workshops for affected and unaffected children, ages 1-8.

Teens & PreTeens: There will be a separate program for children ages 9 - 17, focused specifically on age-appropriate activities and discussions.

2006 National Family Conference: *Soaring to New Heights!*
June 30, July 1—2 ♦ Crown Plaza Ravinia Hotel ♦ Atlanta, Georgia

Hotel Accommodations - The discounted room rate negotiated with the hotel is \$94.00 plus applicable taxes, per night, flat occupancy. For those who want to extend their stay in Atlanta, these rates are available 3 days prior and post the official conference dates.

All attendees must make their own reservations at the Crown Plaza Ravinia. Call toll-free at 800.554.0055 or 770.395.7700. To ensure you receive the discounted conference room rate, you must identify our group name of "Foundation for Ichthyosis & Related Skin Types." Should you fail to identify yourself with our group, the room rate quoted will apply and no adjustments will be made after your arrival. Reservations must be received on or before *June 7, 2006*. All reservations must be accompanied by a first night room deposit guaranteed with a major credit card.

Travel from Airport to Hotel - The Crown Plaza Ravinia is approximately 27 miles from the Hartsfield/Jackson International Airport.

Taxi - Travel from the airport to the hotel is approximately \$50.00. Travel time is 35 minutes.

Train - The hotel stop on the Atlanta public train system, MARTA, is called N9 Dunwoody Station, which is .3 miles from the hotel. The travel time from the airport is 40 minutes and a one-way fare per person is \$1.75 for any stop on the system. The hotel provides a complimentary shuttle between the Dunwoody Station and hotel. For train schedules, visit www.itsmarta.com.

The hotel offers a complimentary shuttle service within a 3-mile radius of its location.

Airline Travel to Atlanta

The Foundation has contracted with AirTran Airways and American Airlines to offer discounted air travel to conference attendees:

AirTran Airways EventSavers Program - AirTran will provide a 10% discount on the lowest available AirTran Airways one-way fare. Attendees may travel three (3) days prior to the conference and three (3) after the conference. Other rules and restrictions apply. Contact the AirTran Airways EventSavers Program at 1.866.683.8368 from 8 am to 9 pm EST weekdays to book your air travel. Please refer to event code: ATL063006.

American Airlines - American will provide a 5% discount on applicable fares for travel dates to Atlanta between June 27 and July 6, 2006. Other rules and restrictions apply. For reservations, contact their Meeting & Services Desk at 800.433.1790 between 5 am and 11 pm CST and refer to code #A0966AQ.

National Patient Travel Center - You may be eligible for free transportation using the Angel Flight America Program. If you live within 1000 miles of Atlanta, Georgia, Angel Flight 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 2006 Foundation for Ichthyosis Family Conference. Special Lift Program.

Driving Directions to Hotel - Contact the Crown Plaza Ravinia at www.cpravinia.com or call their hotel staff at 770.395.7700. Parking is complimentary at the hotel.

Kindly mail completed registration form and payment by **May 31st** to FIRST, 1601 Valley Forge Road, Lansdale, PA 19446. If you have any questions, please call 800.545.3286 or email at info@scalyskin.org.

2006 National Family Conference: ***Soaring to New Heights!***
 June 30, July 1—2 ♦ Crown Plaza Ravinia Hotel ♦ Atlanta, Georgia

Section I - Contact Information (please print clearly)

Name: _____

Address: _____

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

Phone (Day): _____ Phone (Evening): _____

Cell Phone: _____ Email: _____

Section II - Registrant's Information (Please print clearly; nametags will be provided.)

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 13-17), PreTeen (ages 9-12), and Child (ages 1-8). Based upon ages provided, each registrant will be assigned to the appropriate program.

First Name	Last Name	Age	Type of Ichthyosis
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Section III - Child Care Registration

The Foundation has hired a professional child care company to entertain and supervise affected and non-affected children, ages 1-8, 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.

Name of Child	Age	Type of Ichthyosis	List Any Medical Conditions or Allergies
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

Section IV - Volunteering

Please check if you would be willing to volunteer some time: Volunteer Name: _____

_____ Assembling Gift Bags on Thursday, June 29 _____

_____ Chaperoning the teen & preteen groups on field trips, etc. Phone: _____

Registration Form Continued on Next Page

Section V - Clinical Screening Appointments

This is an opportunity to meet with expert dermatologists who specialize in ichthyosis to answer any questions or concerns that you may have. These appointments will take place throughout the day on Friday, June 30, from 9:00 am - 5:30 pm (the first day of the conference). You will be notified prior to the conference of your scheduled appointment time at the contact information provided on page 1.

Name of person for appointment	Age	Male/Female	Type of Ichthyosis	Confirmed by a Dermatologist?
_____	_____	_____	_____	Yes No
_____	_____	_____	_____	Yes No

Please check here if you prefer an afternoon appointment because of your travel distance. We will do our best to accommodate your request. However, the number of attendees requesting appointments is always very high, so we cannot guarantee an afternoon appointment.

Section VI - Other (please circle yes or no)

Does the Foundation have permission to take photos of your family during the conference? **Yes** or **No**

Does the Foundation have your permission to publish photos of you and your family on office materials, including our website and newsletter? **Yes** or **No**

Does the Foundation have your permission to include all your contact information on the conference roster, which will be distributed to all registrants? **Yes** or **No**

Have you ever attended a conference before? **Yes** or **No**

Section VII - Payment Information

The Foundation has received several sponsorships, which allows us to offer a discounted registration fee of \$105 per adult and \$60 per child. The actual cost per person to attend the conference is \$175. Your conference fees help offset the cost of food, beverages, supplies, etc.

Step 1. Conference Registration Fees

# of Adults Attending (18 or over)	_____	x \$105	= _____
# of Children Attending (17 or under)	_____	x \$60	= _____

Step 2. Child Care Registration (ages 1-8)

# of Children (be sure to complete Section III)	_____	x \$15	= _____
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Step 3. Family "Picnic" on Friday evening (optional)*

# of Adult Meals (10 or over)	_____	x \$20	= _____
# of Children Meals (9 or under)	_____	x \$10	= _____

Step 4. Farewell Lunch on Sunday afternoon (optional)*

# of Adult Meals (10 or over)	_____	x \$20	= _____
# of Children Meals (9 or under)	_____	x \$10	= _____

Step 5. Grand Total

___ My check is enclosed, made payable to FIRST, in US funds.

___ Please charge my credit card: Mastercard, Visa, American Express (circle one)

\$

Credit card Number: _____ Expiration: _____ Authorized Signature: _____

*The Foundation is offering two optional social functions at an additional cost per person. These are optional events and are not included in the conference registration fee.

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www.detentednt.com

Or contact Cindy Cooper 610-520-0102

Pam Bonds 610-296-2404

For an informational package or sample

[Please know that we are here to help in any way possible.](#)



News & Notes

Safety Study of Elidel (Pimecrolimus) 1% Cream to Treat Netherton Syndrome

Doctors at Children's Hospital of Philadelphia are conducting a clinical trial to assess the safety of Elidel in the treatment of Netherton syndrome, to see whether the medication is absorbed through the skin, and to see if side effects are associated with its use in children with Netherton syndrome.

Children, ages 2 to 18, with Netherton syndrome are eligible for this study. Other criteria need to be met for inclusion in the study. Please see www.clinicaltrials.gov/ct/gui/show/NCT00208026 for more information. If you do not have access to the Internet, please call Maureen in the Foundation office, 1-800-545-3286, for a copy of the information.

Interested individuals may contact Dr. Albert Yan, the principal investigator, or Dr. Kara Smolinski, sub-investigator. Please refer to this study by ClinicalTrials.gov identifier NCT00208026.

Albert Yan, MD
215-590-2169
yana@email.chop.edu

Kara N. Smolinski, MD, PhD
215-590-2169
smolinski@email.chop.edu

Textbook Authors Looking for Pictures of Patients

The authors of an academic textbook titled "Anesthesia for Genetic, Metabolic and Dismorphic Syndromes of Childhood" (Lippincott, Williams & Wilkins: Philadelphia, 1999) are looking for photos of patients with CHILD Syndrome or Conradi-Hunermann Syndrome to be included in the second edition of their reference book. The book is designed to help anesthesiologists provide safer and more tailored care to children with rare syndromes by providing these doctors with important anesthetic information specific to each syndrome. The first edition has proved tremendously useful and popular, but users have requested that the second edition include more photographs of individuals with the described syndromes, so that they are better able to visualize the descriptions in the text.

If you have a child with CHILD Syndrome or Conradi-Hunermann Syndrome and would be willing to contribute a photo of the child to this work, please contact Jenny O'Flaherty, jeo8m@virginia.edu, or Vic Baum, vcb2n@virginia.edu. Or contact:

The Department of Anesthesiology
University of Virginia Health System
P.O. Box 800710
Charlottesville, VA 22908-0710

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News & Notes

The photo(s) would be used only for publication in this book and/or for teaching purposes in formal educational activities directed by the authors, and would require the parents' written consent for publication.

Dates for Camp Discovery, 2006

Camp Discovery 2006:

July 8 to 14, 2006

Teen Camp at Camp Knutson, Crosslake, Minnesota; ages 14 to 16.

July 15 to 21, 2006

Junior Camp at Camp Knutson, Crosslake, Minnesota; ages 10 to 13.

August 12 to 19, 2006

Camp Horizon, Millville, Pennsylvania; ages 8 to 13.

Those interested in referring a child or volunteering at any one of the camps, please contact Janine Mueller at the American Academy of Dermatology at 847-240-1737, or jmueller@aad.org.

Children must be referred to camp by their dermatologist. For more information about, or applications to, the Camp Discovery program, go to www.aad.org and click on Public Resources/ Parents & Kids/ Camp Discovery. If you do not have access to the Internet, contact Janine Muller at 847-240-1737.

2006 Patient Art Exhibit

The Society for Investigative Dermatology (SID) is pleased to serve as host, with the Coalition of Skin Diseases, for the fourth annual patient art exhibit. Submissions will be accepted through March 31, 2006.

Artwork featured in past shows can be viewed, along with other links, in the "Patient Information" tab of the SID website: <http://www.sidnet.org>.

The exhibit is an excellent opportunity for patients to present the impact of skin disease in a personal and creative manner to the researchers committed to finding treatments and cures. Members of all the Coalition of Skin Diseases organizations are encouraged to submit artwork.

Exhibitor Release Forms must be filled out for each submission. The SID will pay all shipping charges and insure the piece for up to \$200.00. Please contact Becky Minnillo at the SID for additional information via phone at 216-579-9340, fax: 216-579-9333, or email Minnillo@sidnet.org.

Interested individuals who do not have access to the Internet can contact Maureen at the Foundation for Ichthyosis office for more information and a copy of the Artist Release Form, 1-800-545-3286.

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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