

FIRST Board of Directors Meet in Philadelphia

FIRST's Board of Directors gathered in Philadelphia over the weekend of November 5-6, 2011 to plan the 3 year strategic initiatives for 2012 to 2014. The Foundation's previous 4-year strategic plan included a comprehensive marketing plan, website redesign, a new database management system, a funding program for ichthyosis research, and implementation of the regional support network. The Board is very proud that these strategic initiatives have been implemented with great success.



*Seated: Janet McCoy, Amy Paller, Mark Klafter, Eric Schweighoffer, Jean Pickford
Standing: Dave Scholl, Philip Fleckman, Moise Levy, Jeff Hoerle, Moureen Wenik, Mike Briggs, Leonard Milstone, John Schoendorf, Terry Tormey, Brian See, Dan Siegel*

We welcomed a new board member at the retreat, **Jeff Hoerle**, and voted **Dr. Amy Paller** as our fourth Board Member Emeritus. Jeff comes to FIRST with strong leadership and financial management skills. His youngest daughter is affected with a rare form of ichthyosis. Amy has been with FIRST for many years and recently completed her nine year term on the board. Not to be missed is special thanks to **Dan Siegel** for his nine years of service as a board member and his continued service to FIRST as our general counsel for the past four years.



Jeff Hoerle

With the new year, comes new leadership for FIRST as well. Joining our Executive Committee will be **Moise Levy, MD** as Vice-President and **Michael W. Briggs** as 2nd Vice-President (and President-Elect). Moise and Mike will participate in monthly teleconferences with **Dave Scholl, PhD**, our president, **John Schoendorf**, our CFO, **Janet McCoy**, our Secretary, and **Jean Pickford**, our Executive Director.



Dan Siegel



FIRST President Dave Scholl (left) and Executive Director Jean Pickford (right) present a token of appreciation to Dr. Amy Paller recognizing her 9 years of service on the FIRST Board.



2012 NATIONAL FAMILY CONFERENCE

SMILE HIGH!
DENVER, COLORADO



Conference Registration
is Now Open



**UFIRST
Scholars
Application
available**

Rare
Disease
Day
in February



Rare Disease Day



**Ichthyosis
Awareness
Month
will be
in May**

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There is a new app for iPhone

Developed by a resident at the University of Texas Southwestern, it allows you to quickly provide patients with support group information.

This app is called Skin Advocate and can be downloaded from iTunes.

To download the app click on the app store icon, then type either "Skin Advocate" or "Dermatology."

Physicians: Please take a moment to download this valuable resource to provide your patients with the support they need.

Patients: Please let your dermatologist know that this is available.

If you would like more information about this app, visit FIRST's website, www.firstskinfoundation.org



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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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Correspondence Corner

Dear FIRST,

This morning as I doctored up my skin I was struck with a poem. I send it to you just because all of you at FIRST are so nice to me.

Jim Huetson

Asotin, Washington

Dear FIRST,

Thank you very much for connecting me with other people affected by ichthyosis. My communications with them have been extremely helpful. They are empathetic, sincere and highly informative. This is a wonderful thing the FIRST foundation is doing.

Mandy McKenzie

Houston, Texas

Dear FIRST,

I am a 48-year-old-female, I have been told all my life that I just had "dry skin" and that I needed to drink more water, exfoliate, and use a lot of lotion. Of course, none of these friendly suggestions helped my skin condition. I would explain this, only to be told I just wasn't doing enough. Yesterday, I saw a dermatologist for the first time and was diagnosed. I was prescribed a lotion that will treat my condition. I realize it's not a cure, but hope is present concerning this condition. Thank you for your website! It too has given me hope.

Marsha Meyer

Greensboro, North Carolina

ICTHY

How can I explain thee
Ichthy in the fall?
How can I describe
The misery of your call?
Can one who's never felt
Or experienced your drive
To rip off the crusty shell,
To feel truly-truly alive,
Even begin to comprehend
Or to appreciate the want,
To find a way to end
Your ability to daunt.
I can't, nor should I try.
There's no dialect
That can apply.
What you feel is what you get.

James Huetson 11-19-11



NEW & IMPROVED!

**30% Urea
Moisturizer**
for FIRST Members

Hundreds of FIRST members use Dermal Therapy's odor-free, non-greasy moisturizers to improve skin and scalp instead of expensive prescription products.

MONEY BACK GUARANTEE

Ask for FIRST Members' SPECIAL DISCOUNT!

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To order call: **(800) 668-8000** or visit

www.dermaltherapy.com

YOGA FOR SKIN

by Terry Melton

Yoga is widely recognized as a practice that will build muscle, increase joint flexibility, improve core strength, relax the overactive mind, and release tension. It does all these things, but did you know it can be good for your skin?

My 57 years of EHK had made me stiffer, sorer, and more tentative in my daily life as I battled dryness, particularly during the arid winters of Pennsylvania. My body had learned new ways to guard flexural and flat areas when I was sitting, walking, and working in the garden. Too many years of holding my body in this way had led to an inability to stretch my arms fully over my head, hold my shoulders back, stand tall, and walk freely. And it wasn't clear whether my skin had "shrunk" or whether I was just stiff. This feedback loop of stiffness from my bones, joints, and skin sometimes made it just hurt too much to do anything besides sit at my desk or on the couch, and I was having a lot of aching in my body nearly all the time. I was moving and feeling like an old woman and knew I had to do something about it.

I decided to try classes from highly respected *Iyengar* yoga teachers at a local studio. *Iyengar* yoga is practiced with a series of thoughtful and shortly-held poses, or "*asanas*," in a climate-controlled room on a padded mat, and also uses props such as bricks, straps, and blankets. On the first day, I quickly found that my flexibility was poor, and that even standing up straight in the "mountain pose" was painful. And the poses hurt my skin, too, because of rubbing, pressure, and moving.

But I survived, and I will tell you how you, too, can do it. I'm beginning my fourth year as a yoga practitioner, and have learned a lot about how a skin condition can influence a yoga practice, the challenges it presents, and some tricks for feeling good in class.

First of all, choose a "gentle" class level. Bathe and lather up generously with your favorite lotion or cream right before you go to class. Wear close-fitting stretchy clothes that minimize rubbing, such as snug soft yoga pants and a top where you can go braless. Avoid clothing with seams that rub your skin and all but the softest and coolest fabrics. Make sure the studio is not too hot: ask your teacher if you can have a fan on you, or even bring your own. Buy your

own extra thick yoga mat from an online supplier like www.huggermugger.com; this extra padding can make all the difference to scaly sore hips, shoulders, and knees. Most importantly, I take 2 or 3 ibuprofen at least an hour before class and make sure I have eaten a hearty snack like peanut butter, an egg, or cheese. Explain your limitations to your teacher, especially which poses hurt you. He or she will help you find an alternative to the painful *asanas*, or help you work with additional padding. After a couple of years of tinkering with what worked for me, I enjoy nearly every class and do nearly every pose.

I'd never liked sports before because I would get too hot and uncomfortable, and my physical activities for many years were limited to walking and gardening. But because yoga is climate-controlled, moves slowly, improves core strength and flexibility, reduces body aches and pains, and lowers mental stress, it could be helpful for some people with chronic skin conditions. My skin is more supple (because it has now stretched!) and I can remember that wonderful childhood flexibility. Even better, the rest of my body has benefited too and I feel stronger and less achy. You should see me in Shoulder Stand and Head Stand! If you need any information, help, or encouragement, feel free to email me at twm107@mitotyping.com.

*FIRST strives to provide as much information as possible to our members. **Ichthyosis Focus** would love to include an exercise and fitness column in each issue. If you have an activity that works for you in the management of your health, for example, weight lifting or jazzercise, we would love to hear from you and offer your routine to our membership. Please contact Lisa Breuning, Public Relations Coordinator at lbreuning@firstskinfoundation.org or call 800.545.3286 to submit an article.*

Executive Director's Report

Dear Members and Friends of FIRST,

Happy New Year to you and your families! I hope 2012 brings good things for you. FIRST is poised to have a great year too. We recently gathered in Philadelphia for our biennial Board of Directors retreat to prioritize our plans for the next three years. At the top of our list is the maintenance and strengthening of our Research Program, along with our Ambassador Program, and use of technology and physician development. I look forward to reporting updates on the initiatives plus much more in coming issues of the newsletter.

I hope everyone responded to our annual end-of-year mailing, with even the smallest gift. We were very grateful to **Lauren and Matt Kocher** for allowing us to feature their son **Calvin** in our letter. Too many families can relate to their experience and I know it touched the heart of our members and friends.

The stars were aligned in the right place in early December for FIRST. A spot became available on the CBS Times Square Jumbotron holiday production loop, and FIRST was invited to run a 15-second advertisement from December 15 through January 15. The spot ran 18 times per day for 32 days and was viewed by more than 1 million people each day. What a wonderful opportunity for FIRST!

Our 17th biennial family conference will soon be here! Denver promises to be a great location. We look forward to meeting new families who have never attended a conference before, past attendees, plus more of our west coast members this year! Registration is now open, so please visit our website or complete the form on pages 7 to 10. The **deadline to register is June 1**. Keep in mind that FIRST also has limited funding for conference scholarships for those who may have difficulty in affording the registration fees and hotel costs.

You can also look forward to more **FIRST to Know** conference calls in the next few months. It's a great way to connect with other members about a specific topic simply by calling into a dedicated conference line. See our website for upcoming calls, potential topics include workplace issues and aging skin. If you have any idea for the **FIRST to Know** conference call, send us an email. We'd love to hear from you!

Warmest wishes for a wonderful winter season—and, as always, call or email me anytime to check in. I'd love to hear from you!



Jean Pickford, Executive Director



Jean Pickford, Executive Director

Coalition of Skin Disease Leaders meet in Washington, DC

FIRST's Executive Director, Jean Pickford, and other members of the Coalition of Skin Diseases met with Dr. Stephen Katz, Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), at the National Institutes of Health (NIH) campus to learn about their research agenda for 2012.



Jean Pickford, bottom row center, with CSD members

It is with great sadness that FIRST announces the passing of a long-time member and staunch advocate. Patti Steinitz, mother of Hunter Steinitz, passed away in October after a long and courageous battle with pancreatic cancer. Patti was tireless in her support of FIRST and ichthyosis-related issues. We offer our sincerest condolences to the entire Steinitz family.



Patti with Hunter

Spotlight On ... Brittany Alba

It's Complicated

FIRST member, **Brittany Alba** was featured in the Summer 2011 issue of the *Journal of Dermatology for Physician Assistants*. The following is reprinted with permission of JDPA.



Brittany as a toddler

I define myself by my loving family, lasting friendships and passion for helping children with special medical conditions NOT by the only complicated part about me: my medical history. I rarely discuss the fact that for as long as I can remember, my body has always given me a bit of a hard time. Consider this perspective a reflective 22-year recap of what it is like to 'wear' two chronic incurable conditions

daily. My brother sent me the song, Shine On by Eric Bibb, which I adore. The following lyrics summarize how I currently feel about life with these conditions,

"I know what you've been through, I see, but it's time to leave it behind and let it be. Hard earned wisdom is something you can't buy, it's the wings of experience that make you fly high...Baby, you've got to shine on, it's what you were born to do."

My story starts on June 19, 1988, Father's Day

I was born 6 weeks premature with one very noticeable difference: bright red skin. At the time of my birth, doctors were uncertain of the cause and condition that affected my skin. They sent me home to be cared for by my loving, attentive family. When I was four months old my delicate skin developed a staph infection. I was admitted to the Children's Hospital of Philadelphia where doctors still did not have an explanation for my rare condition. No one would have thought a clue to this complicated medical puzzle would arrive with my brother, Matthew. He literally was a "Gift of God" born 15 months later than myself, a perfectly healthy 10 lb. baby boy with one visible difference; his skin. Doctors now knew our condition was genetic.

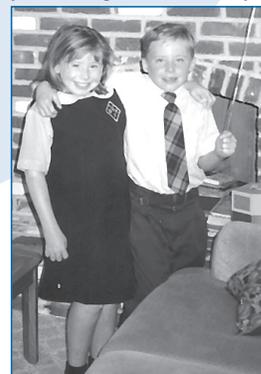
At Yale, we were finally diagnosed with CIE ichthyosis

I am affected with "50 cents" worth of CIE ichthyosis (congenital ichthyosiform erythroderma) while my brother has a "nickel's worth." CIE is a rare genetic recessive skin disorder characterized by redness, minor scaling, and heat intolerance. At the age of two, my finger swelled and my mother took me to the pediatrician; tests revealed I had juvenile rheumatoid arthritis (JRA). My JRA would hurt during intervals of medication, so daily I was more consumed with managing that pain rather than my skin.

As a child I did not comprehend how much care my skin required because my mother seemed to effortlessly manage it. She took care of every doctor's visit, bath, lotion application, scalp treatment, and vacuum clean up that my condition required for thirteen-plus years. Her daily dose of unconditional love was, and still is, the best medicine.

The unexpected allergic reactions

Each year around the holidays I always got very ill. My skin would turn the brightest shade of red, large scales fell off my body because my skin was reproducing at such a rapid rate, and I stayed under three blankets at all times. While walking around a Christmas tree farm with my mother and grandmother, hives spread to my face. It was then clear I was allergic to pine trees. My whole family invested in fake trees and I have been healthy during the holidays ever since. While that allergy was quickly identified, others have plagued me every two years, evidenced by horrific allergic reactions that happen when I least expect them. In high school, right before my uncle's wedding, I took Sudafed for a cold, and forty-five minutes later I had a fever, was vomiting, and my skin turned two shades from purple. I am sure that all of the guests were wondering if I had been burned, but only one guest (who had too much to drink) actually asked me about my appearance.



Brittany and Matt

Treatments

As a child I cried any time my parents applied a lotion with acid, so it somehow ended up that my brother and I coated ourselves in plain old Vaseline® petroleum jelly. Today, I prefer the Walgreens petroleum jelly with shea butter. I shampoo with T-Sal twice a week to reduce the buildup in my scalp. On my palms and feet I use Hydro 35 foam. To calm allergic reactions, I recently found that a hydrocortisone compound works if applied daily for a week or two. When I tire of spending so much time to apply topical treatments, I turn to Accutane. For years, my parents resisted allowing me to try the medication because they were so fearful of all the side effects. I completely understand the dangers that come along with Accutane, but it cleared my skin for high school dances, proms and

Continued on page 6

UFIRST SCHOLARS NOW ACCEPTING APPLICATIONS



The UFIRST SCHOLARS Program, established in 2010 by a seed gift from Valerie & David Scholl is now accepting applications for 2012. The Scholl's are grandparents to an affected granddaughter who wanted to provide an opportunity for affected students to advance their post-secondary education in partnership with FIRST. Their inspiration is to provide the opportunity for students affected with a form of ichthyosis or related skin type to achieve their highest educational potential. Other donors are encouraged to contribute to the fund to help grow its capacity.

Scholarship Selection Criteria

A committee of volunteers will evaluate each scholarship application based on the following criteria:

1. Demonstrated academic ability
2. A written essay (topics vary each year)
3. Extracurricular activities and community activities
4. Financial need
5. Recommendation letters
6. FIRST activities

How to Apply

- The 2012 application will be available online on **Tuesday, February 1st**.
- Completed applications will be **due no later than March 31**. Faxes will not be accepted.
- Scholarship winners will be notified in May.
- Eligible candidates are individuals affected with some form of ichthyosis or a related skin type, seeking post-secondary education at an accredited university, college, junior college, or trade school.
- Qualified applicants may apply throughout the duration of their education career; however, a new application is required every year and proven success in previous year(s) will be required to be considered for future funding.
- Funds can be used either for school tuition and/or fees. All monies for tuition and/or fees are paid directly to the institution.
- Participation in FIRST activities, communication with the national office, and advocating in your local community strengthens your application.

SPOTLIGHT ON...BRITTANY ALBA *Continued from page 5*

summer trips. Speaking of trips, when I studied abroad in England during my junior year of college the water completely cleared up my skin.

Turning the pain into a passion

I do have painful memories of what it feels like to be "different." Classmates did not want to hold my hand during circle time, customers in the grocery store stared, comments of "look at that girl" floated out from the crowd in Disney World, and most recently a guy at the bar asked me if I was holding a piece of sandpaper when I shook his hand. When moments like these happen, I smile, take a deep breath, and remove myself from the situation. I would rather not waste my time or energy on ignorant people. Instead I have discovered my passion lies in helping children who are also affected with special medical conditions. One day I hope to facilitate programs for children with these medical conditions and to organize discussions about how their conditions make them feel. For many years I internalized the painful comments and "covered up" my conditions to appear as normal as possible. I am not convinced this was the best way to deal with the psychological effects of "wearing" two chronic, incurable conditions because when I initially meet people they can barely tell anything is wrong with my skin. However, I'm currently struggling with the elephant in the room conundrum of when to address and acknowledge the only visibly complicated part about me, my medical history

Brittany Alba is twenty-three years old and lives in Worcester, Pennsylvania. Last May Brittany graduated cum laude from the Catholic University of America with a Bachelor of Arts in Media Studies. She is currently a project associate at Dunleavy and Associates, a consulting firm that provides services for charitable organizations in the Philadelphia region. Through this work Brittany is able to help advocate for the missions of organizations that serve children with complicated medical conditions. She is involved with FIRST, Vibrant Lives (the patient support group for Enbrel), and Gywnedd Mercy Academy High School.

Editors Note: Some minor changes, not affecting content were made to this article for space constraints.



2012 NATIONAL FAMILY CONFERENCE

SMILE HIGH! DENVER, COLORADO



17th Biennial Conference Registration Form

Complete this form and return it to the national office or register online at www.firstskinfoundation.org. The conference registration form and payment must be submitted to the national office by **June 1st**. Registrations without a completed form and payment will not be considered complete. *Please note: Registration does not include your hotel room. Accommodations at the Renaissance Denver Hotel must be made separately.* Cancellations received prior to June 1st will be refunded less a \$25 per person administrative fee. **No refunds issued after June 1st.**

Clinical Screening Appointments

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 22. Participation is voluntary. Sign-up is required prior to the conference by completing the Clinical Screening section on this Registration Form.

Kids' Camp

Social programs for all affected children and their siblings are an integral part of the conference. Children in the kids' camp (ages 1–12) will enjoy activities, entertainment, educational programs and refreshments while their parents participate in conference workshops and sessions. Be sure to indicate if your child will be attending the kids' camp on pages 3 and 4. A licensed child care company will be hired to provide this service. A nominal fee is required so FIRST can be sure who is planning to use this service and the appropriate number of childcare providers will be hired for the safety of your children.

Ichthyosis Genetics Study Update

At the 2010 family conference in Orlando, Dr. Keith Choate and his team from Yale University enrolled over sixty families in a gene discovery project to identify the genetic causes of ichthyosis. What a success! This year, the Yale team will be enrolling additional families in this study and following up with those already enrolled. People with ichthyosis who have never had genetic testing and those who have had genetic testing without identification of a disease causing mutation are invited to participate. Previous participants will be asked to meet with the Yale team and to provide additional clinical information.



Come join us at our signature event. Hosted every two years, our national conference promises to provide personal and family support, medical updates, research opportunities, treatment advice, one-on-one conversations with medical experts, plus much more!

Program at a glance...

Friday, June 22	
9:00-11:00 am	Registration
9:00- 6:00 pm	Clinical Screening
11:00-12:00 pm	Opening/Welcome
12:00-1:00 pm	Lunch
1:00-4:00 pm	Kids' Camp (ages 1– 12)
1:00-2:30 pm	Workshop 1 (teens/adults)
2:30-4:00 pm	Workshop 2 (teens/adults)

Saturday, June 23	
7:00-8:45 am	Breakfast
8:45-12:00 pm	Kids' Camp (ages 1– 12)
9:00-10:00 am	Panel 1 Discussion
10:00-12:00 pm	Teens Group
10:00-12:00 pm	Workshop 3
12:00-1:00 pm	Lunch
1:00-5:30 pm	Kids' Camp (ages 1– 12)
1:00-5:30 pm	Teens Offsite Field Trip
1:00-2:45 pm	Panel 2 Discussion
3:00-5:30 pm	Group Networking
6:00-10:00 pm	Dinner/Dance

Sunday, June 24	
7:00-8:45 am	Breakfast
8:45-12:00 pm	Kids' Camp (ages 1– 12)
9:00-11:30 am	Workshop 4 (Focus groups)
11:30-12:00 pm	Closing

www.firstskinfoundation.org

It's Time to Smile High in the Mile High City of Denver with FIRST! Can't wait to see you!

Hotel Accommodations

The discounted room rate negotiated with the hotel is \$119 + tax flat rate. This rate is available from June 16 through June 26. All attendees must make their own reservations at the Renaissance Denver Hotel by calling toll-free 1.888.228.9290 or going to FIRST's website, www.firstskinfoundation.org and clicking the link for our direct online hotel reservation page. To receive the discounted room rate, you must identify our group name as "Foundation for Ichthyosis." *Reservations must be received on or before 5 pm on May 22, 2012 to be guaranteed a room in the room block.* All reservations must be accompanied by a first night room deposit guaranteed with a major credit card. Other hotel rules and restrictions may apply. For questions, contact the hotel directly at 303.399.7500.

Driving Directions & Free Parking

Contact the Renaissance Denver Hotel at 303.399.7500 or visit their website at www.renaissancedenver.com and click on Maps & Transportation. Their street address is 3801 Quebec Street, Denver, CO 80207. Parking will be complimentary for all conference attendees. When making your room reservation be sure to mention that you are with the Foundation for Ichthyosis group. You will use your room key to get in and out of the lot and not be charged.

Meals & Dress Code

The conference registration fee includes lunch on Friday, June 22; breakfast, lunch and dinner on Saturday, June 23; and breakfast and lunch on Sunday, June 24. All registrants are on their own for dinner on Friday evening. Conference attire is casual, including Saturday evening's dinner & family social.

Elitch Gardens Discount Tickets

FIRST has negotiated discounted tickets for nearby Elitch Gardens Theme & Water Park located in downtown Denver, with over 60 rides and attractions, live entertainment and plenty of shopping and dining to keep you busy for hours! The discounted ticket price is \$22.99 per person (children 3 years and younger are free)! If you are interested in visiting the park while you are in Denver, tickets can be purchased on page 4 of the registration form and will be distributed to you at registration. Visit www.ElitchGardens.com for additional info or phone 303.595.4FUN.

Complimentary Area Shuttle

The hotel offers a complimentary shuttle to Quebec Square and the Northfield Shopping Center. Area attractions and shuttle service details are available on our website at www.firstskinfoundation.org.

Airport & Shuttle Information

Denver International Airport (DEN) is the major airport for the Denver area. The Renaissance Denver Hotel offers a complimentary shuttle to and from the airport. From the airport to the hotel, go to Baggage Claim Level 5—Westside Doors 506/Eastside Doors 511. Proceed to the third island where you will see "Hotel Shuttle" signage. When departing the hotel to return to the airport, it is recommended to make a reservation at the front desk. More detailed information is available on the Complimentary Shuttle Service Flyer on our website.

Air Charity Network

You may be eligible for free transportation using the Air Charity Network. To find out if you are eligible for free transportation to and from the conference, please contact Air Charity Network directly at 817.621.7177.

Teen Field Trip

Teenagers, ages 13-17, will participate in a chaperoned offsite field trip to Denver's Museum of Nature & Science/Planetarium/IMAX Theatre (www.dmns.org) on Saturday afternoon. Be sure to check the box on page 4 if you want to participate.

Grand Rounds

FIRST will be sponsoring Dermatology Grand Rounds at Children's Hospital of Colorado on Thursday, June 21 (the day before the conference). The purpose is to teach doctors to recognize the medical signs and symptoms of the ichthyoses and understand the common psychological aspects. Doctors attending will receive Continuing Medical Education (CME) credits. A handful of individuals affected with different types of ichthyosis will be asked to participate. *If selected*, you (or you and your affected child) will sit in an exam room. Medical students/doctors from the area will come to observe your symptoms and ask questions about how the condition affects you and your daily life. It is an incredible opportunity for doctors and future doctors to see a variety of the ichthyoses in one setting and learn firsthand. If you are interested in being considered as a patient volunteer for these Grand Rounds, please check the box on page 4. The number of patients is limited, so only a few will be selected. FIRST will provide accommodations for a Thursday night stay if you are selected to participate. You will receive an email from the FIRST office if selected.

Conference Registration Deadline—June 1, 2012
Register Online at www.firstskinfoundation.org
Hotel Room Reservation Deadline—May 22, 2012

Contact Information

First Name: _____ Last Name: _____

Address: _____

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

Phone: _____ Cell Phone: _____

Email: _____

I give permission to FIRST to publish the names, contact information and type of ichthyosis in the conference roster, which will be distributed to all attendees.



Registrant Information (must include all names, ages, and type of ichthyosis)

First Name	Last Name	Age	Affected by Ichthyosis	Kids Camp Participant	T-Shirt Size circle size
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	YS YM YL S M L XL XXL
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	YS YM YL S M L XL XXL
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	YS YM YL S M L XL XXL
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	YS YM YL S M L XL XXL
_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>	YS YM YL S M L XL XXL

Please indicate which type of ichthyosis affects your family: _____

For the safety of your children, the appropriate number of caregivers will be hired based upon the number of children signed up for the kids' camp. Therefore a nominal fee will be required to ensure we have an accurate number of participants.

Clinical Screening Appointments

Meet privately 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 on Friday, June 22, from 9:00 am - 6:00 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
_____	_____	_____	_____
_____	_____	_____	_____

If you are planning to visit Elich Gardens on Friday night, please check this box so we do not schedule your appointment after 3 pm.

FIRST Idols Talent Sign-Up (ages 5–13)

Back for its third year! This is a popular and heart-warming event for our kids to showcase their talents to our audience. Performances will take place on Saturday evening after dinner. A CD player and microphone will be provided. Please bring your own music, costume, props, etc. All performances will be limited to a maximum of 2 minutes.

Child's Name: _____ Age: _____ Grade: _____

Type/Description of Act: _____

Teen Field Trip Permission & Release

An organized trip has been arranged for teenagers (ages 13–17) to visit the Denver Museum of Science & Nature/ Planetarium/IMAX Theatre from 1:00–5:30 pm on Saturday, June 23. Caregivers from Corporate Kids Events will chaperone your children and they will travel to/from the museum by shuttle bus. I give permission for my son/daughter to attend this trip and understand FIRST is not liable for any incident or injury while my son/daughter is not in my care.

Teen(s) Name _____

Signature of Parent/Guardian: _____ Date: _____

Photo & Video Permission & Release

I hereby give my permission to FIRST 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 2012 Family conference in which I or my family may be a part.

Signature: _____ Date: _____

Payment

Registration

1. Adults (Ages 13 and up) _____ x \$ 215.00 pp USD = \$ _____

2. Children (Ages 1– 12) _____ x \$ 90.00 pp USD = \$ _____

Optional Add-Ons

1. Kids Camp (Ages 1–12) _____ x \$ 10.00 pp USD = \$ _____

2. Teen Field Trip (Ages 13–17) _____ x \$ 15.00 pp USD = \$ _____

3. Elitch Gardens Discount Tickets* (3 & under free) _____ x \$ 22.99 = \$ _____

4. Donation to support the conference scholarship fund = \$ _____

Total Payment \$ _____



Method of Payment

Check, payable to FIRST (in US Funds) Credit Card: Visa, Mastercard, Discover or Amex

Credit Card # _____ Expiration Date _____ Authorized Signature: _____

Grand Rounds

Please check here if you are interested in participating in the Grand Rounds on Thursday, June 21. The number of patients is limited, so only a few will be selected. See more details on page 2.

*You will receive your Elitch Gardens tickets with your registration packets. Arrangements are on your own and transportation is not provided.

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.

Signature _____ Name _____ Date _____

News & Notes ...

Camp Discovery 2012

In 1993, during his presidency, Dr. Mark Dahl founded Camp Discovery with the support of the American Academy of Dermatology (Academy), offering one week of camp to about 50 kids at Camp Knutson in Crosslake, Minnesota. Little did we know how much Camp would grow over the next 19 years. Camp Horizon began in 1995, Teen Camp followed in 1998, and last year we introduced Camp Reflection in Washington State.

This year, the Academy is proud to offer six camping sessions for young people with chronic skin conditions who are between the ages of 8 and 16. Under the expert care of dermatologists and nurses, Camp Discovery gives campers the opportunity to spend a week with other young people with skin conditions, while participating in everything from swimming and fishing to horseback riding to lots of camp games and just plain fun!

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



2012 Dates:

- June 24 – 29, Camp Little Pine in Crosslake, Minnesota (ages 10 – 14)
- June 25 – 29, Camp Reflection in Carnation, Washington (ages 8 – 16)
- July 8 – 13, Camp Big Trout in Crosslake, Minnesota (ages 14 – 16)
- August 5 – 10, Camp Dermadillo, Burton, Texas (ages 9 – 15)
- August 11 – 18, Camp Horizon, Millville, Pennsylvania (ages 8 – 13)
- August 12 – 17, Camp Liberty in Hebron, Connecticut (ages 8-16)

For more information about attending or volunteering, please visit their website at campdiscovery.org or contact Janine Mueller at 847.240.1737 or jmueller@aad.org.

Girls Scouts Lend a Hand for FIRST

FIRST's Board of Directors secretary, **Janet McCoy**, is the mother of 11-year-old **Maggie** who is affected with CIE. Maggie's Girl Scout Troop was interested in performing a community-service project and turned to FIRST. As a result of the marketing initiatives in our latest strategic plan, the Foundation recently re-created many of our brochures and literature. In an effort to cut down on expense when re-creating our Teacher's Guide, only the cover was reprinted. This meant that the old covers needed to be replaced with the new covers. Members of Maggie's Girl Scout Troop met at the McCoy home in Lititz, Pennsylvania during October, and the girls spent an evening replacing the brochure covers. Many thanks to Janet and Maggie McCoy, and the girls of Troop 70013 for their help with this project!

Camp Wonder

Summer is right around the corner and with that comes **CAMP WONDER 2012**.



THE CHILDREN'S SKIN DISEASE FOUNDATION is

now accepting applications for **CAMP WONDER 2012**, an incredible experience being offered to children with skin disease, ages 6-16, at no cost to the children or their families. This week offers the opportunity to participate in exciting activities, form lasting friendships, and ultimately develop a stronger sense of self-esteem while under the careful and loving supervision of an excellent medical staff and counselors.

The session will run from Sunday, June 24 to Friday, June 29, 2012 at Camp Arroyo in Livermore, California (staff arrives one day early for orientation)

For an application or more information, please contact Christine Tenconi, 925.351.7225 or ctenconi@hotmail.com.

Applications are accepted on a first come basis.



Maggie (2nd from right) with members of her Girl Scout Troop.

News & Notes ...

GALDERMA IS CONDUCTING A STUDY FOR A NEW TOPICAL MEDICINE

Exploratory Study to Assess the Safety and Efficacy of CD5789 in Subjects with Hereditary Palmoplantar Keratodermas

Galderma is sponsoring a clinical study to investigate a new topical medication for patients with hereditary palmoplantar keratodermas (thickening of the palms and soles) at Northwestern University in Chicago, Illinois, with an expert in the ichthyoses. This study is open to those meeting the criteria listed below, which would include those who have palmoplantar keratoderma in association with ichthyosis. Many of those affected with ichthyosis have thickening on their feet. This new cream might help with the thickening on the feet (which is what is being studied), and perhaps in the future on the hands and elsewhere. Another study will follow specifically to try the cream for lamellar ichthyosis, but the individuals with lamellar ichthyosis can participate in both studies per Galderma. The company will compensate anyone, in addition to the chance to try the new cream. One thing to be aware of: if you are taking an oral retinoid, you cannot be on the study and, in fact, you would have to be off of it for 6 months to be eligible. During the first month or two of the study, only adult males and women who are not able to have children right now are eligible, but if you are a woman of childbearing age and interested, please let the investigators know: it is likely that the study for the feet will be extended to all adult women shortly, and all adult women will be eligible for the trial of lamellar ichthyosis.



Amy Paller

We are looking for:

- Females of non-childbearing potential or males between 18 and 65 years of age with a diagnosis of hereditary palmoplantar keratoderma; must be able to be in the Chicag area for 6-8 weeks for cream application and weekly visits for 6 weeks

Study Involves:

- Weekday application of study medication for 6 weeks by a home health agency
- Weekly clinic visits for 6 weeks
- Laboratory and ECG assessments

If you decide to take part you will receive:

- Study related medical evaluation, including physical exam and test results
- Study medication at no cost
- Financial compensation for qualified participants

For additional information, contact the site clinical coordinator:

- Northwestern University: 312.695.0287
- Children's Memorial Hospital: 312.227.6484

Principal Investigator:

- Amy S. Paller, MD- Northwestern University, Chicago, Illinois

For information about additional study sites, contact FIRST at 800.545.3286.

2012 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 2012 National Family Conference in Denver, Colorado on June 22-24. The Family Conference Scholarship Fund, funded by the Jean Giroux Charitable Trust, will provide funds for registration 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 adult or child being affected.
- Scholarships are available for hotel accommodations for three nights

Eligibility for Applicants

- Each applicant must be registered in our database and have made a donation to the Foundation.
- 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 for their accommodations at the conference, either on the last day or by mail to them immediately after the event. Registration fees will be waived when you submit your registration form.
- 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, 2012**. They can be faxed to 215.997.9403 or mailed to 2616 N. Broad Street, Colmar, PA 18915, ATTN: Family Conference Scholarship Fund.
- Applications must be submitted with:
 1. Confirmation of hotel reservation
 2. Copy of most recent IRS Form 1040 All applications will be strictly confidential.

Grassroots Fundraising

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

Picklefest in Pennsylvania

In October of 2009, the friends and family of **Paul Pickles**, who was affected with an unknown type of ichthyosis, planned a fundraiser to help him with medical expenses from Hodgkins Lymphoma. Sadly, Paul passed away at age 48, just days before the event. His family and friends decided to go ahead with the event and donate the proceeds to FIRST in Paul's name. More than \$6,000 was raised at the event, and with a match from Merck, the total for FIRST was over \$13,000!

Picklefest 2 was held in Paul's memory on October 15th. Paul's friends, Andrew and Peggy Kerr of Souderton, Pennsylvania, planned and organized this year's festivities. Picklefest 2, attended by 125 people, was a fantastic success! It was held at Camp Sumney in Sumneytown and featured the band, Los Manatees, and DJ Bob Ralston donated his time. The



Kerrs secured a multitude of donations for gift baskets that were offered in raffles and the silent auction. In addition to the band, friends, and fun, more than \$5,000 was raised for FIRST. The Foundation is truly grateful to Drew and Peggy Kerr, Carol Estes, and all of Paul's family and friends for all of their hard work on behalf of FIRST.



Drew and Peggy Kerr



Paul Pickles

Paul's sister, Lois Pettigrew, enjoys the festivities.

The Pickles family wishes to extend sincere thanks to Will Juneau, Charles and Jennifer Juneau, Tom and Lisa Cinciripini, Zach Devine, Kara Luther, Mark Black, Becky White, Jeanne Helmar, Ginny Pickles, and Bob and Carrie McCarthy. This event could not have happened without their behind the scenes support.

Softball Tournament in South Dakota

Chad and Michelle Iott of Flandreau, South Dakota are the parents of 10-year-old **Rylee** who is affected with CIE. In September, the Iott's hosted their 3rd annual co-ed softball tournament. Six softball teams from the area participated in a day filled with fun, food, and friendly competition. After the tournament, the 80 participants enjoyed grilled ribs, chicken, and hot dogs, grilled by a family friend. As family and friends gathered to eat, a free-will-donation bucket was placed on the serving line. Additional festivities of the day included a campfire, horseshoes, and bean bag toss. More than \$1,600 was raised to support the efforts of FIRST.



Golf Outing in New York

Chris and Michelle Dugan hosted their 5th Annual Drive for a Cure Golf Tournament at the Brockport Country Club in Brockport, New York. They are the aunt and uncle of six-year-old **Mattingly**, who is affected with CIE. More than \$3,100 was raised for FIRST.

Candles for a Cause

FIRST member, **Kristi Mack** has created a wonderful online store called *Candles for a Cause*. Please visit Kristi's store on facebook at <https://www.facebook.com/#!/CandlesforaCause>. Kristi is generously donating \$2 from each sale directly to FIRST. Her ultimate goal is to sell 500,000 candles, which would be \$1,000,000 for FIRST! Let's help Kristi reach her goal.



Grassroots Fundraising

South Dakota Pumpkin Paint and Bake Sale



Participants hard at work

The *Iott Family* has once again organized their annual Pumpkin Paint and Bake Sale in honor of 10-year-old *Rylee Lynn Iott*, who is affected with CIE. With 125 people joining in at the Flandreau Aquatic Center, approximately 60 painted pumpkins and many purchased the delicious baked goods available. The day was fun for all and raised more than \$1,600 for FIRST.



Michelle Iott (back row) with participants and their pumpkins.



Rylee helps load the pumpkins

Denim Day in Massachusetts

Marcia Richmond is an employee at COCC a technology services company in Avon, Connecticut. COCC allows employees to submit the name of a favorite charity. Once a month, an organization is randomly selected to be the recipient of a Denim Day donation. On the first Friday of the month, employees are able to wear denim to work by making a minimum donation of \$5 to support the chosen organization. Marcia states her commitment to FIRST, "I have always admired what FIRST continues to accomplish since their inception. As a child with ichthyosis, my family did not have the support network that exists today. You provide such an important point of contact for families that need the initial/ongoing support when faced with a child born with a form of ichthyosis. My ongoing mission has been to continue to share what FIRST does." The generous amount donated by the employees of COCC was \$605.00!

Yankee Doodle Homecoming in Massachusetts

This year's Yankee Doodle Homecoming, an annual town celebration in Billerica, Massachusetts, welcomed *Nancy Hamill* and her beautifully hand-sewn items, to the town center's weekend craft fair. Nancy's wares included pillow case sets, holiday aprons, fleece wraps, and beautiful storybook quilts. Nancy's efforts, with help from her son John, daughter-in-law Shannon, and 7-year-old granddaughter *Lauren* who is affected with Harlequin ichthyosis, paid off after shining a big spot light on ichthyosis and raising almost \$800 for FIRST. The event was held September 16-17 and, as orders continue to pile in, seems to have the potential for an annual event. Get sewing Nancy and see you next year. Nancy is to be commended for her year-round efforts for FIRST. She is a fantastic champion for ichthyosis and a wonderful grandmother to Lauren.



Clockwise from left: Shannon, John, Nancy and Lauren Hamill



Nancy Hamill and granddaughter, Lauren at their table for FIRST

The community really came out to show their support to the Hamill family, and they were able to answer many questions about FIRST and ichthyosis. In addition to the craft fair, Lauren and Shannon walked for Lauren's school in the morning parade and attended the evening firework celebration, which included live music and dancing.



Dawn and Joe Johnson

Monster Dash/Fun Run in Texas

Dawn and Joe Johnson, long-time members and committed volunteers for FIRST, once again held their annual Monster Dash/Fun Run at Friendswood High School in Friendswood, Texas. Joe's and Dawn's daughter, 13-year-old *Jordan*, is affected with EHK. On a beautiful Saturday in October, friends, family, and newcomers came out to support Joe, Dawn, and Jordan, help raise funds for FIRST, and enjoy the festivities of the day. The event was highlighted with a special appearance by Miss Texas USA,



Jordan Johnson (right) with Gina Concialdi

Brittany Booker. In addition, the Concialdi family, who have 11-year-old *Gina*, affected with CIE, traveled to Friendswood from their home in Houston for the day to enjoy the event. This year, 194 runners participated in the event and were given a Monster Dash t-shirt. There was a race for children, and walks/runs for adults. Prizes were awarded for 1st, 2nd, and 3rd places in each category. Every participant left the day with a smile! The Johnson family's efforts raised more than \$16,000 for FIRST!



The race gets underway

Art & Crafts Sales in Maine and Online

Patti Sundik, grandmother of 6-year-old *Evan Mayone* who is affected with EHK, operates an online shop on etsy.com. In addition, Patti participated in Art in the Park in Fort Williams, Maine over Labor Day Weekend.

On her etsy.com shop, Patti sells posters, photographs, and necklaces. Patti sends 10% of all of her online sales to FIRST. In addition, Patti features specific items throughout the year and designates 100% of her proceeds to FIRST for those items. One poster, in particular, is close to her heart. Evan drew a picture and Patti worked with winkflash.com to have it made into a poster. Winkflash generously donated more than \$550.00 of posters for Patti to sell in her shop.

The Art in the Park event took place over Labor Day Weekend in Fort Williams, Maine. Patti set up a table to display her wares and had help from her grandchildren, Evan and his older brother and sister, Harrison and Sophia. In addition to Patti's items, Sophia and her friend made butterfly necklaces and sold them at the family booth. Patti's grandchildren were great ambassadors for FIRST, educating art fair visitors about FIRST and EHK and handling the sales and promotions throughout the day.

Please visit Patti's etsy shop at www.lovesparis.etsy.com and help her raise funds for EHK research.



Harrison (left) with younger brother, Evan



Sophia (right) with her friend Abby, selling their necklaces



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SAVE THE DATES!

Last year, as part of FIRST's Ichthyosis Awareness Month festivities, FIRST sponsored an evening at the Philadelphia Phillies game. It was so well-received, that we are expanding our efforts and sponsoring **FIRST Night at the Ballpark in Philadelphia and New York!**



MONDAY, MAY 7, 2012

The Philadelphia Phillies will take on the New York Mets at Citizens Bank Park in Philadelphia, PA.

THURSDAY, MAY 30, 2012

The New York Mets will host the Philadelphia Phillies at Citifield, in New York, New York.



If you would like additional information about these events, please contact the FIRST office at 215.997.9400 or toll-free at 800.545.3286.