



Driven by a Passion for Patients

Brittany G. Craiglow, MD
 Keith A. Choate, MD, PhD
 Leonard M. Milstone, MD
 Christopher Bunick, MD, PhD

By Maureen Neville

As many of you know, FIRST is closely affiliated with a team of unique medical professionals, from universities and hospitals around the world, who are dedicated to the research of ichthyosis.

Continued on page 8



Inside This Issue:

Medically Speaking: Topical Tazarotene for the Treatment of Ectropion in Ichthyosis	6
You Are Not Alone	7
FIRST 18th Biennial Conference	11

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New Plans, New Faces, a Renewed Hope for the Year Ahead...



**Jean R. Pickford,
Executive Director**

Our winter newsletter, kicking off 2014, is not only a tribute to the excitement and successes of 2013, but an open-armed welcome to new plans, new faces, and a renewed hope for the year ahead. You'll learn about our day spent with the extraordinary doctors at Yale University, solely focused on treating ichthyosis patients and ichthyosis research. Plus there's so much to celebrate! In 2013, we were awarded the National Health Council Standards of Excellence, broke our record for grassroots fundraising, and launched three new (and very active!) groups on Facebook. And if you haven't done so already, you'll have the opportunity to explore the itinerary for our 2014 National Family Conference, chock full of workshops, entertainment, and unique ways for the whole family to connect with new friends. And, last but not least, we'd like to introduce four new board members and offer them a warm welcome to the team: Kimberly Cole, Greg Licalzi, Tracie Pretak, and Bob Silverman, MD. We'd also like to thank board members Jennifer Hillman and Terry Tormey for their years of commitment and dedication, and wish them the very best. Dave Scholl, president of FIRST from 2006–2012, was nominated to Board Member Emeritus, joining this prestigious group of lifetime advocates for FIRST.

Happy New Year...I hope 2014 brings everything you are hoping for!

Jean R. Pickford



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Grassroots Fundraising

Monster Dash – A Frightfully Huge Hit!

The 12th annual “Monster Dash” Fun Run 5K race was held at Friendswood High School, bringing together an enthusiastic community of approximately 200 runners. Dawn Johnson, her family, friends and neighbors put on the event every year as a fundraiser for FIRST, as Dawn’s daughter, Jordan, has epidermolytic ichthyosis. This year’s event raised nearly \$16,000! Since holding these runs, the Johnson family and Friendswood community have raised approximately \$115,000 for FIRST. We are so fortunate to have them as a part of our FIRST family, and would like to extend our gratitude for the passion and commitment they bring to their event each year. Thanks for making a difference!



The Jane Effect

What’s possible when a community unites for a common cause?

On October 27th, Margie Sherlock and an enthusiastic team of friends and family ran a 5K race at Washington County Agricultural Center in Hagerstown, Maryland. The race was planned as a fundraiser to support medical research and the mission of FIRST, as Margie’s daughter, Jane, is affected with harlequin ichthyosis.

“Cousins, friends, everyone just kept coming up with ideas,” Katie Burden (Margie’s sister) said during a recent visit to the FIRST office. “And our family, luckily, is very competitive!” When family and friends first learned of the upcoming Jane’s 5K Race for a Cure, and the fact that an online service was being utilized to accept registrations and donations (Active.com), it was as if a fundraising wildfire broke out across the Delaware Valley and beyond. Jane had inspired hundreds of people to roll up their sleeves, get involved...and give.

The family began promoting the 5K back in August 2013. “We mostly just posted about it on Facebook with a link to Active.com,” said Margie. “So, I would say it was all really word-of-mouth. Then people started posting all sorts of online fundraisers for Jane’s 5K. Some even sold gifts and baked good items at the race to raise money. It was unbelievable. And we are so incredibly grateful to everyone. We’d actually raised over \$70,000 dollars before the race even began, and then another nearly \$30,000 at the race, and even after.”

It seems Jane had inspired anyone she touched. In addition to the registrations for Jane’s 5K itself, fundraising activities included: Facebook cakepop giveaway and fragrant gift set giveaway, Janie’s angel hats, T-shirts and bracelets, an online auction for gift baskets and purses and the many generous donations from a warm and compassionate community.

The afternoon of the race itself, attended by over 150 runners, was not only filled with running, but with hugs, laughter, Elvis, and a good share of shenanigans as this is a community of people that, admittedly, likes to have fun. “Jane felt like a celebrity and started to charge twenty dollars for autographs,” said Margie. “She raised quite a few dollars just signing T-shirts!”

When a community unites for a common cause, it appears that anything is possible. In total, the race registrations, and all of the fundraising activities raised \$100,000 for FIRST, a record-breaking amount of money in our 32-year history of grassroots fundraising!

But no matter how big or small your event, your community, or your donations, always remember every single penny counts. For more information about how you can create your own grassroots fundraising event, contact cwassel@firstskinfoundation.org.





Shop with Santa

Member Rhianon Miller held a “Shop with Santa” fundraising event, with over 200 people attending throughout the day. Donated items included: a handmade quilt, silk scarf, Mary Kay products, Lia Sophia Jewelry, Oragami Owl gift certificate, a golf gift basket, 3 free hair cuts, mugs with hot cocoa and handmade coasters, Pink Papaya skin products, Motives make up certificate, gift wrapping basket, Miche coin purse, Partylite jar candle, sweatshirt, and more. The silent auction raised \$425! Great job, Rhianon!



Celtics Success!

Shannon Hamill, mother to Lauren Hamill affected by harlequin ichthyosis, and Melissa Hamelin, mother to Akyla Frankin affected by KID syndrome, coordinated a fabulous Ichthyosis Awareness Night with the Boston Celtics and the Shamrock Foundation. Families were thrilled to stand on the court during the



national anthem and over \$2,500 was raised for FIRST! Harrison Mayone even caught a ball leaving the court during warm-ups and was able to pass it back to Paul George, guard for the Indiana Pacers. Many thanks to April Pinette Cloutier for saving the day with all the Celtics gear! A great big thank you from FIRST to all who participated!

Fine Art America

Patti Sundik, whose grandson Evan is affected with Epidermolytic Ichthyosis, held a Caravan Beads night, raising \$144! She also recently sold her first photo on Fine Art America (www.fineartamerica.com)! The lovely photo was taken from her garage back door last February, and a portion of the proceeds will go to FIRST. Congratulations Patti...and many thanks!

Stewardship Program & Change Collection

Lani and Roland Coates, whose daughter Sophia is affected with epidermolytic ichthyosis, displayed a change collection at St. Irenaeus school, collecting nearly \$400 for FIRST! Also, as part of The Stewardship Program, Sophia’s second grade class decided to raise money for FIRST by collecting donations and bottles and cans to return for cash. Plus, earlier this month one of the very good friends of the Coates family held a fundraising poker night, raising nearly \$500 for FIRST. Wow! So many thanks to the entire community!

Member Raises Funds for Cooling Vests

Anna Bryson, age 8, affected with lamellar/CIE, held a fundraiser during her community’s Fourth of July “Freedom Fest” to buy a cooling vest for Ethan Barillas, age 2, affected by autosomal recessive congenital ichthyosis (ARCI). She baked more than 200 cookies and raised \$380! It was enough to buy a vest for Ethan and for the Jackson siblings in Jackson, Mississippi, also affected by lamellar. Super job, Anna!



Sign up for our monthly e-news & updates at www.firstskinfoundation.org

Correspondence Corner



In addition to my usual monthly donation, there is a “bonus” here! O...what an overwhelming surprise! Two of my students (mother-daughter) gave me a Christmas gift...an “ichthyosis gift to inspire hope”...in the amount of \$75! Yep, Bailey and I were stunned and speechless! There are no words to describe what we felt. Yes, that’s what we want to do...inspire hope. Thanks for all you do!

Tracie Pretak

Wilcox, Pennsylvania

So interesting to read tips for putting lotions on children (in response to FIRST Blog: We asked. You answered.) Reminds me of how my parents who had three children with ichthyosis managed to cover us with lotion every night. Just like these moms and dads, they turned it into a fun game, giggling and tickling, and smiling the whole time. I’m sure they were covered in lotion, too, after it was all over! We are now 62, 60 and 54 years old and have raised children of our own, none of whom had ichthyosis. But our parents were great role models! They helped us build a good sense of self by telling us, “It’s only skin. It doesn’t define who you are. It’s what’s on the inside that counts.” And we’ve passed that message on to the next generation!

Ellen Clemmer

Raleigh, North Carolina

THE SKINNY: *Helpful Tips for Lotioning Infants and Toddlers:*

Recently we posted a question on Facebook regarding the best solutions for putting lotion on an infant or toddler with ichthyosis, (so it doesn’t feel like a wrestling match!) The answers were so remarkably unique, we not only wanted to say thank you for your creativity, but we also wanted to share these helpful tips with the entire FIRST family – particularly those caring for a child with ichthyosis...

- Sing to her! Or let her run around while you chase them and apply her lotion. This gives you both a good workout!
- Give your toddler a plastic doll and lotion so they can play at being the one in charge. Give lots of time for open ended play.
- Let him “help” with a little coconut oil so if it goes in his mouth it’s safe.
- Make up creaming songs with all the body parts. “This is how we cream our tummy...”
- My husband and I make it a game and have our 23 month old help us out. She’s gotten to the point where she will tell us where to put it on next.
- If she isn’t a light sleeper, while she slumbers. Otherwise you need two people, one to hold her still, the other to apply. Singing was always a way to improve an arduous task.

Why Join a *FIRST to Know* Call?

Sharing tips, stories and challenges with others makes living with ichthyosis just a little bit easier. The *FIRST to Know* calls are a great way to “meet” other families and individuals and share tips, stories and challenges. Plus, each call centers on a particular ichthyosis-related topic. **To participate on a call, simply dial 862.902.0250. When prompted, enter the pin# 261618915. All calls are eastern time. For more information contact mwenik@firstskinfoundation.org**

Call Date	Topic	Call Date	Topic
February 4	What is Going on with Research?	March 20	Lamellar: Meeting Each Other
February 20	X-linked: Meeting Each Other	April 3	Keeping Cool: Overheating Tips
March 4	School Resources: Getting Your Child Ready for School	April 15	EI: Meeting Each Other

Medically Speaking

Topical Tazarotene for the Treatment of Ectropion in Ichthyosis



Brittany G. Craiglow



Leonard M. Milstone



Keith A. Choate

**Brittany G. Craiglow, MD; Keith A. Choate, MD, PhD;
Leonard M. Milstone, MD**

**JAMA Dermatol. 2013;149(5):598-600.
doi:10.1001/jamadermatol.2013.239.**

Many individuals affected with ichthyosis cite ectropion—an abnormal eversion of eyelids—as one of the most cosmetically displeasing aspects of their skin disorder. And although ectropion almost universally improves beyond the neonatal period, it can persist throughout life and medical consequences including keratitis*, conjunctivitis*, and epiphora* can ensue.

“Patients with ectropion usually try several different types of drops, creams and even surgery, with varying results,” said Dr. Brittany Craiglow. “Surgery can be a risky option, with a high rate of recurrence, or cosmetic results that are unsatisfactory. After our recent findings we are encouraging doctors to try less invasive alternatives, like topical tazarotene and other topical retinoids, as another potential treatment option.”

Dr. Craiglow, a former FIRST ichthyosis fellow and now an instructor of dermatology at Yale University, is the newest member of a team that includes Dr. Leonard Milstone, Chairperson of FIRST’s Medical and Scientific Advisory Board, and FIRST-funded researcher Dr. Keith Choate. This group is working to gain a better understanding of the genetic mutations that cause ichthyosis and to develop better treatments for ichthyosis. They have used topical retinoids on the lids of many ichthyosis patients and recently reported their experience treating a 77-year-old woman with autosomal recessive congenital ichthyosis (ARCI) and bilateral lower eyelid ectropion. The observations were published at JAMA Dermatology Network. An abstract of their observations is as follows:

Importance: Ectropion is a complication of certain subtypes of ichthyosis and is often associated with substantial medical and cosmetic consequences. At present there is no standard of care for the treatment of ectropion in this population. Retinoids cause dyshesion and thinning of

stratum corneum, thereby reducing hyperkeratosis that likely underlies ectropion in patients with ichthyosis. As such, retinoids provide a potential effective treatment for ectropion in this group of patients.

Observation: We describe a patient with recessive ichthyosis for whom daily application of topical tazarotene produced rapid and persistent improvement of bilateral lower eyelid ectropion without adverse effects.

Conclusions and Relevance: Additional studies will be necessary to more fully and systematically address the safety and efficacy of topical retinoids for the treatment of ectropion in patients with ichthyosis; however, this case illustrates that topical tazarotene and other retinoids provide a potential treatment option for ectropion in this population. We encourage clinicians to explore medical therapies as alternatives to surgical intervention for the treatment of ectropion in patients with ichthyosis.

Dr. Craiglow also noted, “It’s a good idea to start out slowly, as topical retinoids have the potential to be irritating. Patients can try the retinoid on one eyelid and compare it to the other to see whether or not it is effective.” Dr. Craiglow also stated, “It is very important that this treatment be done under close supervision of a knowledgeable physician.”

FIRST will provide updates to this clinical study, as they occur.

*keratitis def: inflammation of the cornea — the clear, dome-shaped tissue on the front of your eye that covers the pupil and iris. Ref. www.mayoclinic.com

*conjunctivitis def: pink eye. An inflammation or infection of the transparent membrane (conjunctiva) that lines your eyelid and covers the white part of your eyeball.

*epiphora: def: watery eyes. Ref. www.mayoclinic.com



FIRST Earns National Health Council Standards of Excellence Certificate

We are proud to announce that FIRST has recently earned the National Health Council Standards of Excellence Certificate! The certificate was granted upon a review of FIRST's adherence to the 43 standards of excellence adopted by the NHC's board of directors, to ensure that their voluntary health agency members maintain the highest level of transparency, accountability and public stewardship. FIRST is proud and honored to be included among the NHC's list of esteemed voluntary health organizations.



FIRST Board of Directors Meet in Philadelphia

FIRST's Annual Board Retreat took place from Friday, November 1, to Sunday, November 3, at the Philadelphia Airport Marriott. The weekend kicked off with members meeting and reuniting at the hotel on Friday evening, followed by a spirited day of discussion, planning, and a careful review of FY 2013's successes, challenges and lessons learned. On Sunday, the team met once again for a morning session to discuss FIRST's investment portfolio, followed by a formal Board of Directors meeting, where four new board members were officially elected for a three-year term—Kimberly Cole, Greg Licalzi, Tracie Pretak, and Robert Silverman, MD. Welcome aboard!



You Are Not Alone

It never ceases to amaze us here at the FIRST office, how many lives are affected, changed, or have even been transformed, when affected members find solace in the experience of another affected member. Perhaps it's just the simple knowing that someone out there is listening, and at a very deep level, truly understands your situation. Social media is making that possible every single day. Members are seeing the value in engaging in daily conversation with those who walk in the very same shoes.



So if you haven't done so already, we encourage you to find a FIRST Facebook group that speaks to your particular stage in life. FIRST Facebook groups are: Adults with Ichthyosis, Young Adults with Ichthyosis (18-30), Parents of Children with Ichthyosis and Teens with Ichthyosis—and they are all currently accepting members. Additionally, we are excited to share the news that these groups have been engaging in spirited and supportive conversations every day. We are so inspired

that so many of you are bravely answering the call to not only educate and inform yourselves as much as possible, but to share your experiences, your thoughts, and your personal stories of living with ichthyosis, with those who have reached out and expressed the need for connection. Please accept our bottomless thank you for reaching back.



For additional information on these stories and other news from FIRST, visit www.firstskinfoundation.org

Driven by a Passion for Patients

... continued

By Maureen Neville

Not only does their dedication and commitment offer our community a ray of hope for a better tomorrow, but in turn we have the opportunity to provide them with patient insights, research, grants and the emotional support necessary to continue their quest for better treatments, and an eventual cure for ichthyosis. We reap the rewards, every single day, of embracing a “one team” culture with this remarkable group of physicians.

In fact, on November 20 of this year, FIRST had the good fortune and rare opportunity to meet with the entire Yale University ichthyosis research team, face-to-face, as they shared their special “patient first” philosophy, their passion for combining multi-disciplinary scientific discovery with real-world patient treatments (a field known as translational medicine), and what these doctors envision is possible for the future of ichthyosis research.

One of the goals of the visit to Yale was to video tape individual interviews that FIRST could use in various presentations, either to solicit a new donor, enlighten our current members, or engage others who are not familiar with the ichthyoses. The video “campaign” would introduce the disorder of ichthyosis, the doctors spearheading the field of ichthyosis research, and the idea that their support will bring these doctors that much closer to better treatments—and perhaps even these advances in research would have an effect on other diseases as well.

As the day unfolded, it was quickly evident that these doctors, Dr. Leonard Milstone, Dr. Keith Choate, Dr. Brittany Craiglow, and Dr. Christopher Bunick, who are all approaching the same disease from differing angles, were inspired by the exact same component of the field of medical research: the patients.

When asked about his decision to go into the field of ichthyosis research, Dr. Keith Choate shared not only a profound story of clinician and patient interaction, but his exact moment of certainty—his very first time meeting an ichthyosis patient in Dr. Mary Williams’ clinic, one of founding physicians of FIRST. Although his initial reaction was that ichthyosis presented itself rather mildly, the next moment of his life would carve the pathway for his entire career. “As she took the layers of make-up off, she began to cry. It was clear that this woman was severely affected. And that ichthyosis was affecting this patient’s life in a fundamental way. She felt ashamed and I could see that,” he said. “People talk about scientific epiphanies and the moment of knowing. I knew right then that this was important work, and that this was exactly what I wanted to do—research in ichthyosis.”

Dr. Brittany Craiglow, initially entering medical school with the intent of becoming a child psychiatrist, discovered during a volunteer mission at Camp Discovery, a specialized sleep-away camp for kids with skin disorders, that a physician-scientist track in dermatology might better suit her desire to connect and care for families and children. “When you’re a kid and you’re sick and everyone else can see it, it’s right there on your skin, it adds a whole other element. So it’s important to treat not just the condition, but the whole person. I love my job because I can do just that. I love building relationships with patients and, at the end of the day I just want to be a good doctor for them.”

The physician-scientist possesses the capacity to envision the entire process—a mastery of biotechnology as well as a passion for face-to-face interaction and treatment of patients and families. As we stood in Keith Choate’s laboratory, surrounded by cameras, lights and an audio boom, we were overwhelmed by the feeling of privilege; after all, we were among this unique breed of four passionate physician-scientists as they discussed the latest computer programs for genetic



sequencing, the electron-micrograph, the Yale Center for Genome Analysis and, with equal enthusiasm, interacted with their patients and families right down the hall.

Dr. Leonard Milstone, a veteran doctor in the field, was as energized and excited as any new doctor entering the field of ichthyosis research today. Not only does he bear an obvious warmth and affection for his patients, two of whom had joined us for the day, but he possesses a truly remarkable willingness to support and mentor the progress of the next generation of ichthyosis scientists in any possible way. “It’s like the perfect storm. It is so very rare to have three young people at the same place with interest in the same rare diseases, each contributing complementary expertise to help these patients,” he said with regard to Drs. Choate, Craiglow and Bunick. “Plus, we have an unusually large and devoted group of ichthyosis patients, and the environment at Yale provides unique opportunities for these collaborations to flourish: a Genome Center that has a special interest in rare diseases; an outstanding group of structural biologists; a high throughput screening facility; and a group of additional young skin scientists who utilize the latest technologies to understand skin disease. And the final critical component is FIRST, a remarkably effective organization that grabs your attention and makes you want to do more, while supporting each of us emotionally in terms of encouragement for the science and the clinical work that we do.”

The doctors all agreed that medical research itself is advancing at lightning speed. “Questions that would have taken decades to answer, or thought impossible to answer, now may take only a few years, or even months,” added Milstone. An optimistic Dr. Choate, with regard to the speed of medical advancement, offered his own vision of what may be not too far down the road. “What I see and hope for the future is a post-genomics era. Genomics is the key that unlocked the door for us and opened the possibility of identifying all the genetic mutations of ichthyosis of all types. We now have the information and are using it with next-level biology such as high-throughput chemical screening, identifying natural compounds, synthesizing compounds and creating new medicines to treat these disorders. We are leveraging genetic insights to make a difference in patients’ lives.”

Included in our physician-scientist interviews was Dr. Chris Bunick, a unique physician-scientist among dermatologists because of his application of X-ray crystallography to the field of dermatology research. Dr. Bunick brought an even more expansive view to the notion of what can scientifically be achieved to help patients. “X-ray crystallography technology enables determination of a 3-D image of what a protein looks like in living cells. Therefore I am able to see the structures of the proteins that make up the skin barrier. This technology is going to greatly improve our understanding of the science behind skin function,” he explained. When asked about his futuristic vision, Bunick stated, “What I imagine is creating a niche of dermatology research, ‘molecular dermatology’ so to speak, and one by one, determining 3-D structures of proteins highly relevant to normal and diseased skin. I am in a position

to identify and to tackle many disorders in the field of dermatology from this structural perspective, and my hope would be translation of this work into new classes of topical therapeutics to help patients with skin disorders.”

The importance of research funding was another topic that continuously surfaced throughout the day, and it is clearly encircling the thoughts of these physicians, day to day, as well. “But it’s only my two hands and we need more funding and more scientists working together to achieve this,” Bunick added.



But it was the words (or lack thereof), offered by the patients themselves, that illustrated the results from long hours in the lab and the tireless years of dedication, in the most meaningful way. “There really are no words for what they have done for me; they saved my child’s life. They knew exactly what Evan needed and exactly what to do, and if they weren’t there by our side, there’s a good chance Evan would not be here today,” remarked an emotional Dianne Fasciano, as she spoke about the days following the birth of her now 3-year-old son, Evan, affected with harlequin ichthyosis. “I have the best doctors in the world, and they are on it, always ready to help at a moment’s notice. I am so lucky.”

Rita Tanis, a middle-aged woman affected with lamellar ichthyosis, also spoke of her unique kinship with the doctors at Yale. “I have seen many doctors over my lifetime. But these doctors here, they really get it. And they have real empathy. There is no need to keep explaining it to them, as they really understand the condition in a way no one else ever did. Now there is so much hope for better treatments, and even for that big, big word that we’re not supposed to talk about, a cure. It feels like it is right there in front of us. It’s palpable.”

Our day at Yale inspired many new stories for FIRST to share with members, supporters, the media and the world. In upcoming months, we look forward to bringing you more articles and videos discussing our powerful advocate-doctor relationships, our collective vision for the future and more details about the cutting-edge research being conducted in both lab and clinical settings for ichthyosis research.

INTRODUCING: Diya & Aliya's Friends (DAF) Fund

Thanks to the generosity of the Shahnaz Kraybill family and their family and friends, (Aliya, affected with ichthyosis, her sister, Diya, and their parents Durreen and Robert), FIRST has established the Diya & Aliya's Friends (DAF) Fund to help alleviate some of the financial burden that may be facing families with affected children. This special fund is available for children around the world affected with ichthyosis and is intended to provide financial assistance to purchase lotions, medicine, and treatment necessities. Applications must be received by April 30 or October 31 each year to be considered for each cycle (not to exceed \$250). While this fund is available to affected children from around the world, however, two-thirds of the fund disbursements have been designated for non-US families; the other one-third is designated, but not limited to, US families. More information and an application can be found at www.firstskinfoundation.org. Application can be downloaded from FIRST's website and emailed to Jean Pickford at the national office at jpickford@firstskinfoundation.org, faxed to 215.997.9403 or mailed to the attention of:



Foundation for Ichthyosis & Related Skin Types, Inc. ® (FIRST)
Diya & Aliya's Friends (DAF) Fund 2616 N. Broad Street, Colmar, PA 18915 USA

Jane & Henry Bukaty Skin Care Fund

Thanks to the generosity of Jane and Henry Bukaty, FIRST has established the Jane & Henry Bukaty Skin Care Fund to help alleviate some of the financial burden that may be facing our members. Here's your opportunity to apply for some financial assistance for ichthyosis treatment. Since the fund is limited, the following criteria must be met by the applicant in order to be eligible for a grant.

The applicant must be registered in our database and is required to submit an application indicating his/her need for funding. The application can be downloaded from FIRST's website and requests the specific product/treatment for which funds are needed, and a demonstration of the financial need for this product/treatment.

Awards will not exceed \$200. Applications will be awarded two times per year as determined by the Review Committee. Applicants will be eligible to receive one award every two years.

Please download the application from FIRST's website and email to the national office at jpickford@firstskinfoundation.org, fax to 215.997.9403 or mail to the attention of:



Jane & Henry Bukaty Skin Care Fund Foundation for Ichthyosis & Related Skin Types, Inc.®
2616 N. Broad Street, Colmar, PA 18915

The deadline for submitting an application is July 31, 2014.

You will be contacted by the office if you have been awarded aid from this fund.

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Thanks to a partnership with Stream Energy, and the Power UP! program for non-profit organizations, you, your friends, and your family can help support FIRST each and every month of the year. Now you can convert your energy provider to Stream Energy, and THEY will donate on your behalf to FIRST each and every month you remain a customer. There's no cost to sign up, no change in the reliability of your service, and you'll enjoy competitive utility rates. This program is open to any resident of Texas, Georgia, Maryland, New Jersey, New York and Pennsylvania. So....spread the word! (For more information, visit: <http://firstskinfoundation.streampowerup.biz>)





18th Biennial Conference June 20-22, 2014

Why Should I/We Attend?

We think the best way to explain why you should attend a national family conference is to hear firsthand what others have said:

- *I really enjoyed being able to not worry about the stares. I also really liked having doctors here who we didn't have to educate about my condition; they already knew what I had.*
- *I most enjoyed networking with others and realizing how important it is that our population interacts collectively with the researchers so that connections toward research can be made.*
- *Every year this experience changes my views on life and makes me a more positive and comfortable person.*
- *Fantastic! Thank you so much. This conference was truly incredible and inspiring. I learned so much.*
- *Everyone in my family was involved – my kids loved the Kid's Camp, my teenage son enjoyed talking and hanging out with his peers, and my wife and I really connected with other parents.*

What's on the Agenda?

In addition to the exclusive opportunity to participate in the Yale Ichthyosis Research Project and a one-on-one consultation with a medical expert, here's what's on the agenda and featured workshops:

- *Disease-specific workshop focused on your type of ichthyosis or related skin type, moderated by a knowledgeable physician*
- *Lotions, creams and 'what works' information sharing*
- *Newly-diagnosed families workshop*
- *Understanding the complicated world of genetics*
- *Research updates and how it will impact you*
- *Group networking workshops focused specifically for moms, dads, teens, affected men and women, grandparents, young adults and spouses*
- *Specific care workshops – foot, scalp, hair, diet, nutrition, natural care, exercise, eyes, ears and pregnancy*
- *Skin management workshops – infections, long term use of antibiotics, retinoids and overheating*
- *Communications workshops – confidence building, addressing rude people, dealing with doctors, school and bullying concerns, and teenage/young adult issues*

All workshops feature a question & answer period and are very casual, allowing the opportunity to share and learn from each other.





What Should I Expect?

The conference is an amazing, worthwhile, and moving event for the entire family. Attendees will arrive at all different times, most arriving on Thursday. It's typical to see clusters of people gathered in the lobby, hallways, and sitting areas chatting with old and new friends. Registration takes place early Friday morning and is complemented by a group breakfast. Kid's Camp and educational workshops run throughout the rest of the day on Friday, with a break for lunch. Friday's workshops will end by 4:30 pm, and attendees are on their own for Friday night activities.

We begin early again on Saturday morning with a group breakfast followed by Kid's Camp and workshops throughout the day until 5:15 pm, with a break for lunch. Everyone has a chance to freshen-up before the dinner/dance party which begins at 6:30 pm. The dance party features a live DJ who will play the latest hits and party games. Some people think this is the best part of the conference...you'll be sure to see some smooth dance moves by young Michael Jackson and JLo wannabes! The evening also features a raffle and auction items.

The last day on Sunday begins with the group breakfast, Kid's Camp and workshops until 12:15 pm. This is followed by a closing session and farewell lunch. Friends and families exchange addresses, hugs, and best wishes until the next conference! Friendships are made that will last a lifetime.

Registration

Registration for the conference can be completed by using the registration form or registering online at www.firstskinfoundation.org by June 2nd. Registrations without a completed form and payment will not be considered complete. Cancellations received prior to June 2nd will be refunded less a \$25 per person administrative fee. No refunds issued after June 2nd. Please note: Registration does not include your hotel room. Accommodations at the Hilton Indianapolis must be made separately.



Kid's Camp

Social programs for all affected children and their siblings are an integral part of the conference. Children in the Kid's 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 Kid's Camp section on the registration form. A licensed child care company will be hired to provide this service. A nominal fee is required so FIRST can confirm who is planning to use this service so the appropriate number of childcare providers will be hired for the safety of your children.

FIRST Continues to Advance Ichthyosis-Related Research – Be a Participant!

Yale Ichthyosis Project – Dr. Keith Choate and his team from Yale will once again be enrolling patients in the Yale Ichthyosis Project, which is seeking to better understand disorders of keratinization from a genetic and clinical perspective. The group has been making excellent progress and is poised to address several important questions about ichthyosis, largely thanks to the participation of members of FIRST. For interested new families, the study will involve a blood draw, photographs, and completing a questionnaire. For those who are already involved with the study, there will be an opportunity to update information. More information will be provided as we get closer to the conference.

Meet with an Expert Physician for a One-on-One Consultation /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 Thursday evening (June 19) or early Friday morning (June 20). Participation is voluntary. Sign-up is required prior to the conference by completing the clinical screening section of the registration form.





Making Hotel Room Reservations

FIRST's discounted rate for an oversized room at the Hilton Indianapolis is \$119 plus taxes and fees, per night. This rate is available from June 17 through June 24 and includes complimentary internet access in each room. All attendees must make their own reservations at the Hilton Indianapolis by calling toll-free 1.800.315.1906 (to receive the discounted room rate, you must identify our group name as "Foundation for Ichthyosis") or making online reservations by using our dedicated group link at <http://tinyurl.com/FIRSTHilton>. Parking is \$14 for self-park and \$20 for valet parking. Other hotel rules and restrictions may apply.

For general questions about the hotel, driving directions, amenities, etc., contact the hotel directly at 317.972.0600 or visit their website at www.indianapolishilton.com.

Meals, Area Attractions and Dress Code

The conference registration fee includes breakfast and lunch on Friday, June 20; breakfast, lunch, and dinner/dance on Saturday, June 21; and breakfast and lunch on Sunday, June 22. All registrants are on their own for dinner on Friday evening, June 20.

Positioned in the heart of downtown Indianapolis, the hotel offers you multiple choices of activities and is just steps away from the Circle Centre Mall, cultural attractions, great restaurants and evening entertainment options. Within a two to four block radius of the hotel, you will find the Indiana Convention Center, Lucas Oil Stadium, NCAA Hall of Champions, Bankers Life Fieldhouse, Indianapolis Zoo, and an IMAX 3D Theatre, just to name a few. To learn more, visit the hotel website at www.indianapolishilton.com or visit the Visitors & Convention Center website for discounts and choices of things to do - <http://visitindy.com/fnfc14>. Conference attire is casual

Airport & Shuttle Information

Indianapolis International Airport (IND) is the major airport for the Indianapolis area. Carey Limousine is the local shared ride service to/from the airport to downtown Indianapolis. Proceed to the ground transportation/baggage claim area to locate their services. The discounted cost for conference attendees is \$16.95 per person one way. Pre-reservations are encouraged. Please call toll-free: 800-888-INDY or use their website to make your reservation - <https://careyindiana.hudsonltd.net/res>.

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 877.621.7177.

Teen Field Trip

Teenagers, ages 13-17, will participate in a chaperoned offsite field trip to the Circle Centre Mall on Saturday afternoon of the conference. The mall features an IMAX Theatre, so depending on showtimes, an age-appropriate movie may be included. Be sure to complete the information on page 15 if you want your teen to participate.



Photo credits: Meredith Rizzo

Registration Form

Contact Information _____

First Name _____

Last Name _____

Address _____

City _____ State _____ Zip _____

Home Phone _____ Cell Phone _____

Email _____



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

First Name	Last Name	Age	Affected	Kid's Camp*	T-shirt 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 Kid's 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 Thursday evening, June 19, from 3:00–9:00 pm and Friday morning, June 20, from 7:00–10:00 am. 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	Age	Male/Female	Type of Ichthyosis	Would you like a:	
				Thurs Appt	Fri Appt
_____	_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>
_____	_____	_____	_____	<input type="checkbox"/>	<input type="checkbox"/>

FIRST Idols Talent Sign-Up *(ages 5-17)*

Back for its fourth year! This is a popular and heartwarming 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 two minutes.

Performers Name _____ Age _____ Grade _____

Type/Description of Act: _____

Teen Off-Site Field Trip

An organized trip has been arranged for teenagers (ages 13–17) to visit the Circle Centre Mall from 1:00–5:00 pm on Saturday, June 21. Licensed chaperones will accompany and travel to/from the mall with the teens. 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: _____

Permissions

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.

I hereby give my permission to FIRST to use and distribute any photos or video tapes taken at the 2014 family conference in which I or my family may be a part, including but not limited to use in newsletters, guides, documentaries, appeals, website and reports at their discretion.

Signature _____

Registration

Adults (Ages 13 and up) _____ x \$ 225.00 pp USD = \$ _____

Children (Ages 1–12) _____ x \$ 75.00* pp USD = \$ _____

Optional Add-Ons

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

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: _____

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 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 _____

*Children's rate discounted through grant from the Lennox Family Foundation



FIRST

Foundation for Ichthyosis & Related Skin Types®

Educate • Inspire • Connect

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Camp Discovery 2014 Dates!



The American Academy of Dermatology's (AAD) Camp Discovery program is for children ages 8-16 who have a chronic skin disease. 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 having fun and participating in activities such as swimming, horseback riding, arts and crafts and many more.

There is no fee to attend, all costs, including transportation, are provided by the AAD through generous donations from its members, outside organizations and individuals. All campers must be initially referred by their dermatologist.

This year the Academy is proud to offer six camping sessions:

- **June 22–27**, Camp Little Pine in Crosslake, Minnesota (ages 10–14)
- **June 23–27**, Camp Reflection in Carnation, Washington (ages 8–16)
- **July 6–11**, Camp Big Trout in Crosslake, Minnesota (ages 14–16)
- **August 10–15**, Camp Dermadillo, Burton, Texas (ages 9–15)
- **August 9–15**, Camp Horizon, Millville, Pennsylvania (ages 8–13)
- Camp Liberty, Connecticut (ages 8–16), change in venue, details to be determined

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

Thank You to Allergan Pharmaceuticals for Their Support of FIRST Publications.