



Looking Forward Giving Back

FIRST member Katie Smith is more than excited to share her story. After all, it's not just a story about living with ichthyosis. Nor is it simply a story about an "aha" moment, or the journey of a young woman setting out to find her true purpose.

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Survey says...



I'd like to extend our gratitude to the nearly 500 members who participated in our recent FIRST Quality Assurance survey. I am happy to report that the responses reaffirm our overall goals and objectives for the FIRST community. I was also encouraged to learn some new insights that came directly from you, our members. Day-to-day tips like bathing additives and exfoliants, along with research updates and advocacy efforts were all high on the list of topics you'd like to hear more about. You have spoken, and we have listened. In this issue you will find a physician's guide to bathing additives, updates from our Medical & Scientific Advisory Board members about ichthyosis research, and comprehensive information about retinoids. You will also learn about the health care bills currently being discussed on Capitol Hill and featured at the recent AADA Legislative Conference. See how you can best use your voice and make a difference. You'll also meet FIRST member Katie Smith, and learn how this passionate young woman is looking forward, giving back, and living with passion and purpose. It's also time to start planning for the National Conference, so you'll find highlights about the conference scheduled for June 24 - 26 in San Diego, California, along with financial aid information for those who may need some assistance.

Enjoy the cooler temps and fall weather! And thank you again for all your support and dedication to FIRST. We couldn't do it without you!

Jean R. Pickford

CEO, FIRST

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Correspondence Corner



Dear FIRST Foundation,

I wish I could describe the feeling to you, the feeling of knowing we are meant to do this (regarding the Release the Butterfly FIRST benefit tour), the feeling of knowing how important it is to the families we are connecting with and that we are not the only ones feeling this. Hunter and Mark and Mikela and Abby and Ross and Sophie and Sami and the Sterns (referring to members of FIRST and concert participants), all just want to keep coming. We all know we are making a difference in the lives of everyone, not just those with ichthyosis, and the feeling of KNOWING we have the support of such an amazing foundation and its staff behind us, is beyond words!

Tracie Pretak

I graduated! Thank you so much for your generous scholarships. They helped me out tremendously during my time at College of the Ozarks. I was able to graduate debt free with a psychology degree.

UFIRST scholarship recipient

My angel was born six weeks early and diagnosed with ichthyosis at birth. He is now almost 3 months old and my partner has been on your website every day for the past 12 weeks. Thank you for having such wonderful resources.

FIRST member and new mom

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Science, Innovation and Research in Ichthyosis & Related Skin Types

What's new in X-linked ichthyosis?

Submitted by Dr. Jennifer Hand, FIRST Medical & Scientific Advisory Board member



Review of new medical literature from the last two years revealed that authors have made some new discoveries about X-linked ichthyosis (XLI). X-linked ichthyosis (XLI) is an X-linked recessive disorder which affects one out of every 1,500 males and is considered to be one of the most common and mildest forms of ichthyosis. The medical literature describes that most affected males have dark brown scaling of the skin, especially on the lower legs. Most cases (up to 95%) are caused by a small deletion of genetic material on the X-chromosome. With routine genetic screening of some pregnant women, babies are being identified with XLI in the womb as an incidental finding. A group of patients identified incidentally in the lab to have a deletion that causes XLI was found to have a milder scaling as children described as dryness and/or eczema. This group lacked dark, polygonal scale, suggesting a milder skin type may be more common than previously realized, especially when the diagnosis is made incidentally.

You may remember from biology classes that females have two X chromosomes in every cell and males have only one X and a Y. In each female cell, one X is inactivated and stays dormant as a tiny ball (a Barr body) and the other X stays fully active. The mutated gene that causes XLI, called "STS" is located in a small, special region of the X-chromosome that escapes X-inactivation. As a result, females always express both copies of their STS gene. This is the reason females do not show the skin changes of XLI. That is, if one X is mutated, the other normal X makes up for the mutation. In 2014, a rare case of an affected female was reported due to a deletion of the STS gene, one on each X chromosome.

Ref. What's New with Common Genetic Disorders? PubMed.gov 2015 Aug;27(4):460-5.

All About Retinoids

*Submitted by John J. DiGiovanna, MD
(Previously published. Updated October 2015)*

Retinoid is a term used to describe Vitamin A and its chemical derivatives. Both the good and toxic effects of Vitamin A have been known for a long time. In the early 1900's, a lack of Vitamin A was associated with cancer development and also with skin changes. Based on these findings, retinoids were studied as a treatment for skin disorders and cancer. One problem with natural occurring Vitamin A is that the amount needed to cause the good effects is close to that which causes the toxic effects. By the time enough is taken to achieve a clinical benefit, side effects such as headaches, bone pain, and bone changes begin to occur. To try to increase the amount of benefit and decrease the toxic side effects, researchers and pharmaceutical companies became interested in creating and studying synthetic derivatives of Vitamin A.



Retinoids work in several different ways by different mechanisms. These compounds are required for normal

growth and development of many cells and tissues. Retinoids enhance the process of cell differentiation (the process by which cells grow and develop), so that for cells, which are not growing normally, the addition of retinoids can push their development towards normal. In many of the scaly skin conditions, such as ichthyosis, additional retinoids can help the skin cells grow more normally.

Several retinoids are used as drugs either topically (applied to the skin) or systemically (delivered to the whole body, as in a pill). Retinoic acid (tretinoin, Retin A, Renova), is used as a topical treatment for acne and may help other skin conditions such as sun-induced skin damage, and thick or scaly conditions such as ichthyosis. Tazarotene is a different retinoid compound that is used topically for similar problems and has shown benefit when used to treat ectropion (pulling down of the eyelids). Isotretinoin (known as Accutane before 2009) is an oral medication used for a type of severe acne and may also help scaly skin conditions. Acitretin (Soriatane) is used for psoriasis, ichthyosis, and other skin disorders.

Systemic retinoid therapy almost always causes some side effects. Most are usually mild and easily controlled. The side effects include: dryness and scaling of the skin and mucous membranes; blood test abnormalities, such as increases in triglycerides and cholesterol, and abnormal liver function; and joint stiffness.

Naturally occurring retinoids (as vitamins) are important for the normal development of the fetus, but if a pregnant woman takes other oral retinoid drugs they can interfere with development and lead to birth defects. Even one pill of a retinoid drug taken during pregnancy can lead to severe birth defects such as a malformed brain, severe retardation, abnormal eyes, abnormal ears, and serious heart defects. Any woman of childbearing age must be on two effective forms of birth control (birth control pills, implanted hormone therapy, condoms, diaphragms, etc.) while taking retinoid drugs. In addition, certain retinoids can stay in the body for a very long time (possibly several years), and should not be taken by women who could possibly get pregnant without significant discussion with a physician and an understanding of the risks.

The retinoid drugs available today may be of some use to individuals with severe acne, psoriasis, ichthyosis and cancer. Whether retinoid treatment would be beneficial to you is something you need to discuss in great detail with your physician. The use of retinoids to treat your ichthyosis should be an informed, negotiated agreement between you and your physician. Retinoids should NEVER be taken except under the supervision of a doctor, and under strict guidelines, as outlined by the FDA and the drug manufacturers. Regular pregnancy tests must be done, as well as frequent visits to the doctor. Under no circumstances should retinoids be taken by anyone other than the person for whom the drug was prescribed.

FIRST ADVOCATES

Senior Director, Programs & Research, Moureen Wenik, along with Director of Operations, Chris Wassel, spent a busy three days on Capitol Hill during the American Academy of Dermatology Association (AADA) Legislative Conference, September 26-29. The weekend kicked off with an insightful and collaborative meeting with the Coalition of Skin Diseases (CSD), where the discussion primarily focused on common issues facing patient advocacy groups. Topics included strategies for reaching new members, the importance of partnering with physicians, and keeping members engaged throughout their lifetimes. "Getting together with the CSD reinforced that our issues are not unique. It was really interesting to hear their perspectives and learn how each organization takes a slightly different approach to the same issue. It was also wonderful to meet many of the CSD members in person," said Chris Wassel, first-time conference attendee.

During the second half of the conference, Moureen and Chris met with legislators to advocate for increased funding to support rare diseases, educate leaders on Capitol Hill about ichthyosis and the related skin types, and discuss three primary issues, or "asks," promoted at the AADA Legislative Conference:

- 1) Patient Access to Pharmaceutical Treatments - (HR16 Act)** This bill will ensure that patients can access the most effective treatment and eliminate barriers such as high cost and specialty tiers.
- 2) Adequate and Transparent Physician Networks - (Medical Bill of Rights Act)** This bill will ensure patients will have access to the physician of their choice, and specialty areas, such as dermatology, will not be dropped from their insurance network.
- 3) Promoting Public Health** - This bill will raise awareness and prioritize funding for medical research.

To strategically spread these messages throughout Congress, the conference attendees were separated into lobbying groups based on each individual state. Moureen and Chris, along with seven dermatologists and FIRST member, Angela Godby, met with Pennsylvania's two senators and six representatives.

Moureen noted, "It was interesting to speak with the physicians and learn their point of view. Dermatologists have been dropped from the Medicare Advantage network plans in a number of states, which threatens patient access to specialty care, and can cause a delay in access to proper treatment. One physician emphasized that treatment delay is like denial of treatment. Fortunately, the legislators we met with really seemed very interested in health care change. Both sides are working together for health care, so it truly was a bipartisan event."

When asked how FIRST members can join this advocacy cause, both Moureen and Chris agreed, "If your congressman hasn't co-sponsored bill HR16, ask them to consider supporting this bill. They should get on the email list of their Senator and Congressman to stay informed on the position of their elected official. And write to their elected official, both state and local level, thank them for passing the 21st Century Cures Act*, and let them know their own personal story and how they have been impacted by the limited access to care."

Please contact Chris at cwassel@firstskinfoundation.org to learn more ways to use your voice and get involved.

*The 21st Century Cures Act features many positive changes for patients, including making research collaborations easier and promoting therapies, like biomarkers, to enhance personalized drug treatments targeted at individuals and not just broadly at diseases. It is also reforming and streamlining clinical trials, making it less challenging and expensive for companies to bring drugs to market and creating incentives for developing drugs for uncommon but deadly diseases. It is creating an Innovation Fund to encourage young scientists to do path-breaking research as well as putting more money into both the National Institutes of Health and the Food and Drug Administration to make these innovations work.



Looking Forward Giving Back

Meet FIRST member Katie Smith

by Mo Neville, Senior Director, Marketing & Communications

FIRST member Katie Smith is more than excited to share her story. After all, it's not just a story about living with ichthyosis. Nor is it simply a story about an "aha" moment, or the journey of a young woman setting out to find her true purpose. To Katie, her life, her skin disorder, her future, are all a part of something bigger, not just a story, but "an obligation to do good in the world."

Katie, affected with ARCI-lamellar ichthyosis, was born in Providence, Rhode Island, in 1984. And as is the case for many individuals with a visible rare condition, Katie was often subjected to rude behavior, bullying and the intolerance of people with differences. "But my parents wanted to make sure that I didn't feel different, that I felt safe," she said. Katie's parents enrolled her in a small private school and in doing so gave her a reprieve from the stares and whispers. "And since my school was so small and private, everyone knew me, which definitely made my skin condition more bearable," she said.

However, when Katie stepped out of her comfort zone, away from those who'd been familiar with her skin condition, her experiences were quite different. "When I went out in public, to new places, that's when all of the stares and comments started again," she said.

Katie's mom often tells her the story of when she was only 2 or 3 years of age and she was in the stroller with her at the grocery store. A woman standing next to them looked at her and started to scream "It's a monster! It's a monster!" The woman's young son, walked over and took Katie's hand. "I think she's pretty," the boy said.

"My mom has told me this story so many times, I don't know if I really remember it or only think I do because she made it feel like mine," she said.

As hurtful as some of her interactions with others have been, Katie has chosen to cope with it in a way that has not only made it tolerable, but has allowed her to feel empowered.

She has looked at the glass, and decided it is unequivocally half-full. As a 31-year-old adult out in the world, Katie



has learned that there actually is a productive way to react in these situations. "If a child stares, I usually say 'it's not as bad as it looks,' with a smile. And it usually makes them smile," she said. Just recently, at a One Direction concert, a family sitting in front of Katie, after repeatedly turning back looking at her and whispering, got up and left the concert. "I was by myself and that really upset me. But, it's not stopping me from going to see them again next weekend," she said, again, flipping a negative encounter on its head.

And despite the occasional brushes with ignorance, Katie considers herself lucky. "When I look back at photos from middle school, when I wasn't taking care of myself the way I should have, I can't believe the poor condition of my skin!" she said. "I wouldn't let my mother help me because, honestly, I didn't know how bad it was. For the most part, my immediate circle accepted me, so it just never seemed that bad."

Although she has chosen the path of positivity for herself, relating on a personal level to just how painful it can be to be singled out has made Katie extremely sensitive to the struggles of others. She's often wondered how difficult the road must be for those who are subject to even more criticism and even greater discrimination; for those who may have little or no support.

For many years Katie has enthusiastically attended and volunteered at the American Academy of Dermatology camp for kids with skin disorders. She initially attended the camp as a camper, then a counselor, and, most recently, as a medical volunteer this past summer in Millville, Pennsylvania. She gives these experiences much of the credit for her confidence to pursue her goals, to discover her true passion, and her ability to not let anything or anyone get in her way.

Both FIRST and the camp have a profound connection for Katie. "I would never have known about the camp if I hadn't gone to the FIRST Conferences. We'd known about the conferences for quite a while, but before I actually went when I was 12 years old, I didn't realize there were other people like me in the world," she said. "There was a girl at the conference that looked just like me. I saw her right away. Her name is Laura Ashton. She also has ARCI-lamellar ichthyosis, and she's from Bermuda. We hit it off right away. To this day, she is still a good friend." As well as offering a lifelong friendship, Laura introduced Katie to the AAD camp. "This camp, as I said, in many ways, changed my life. Over the years I have had the honor of working with so many of the kids from FIRST as they have become campers and then counselors."

In 2007, after graduating from Emmanuel College in Boston with a degree in Art Therapy, Katie was particularly interested in using her skills to help children transition after natural disasters. She soon accepted an internship in Africa as a grant writer and also started working at a camp with kids that are HIV positive. "All of the kids at the camp were orphans. I was responsible for communicating their needs to the nonprofit organization. I loved working with them, helping these kids that were at the most risk," she said. Yet all the while, Katie was convinced that although she enjoyed working with the children, and wanted to pursue working with them, the field of nursing would be out of the question. "Since I wasn't good at science I never really thought nursing was in my future. Eventually I realized in the real world, nurses work with real people, real faces, and not just scientific facts!"

It wasn't until volunteering at Camp Discovery in Minnesota in 2010, and again working with kids that were most in need, that her "aha" moment happened. This time, it was loud and clear. "This actually is nursing! I should be a nurse. I need to be a nurse!" she said to herself. Suddenly a career that seemed too far-reaching, too out of her realm of interests and skills, became the most important goal in the world.

In 2012, Katie enrolled in the Lawrence Memorial Regis College Nursing Program in Medford, Massachusetts. Today, she is a registered nurse and is finishing up her bachelors degree in nursing.

"My ultimate dream is to be working in the developing world. To be working in the most at risk communities. I'd like to work with an HIV prevention organization. I have never actually considered primary care. Like I said, my life has sort of led me to the fringe. Actually, my primary doctor knows me very well. We talk a lot about global health and he has volunteered around the world. He wants me to accompany him as a nurse this coming May in Haiti! He has been a rock for me." Katie is also currently exploring other global opportunities for nursing.

When asked what she would like to share with others about having



ichthyosis, Katie passionately said, "Well, I have a message for others who are affected. There's a reason why I do what I do, because I know what it's like to be an outsider, to be disenfranchised. I have to help those who are at risk, who are considered outsiders themselves. I really think I have an obligation to do good in the world, to reach out to those who feel badly. I want other people with ichthyosis to realize this. We are very good at compassion! Because of our experiences of being different we know how to help them find their voice. And it's our obligation to do so."

And for those who aren't affected? "More hugs! People with ichthyosis or anybody with a physical difference, you may be less likely to hug them. Well let me tell you, they are in the most need of a hug. They are self-conscious enough and they need to feel accepted, not different and afraid all the time. Katie shared a personal moment when she realized the importance of touch and human affection. "I remember when I worked with autistic children that weren't verbal. They loved to touch different textures and would love to touch my hand and arms. It actually made me feel so normal."

When asked how she will handle her ichthyosis while working around the world, Katie said, "I think ichthyosis should be an afterthought. Yes, it should be acknowledged and prepared for, especially if you're planning to backpack across Europe or something like that. But it shouldn't be the first thing you think of. The adventure you're going to embark on, should definitely be the first thing you think about."

It seems, for Katie, every lesson, every experience, leaves a tiny trail of wisdom.

"Recently, I had alopecia very badly. I was definitely upset. It was another challenge tied to ichthyosis. But quickly I realized that my hair was certainly not the biggest part of me, not the part I'm concentrating on. Finally, I decided to cut my hair short and just get on with life."

And that she is.



Living Well With Ichthyosis

Bathing with ichthyosis or a related skin type

Submitted by Leonard M. Milstone, MD, Yale University

There's no question, for those affected by ichthyosis, frequent bathing is very important, as it is not only the best way, but the most natural way, to remove dry scales and skin – and, most importantly, more frequent bathing can ease the distress of ichthyosis, making day-to-day life much more comfortable.

The following physician-recommended recipes assume an average tub size of 90 gallons, filled to the brim. If you normally fill the tub one-third full before you get in, these are the amounts to use. Soak for a minimum of 30 minutes; one hour is better. Each of these baths should be followed by generous application of emollient.

Salt Bath for Removing Scale: Aim for as much as a 3% solution. This is just less than the amount of sodium chloride in the ocean. This equals 1/4 pound per gallon of water - or 5 lbs in 20 gallons or 7.5 pounds in 30 gallons. Less salt may work for some, if you soak for at least an hour. This is safe to use every day.

Baking Soda Bath: Aim for a pH of 7.9. The amount of baking soda to add may vary with the quality (pH) of your tap water. In most cases, adding one-third cup to a tub one-third full with water will raise the pH to 7.9. You can test the water after the baking soda is dissolved with pH indicator paper. You must soak for 45 minutes to one hour before starting to gently slough scale with a washcloth, loofah or other gentle mechanical desquamator. Baking soda baths can be used up to several times a week

Antimicrobial Bleach Bath: Measure the amount of water usually put in the tub. Add 10ml (2 teaspoons) of household bleach per gallon - i.e., about 1 cup in a half-full tub (40-50 gallons). Soak for a minimum of 15 minutes - longer if you want to remove more scale. Bleach baths once or twice a week should be adequate to reduce the frequency of infections; daily for one week may be necessary for someone currently infected. Remember, undiluted household bleach is quite irritating. Be careful how you handle it.

Post Bath Emollient: It is important to use an emollient after bathing. If you have taken an alkaline bath (by using baking soda or bleach) it is a good idea to restore the natural acid pH of the outer layer of skin by using an emollient with a slightly acid pH, such as Lac-Hydrin or AmLactin.

Rewards (and Risks) of Bleach Baths

Submitted by Leonard M. Milstone, MD, Yale University and Peter M. Elias, MD, UC San Francisco

Why do dermatologists recommend bleach baths to many of their patients with ichthyosis?

Many patients with ichthyosis, despite their best attempts at personal hygiene, become colonized by an overgrowth of bacteria, yeasts, or fungi. An unfortunate consequence of this colonization by these microbes can be an unpleasant odor. When these same microbes try to reside on normal skin, they encounter a much thinner, and much more acidic stratum corneum. The 'acid mantle' of normal skin (pH 5.0 - 5.5) resists the growth of many microbes, while selectively encouraging colonization by the microbes that normally occupy the niche of the stratum corneum. In contrast to the low pH of normal skin, the pH of ichthyotic stratum corneum rises (to pH 6-7) due in part to excess scale, inflammation, and a defective barrier. This elevated pH and the thickened stratum corneum niche favor the overgrowth of many microbes, including not only those that populate normal stratum corneum, but also pathogenic microbes, such as *Staphylococcus aureus*. The chief reason we recommend bleach baths is:

Decrease Odor – Bleach baths reduce the amount of odoriferous colonization by potentially pathogenic microbes on the skin surface.

Decrease Infection – Bleach baths can decrease the risk of infection.

However, there is a second consequence of the elevated pH of ichthyotic skin, and the even more elevated pH of bleach. There are enzymes in the stratum corneum that are more active at an elevated pH, and whose activity can have two important consequences:

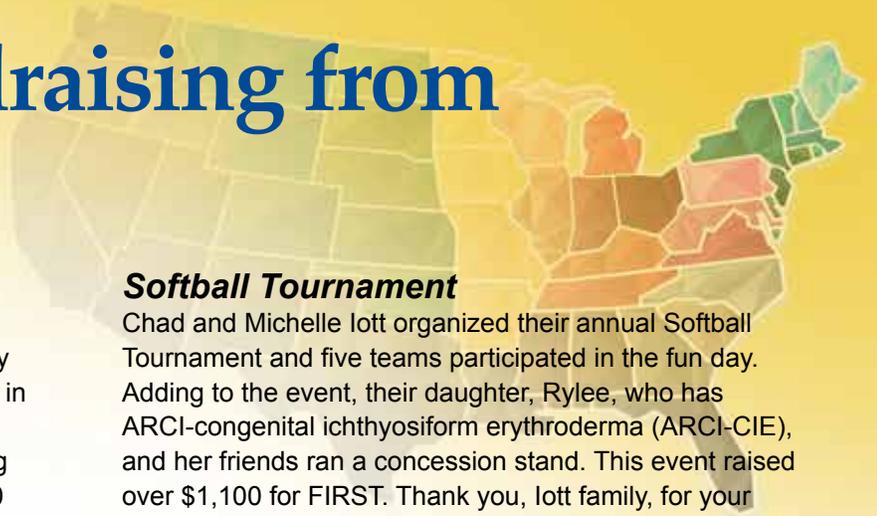
Separation of Cells - First, some of these enzymes degrade the connections that hold the cells of the stratum corneum together, causing these cells to separate from each other, and eventually to be shed from the skin surface. Obviously, for someone who has too-thick a stratum corneum, bleach baths could prove to be an advantage. It should be noted, however, that there are no experimental or clinical data proving that bleach promotes desquamation.

Inflammation - Second, some of the enzymes that are more active at higher pH can provoke inflammation, because they activate and release pro-inflammatory cytokines, proteins that normally are stored inside stratum corneum cells and shed harmlessly. Currently, there are no studies that address whether the slightly alkaline pH of bleach baths increases inflammation in those who have inflamed skin. Somewhat surprisingly, there is one study showing that dilute bleach has the ability to reduce inflammation in an animal model of inflamed (not ichthyotic) skin. So in sum, we still have questions about the impact that bleach baths have on inflammation in our patients.

Most of us would agree that, taken together, the benefits of bleach baths in reducing microbial overgrowth, odor and infections far outweigh the uncertainties arising from its slightly alkaline pH. Yet none of us would see any advantage to prolonged exposure to the abnormally high pH of dilute bleach baths for patients with ichthyosis. Instead, it would seem prudent to follow one's bleach bath with a generous application of a slightly acidic emollient, such as AmLactin or Lac-Hydrin, to help restore the skin's natural acid mantle.



Grassroots Fundraising from Coast to Coast



Car Show

The Straight family of Troy, New York, continued their commitment to FIRST by participating in the South Troy Timing Association Classic Car Show for the sixth year in a row! Their son, Aaron, and daughter, Quinn, are both affected with ichthyosis. Since they started participating in this event, the Straight family has raised over \$6,000 for FIRST. Thank you for raising awareness of ichthyosis and FIRST in your community!

Softball Tournament

Chad and Michelle Iott organized their annual Softball Tournament and five teams participated in the fun day. Adding to the event, their daughter, Rylee, who has ARCI-congenital ichthyosiform erythroderma (ARCI-CIE), and her friends ran a concession stand. This event raised over \$1,100 for FIRST. Thank you, Iott family, for your continued support of FIRST!

Release the Butterfly Tour Stop #2

The second stop of the Release the Butterfly Tour brought Tracie & Bailey Pretak to Lancaster, Pennsylvania, the hometown of the Stern family, whose daughter Bella, is affected with ARCI-congenital ichthyosiform erythroderma (ARCI-CIE)

Eight individuals affected by ichthyosis were in attendance: Bailey Pretak, Mikela Murphy, Abby Evans, Bella Stern, Daniel Saylor, Brooklyn Taylor, Alec Kober and Evan Musso. Hunter Steinitz, who is affected with harlequin ichthyosis, also made an appearance via FaceTime as she is studying abroad in London.

The event featured its signature interview portion, entitled Behind the Butterflies. Panelists Bailey Pretak, Mikela Murphy, and Abby Evans were questioned about living with a rare genetic skin condition. Adding a special touch to the day's event, Dr. Zaenglein, a dermatologist from Hershey, organized a "family gathering" prior to the concert to give ichthyosis families an opportunity to connect.

Also, earlier in the day, Bella Stern and her older sister, Ava, wanted to put their own special touch on the fundraising and awareness efforts. Bella sold drinks in front of her house, while Ava got together with three of her friends to make bead jewelry to sell. The girls surpassed their goal of raising \$100, and contributed \$290 to the event's total. "Their enthusiasm

and excitement was so contagious and added a special touch to the event," said Tracie Pretak.



- Bailey Pretak (Wilcox, PA) Vocal/Dance/Piano Accompaniment
- Tracie Pretak (Wilcox, PA) Vocal/Piano Accompaniment
- Mikela Murphy (Baltimore, MD) Viola
- Mark Saylor (New Cumberland, PA) Bass Guitar
- Nicole Saylor (New Cumberland, PA) Vocal/Piano Accompaniment
- Dominique Benninger (Camp Hill, PA) Vocal/Guitar
- Brittany Leitzel (Lancaster, PA) Vocal
- Ross Bish (Ridgway, PA) Vocal/Director of Group Song
- Sarah Timm-Hess (Lancaster, PA) Vocal
- David Timm (Lancaster, PA) Vocal
- Leah Timm-Wolgemuth (Manheim, PA) Vocal
- Hannah Timm (Havre de Grace, MD) Vocal
- Matt Macis (Baltimore, MD) Vocal
- Liz Fulmer (Lancaster, PA) Vocal/Guitar
- George Swank (Lancaster, PA) Vocal/Mandolin
- Abby Swank (Lancaster, PA) Vocal
- Asa W. Carns (Clearfield, PA) Piano/Organ/Accompaniment
- Melody, Juliana & Savannah Saylor (New Cumberland, PA) Vocal



BATTER UP!

Boston Red Sox

Labor Day Weekend is the perfect time for barbeques, picnics and baseball! The Robinson family, whose daughter Sienna, is affected with epidermolytic ichthyosis (EI), organized the FIRST Day Out with the Boston Red Sox on Sunday, September 6. Several FIRST families and friends watched as the Red Sox took on the Philadelphia Phillies. Joining in on the fun was the Hamill family, whose daughter, Lauren, is affected with harlequin ichthyosis. The day turned out beautifully and was capped off with an exciting win for the Red Sox. Through ticket sales and donations, the event raised \$1,585. Many thanks to the Robinson family for their passion and continued support, and to everyone who came out to raise awareness for a very worthy cause.



Cleveland Indians

Family and friends of Emma Klima, who was born with epidermolytic ichthyosis (EI), got together for the fourth time to support FIRST at Progressive Field and watch the Cleveland Indians take on the Los Angeles Dodgers on Friday, August 28. Not only were attendees treated to Dollar Dog Night and fireworks, but the Indians also won the game! Adding to the victories, the event raised \$420 for FIRST. Thank you to all the supporters who came out to cheer on the Indians and Emma!

Butterfly Greeting Cards

A gracious shout-out to Adam Klafter who sold his signature "Butterfly" greeting cards to raise money for FIRST as part of his project for his bar mitzvah. Adam, who has epidermolytic ichthyosis (EI), designed the butterfly artwork when he was eight. He raised \$355 for FIRST's programs and services.

LulaRoe Fundraiser

LulaRoe by Corey held a clothing fundraiser to support the Smith family. The event raised \$88 for FIRST. Way to go!

The Thomas Family Raises Awareness in Hong Kong

Roger and Tina Thomas lectured at a local school in Hong Kong about their daughter, Mui, who is affected with harlequin ichthyosis. The school was so moved by the speech that they donated over \$700 to FIRST.

Thank you to the Thomas family for continuing to raise awareness of ichthyosis around the world! **Learn more about Mui's story at the Girl Behind the Face:** <http://thegirlbehindtheface.weebly.com/>.



Penny Challenge

At the Northwestern University patient picnic, Michael, Aurora and Matthew Green presented FIRST with a check for \$254.44, raised through a school penny challenge! Great job!



4th Annual Dane's Friends for FIRST Concert

In honor and loving memory of Dane Christian Phelps (12/21/04-6/25/08)

The Phelps family held the 4th annual Dane's Friends for FIRST Concert at the Flint Center in Cupertino, California, on September 12. A silent auction kicked off the event as over 400 members of the community joined in to support the cause and enjoy a special evening of entertainment and ichthyosis education. This year, Jean Pickford, CEO of FIRST, took to the stage to share FIRST's mission and introduce this year's headlining act, Sons of Serendip, fourth place runner up on Season 9 of America's Got Talent. Sons of Serendip were followed by a variety of local and professional musicians, singers and dancers. A spectacular evening was had by all. Thank you to the Phelps family and Dane's Friends for FIRST committee and volunteers for your continued commitment. The event raised nearly \$50,000 in honor of Dane and his legacy to FIRST.



Testimonial Dinner

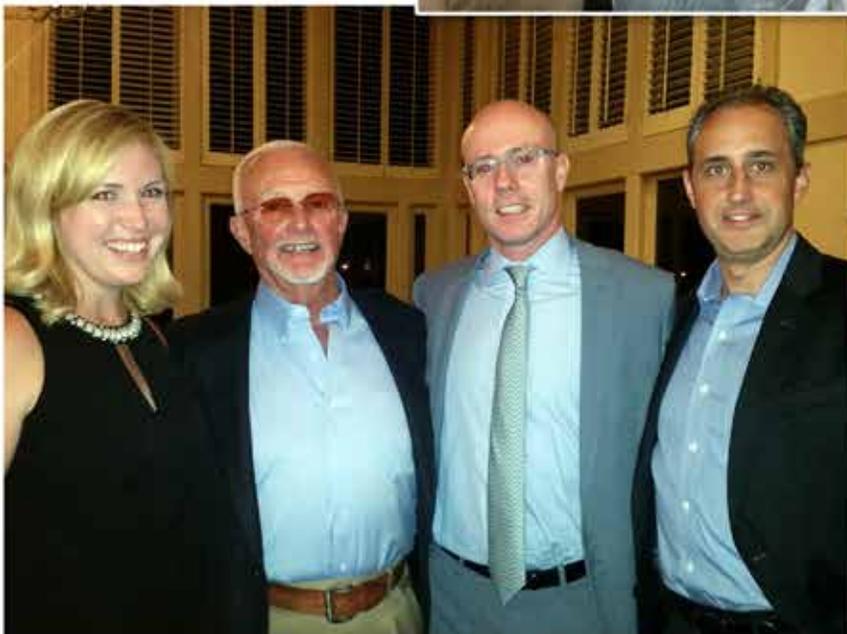
Over 70 guests joined with FIRST as we proudly honored Kelly and Mark Klafter on September 18 at the Country Club of the South in Johns Creek, Georgia. The Klafters have been fiercely committed to the mission of FIRST since their very first introduction to the organization nearly 13 years ago, when they became the proud and loving parents to their son Adam. Adam was born with epidermolytic ichthyosis. Over the past 13 years, both Kelly and Mark have taken an active role in FIRST, by attending and participating in several FIRST National Conferences and regional Patient Support Forums and hosting several fundraisers, raising over \$150,000 to support FIRST's valuable programs and services.

Kelly and Mark continue to work to unite families affected by this rare genetic skin condition. Kelly serves as a volunteer in FIRST's Regional Support Network, where she connects with families who have a child recently diagnosed with ichthyosis. Mark often answers questions posted by families on the FIRST Facebook group page and serves as a guest "Dad" blogger on the FIRST Blog. Both Kelly and Mark guide new families through challenging times with a sense of understanding, compassion and a much-needed laugh. Parents of newly diagnosed children hear about Adam's successes and the environment of love and support Kelly and Mark created for both Adam and his older brother, Matthew.

Their participation in FIRST has helped shape the organization to what it is today, the leading global patient advocacy group for individuals with ichthyosis. Mark served on the FIRST Board of Directors for several years, including a term as the organization's Chief Financial Officer.

The event, which raised over \$39,000, was a spirited evening of friends and family reuniting, guests mingling, and a special educational video presentation. A touching tribute video was also presented, comprised of personal messages from FIRST families about the role Kelly and Mark played in their lives. Speakers for the evening included Kelly's parents, Michael Briggs and Edie Wohlgang; Frank Selvaggio, Director, National Sales, SE Region, Spectrum Reach; Dr. Dennis Roop, professor of Dermatology at the University of Colorado; and Jeffrey Hoerle, President of the FIRST Board of Directors.

When the speeches and tributes came to an end, it was clear that FIRST had made the very best decision for their 2015 honorees, and that each and every attendee was proud to take part in such a deserving tribute.



Surf's Up for the 2016 National Conference

June 24 - 26 • San Diego Marriott Mission Valley



National Conference Program At-A-Glance

Thursday, June 23	Evening Social (optional)
Friday, June 24	Educate & Learn
Bathing, scalp care, exfoliation breakouts—How to deal with infections, overheating & itching—Discover the impact of nutrition and emotional wellness—Hear about and share natural product ideas among others—Ideas on ichthyosis equipment, gear, and useful tools—Personalized breakouts for your skin type—Optional offsite group activity!	
Saturday, June 25	Inspire Yourself & Others
Inspirational talks about living with a visible difference—Teens & siblings speak out from their perspective—Research updates from the lead investigators themselves—RAISE Campaign & fundraising ideas—Closed support sessions for moms, dads, teens, men, women, and other family members—Beach party, awards, dancing & fun!	
Sunday, June 26	Connect for a Lifetime
Tips on enjoying beauty & spa splurges—Learn the difference between over-the-counter products vs. prescriptions—How to avoid and treat blisters, fissures & infections—Best practices for dry eyes & ear care—What to expect for school-aged children— Cherish how you are part of this amazing and unique community!	

Clinical Appointments

All affected individuals and their families have the opportunity to meet with expert physicians on Saturday, June 25, for a one-on-one free 15-minute private consultation. Participation is optional.

Calling All Tweens & Teens

There will be breakouts and hangout time throughout the weekend. Special teen & sibling panel and opportunities to interact with your peers. Many activities planned!

Participate in Research

On Saturday, June 25, investigators from Yale University will be enrolling patients in the Yale Registry, the only US-based program focused on better understanding disorders of keratinization from a genetic and clinical perspective. This group continues to make remarkable progress, largely thanks to the participation of FIRST members. For new enrollees, the study will involve providing a saliva sample, photographs, and completing a questionnaire. For those already enrolled, there will be an opportunity to update information. Sign-ups will be included on the registration form.

Registration Fee

This discounted registration fee has been made possible by a generous grant from the Lennox Foundation

Adult (ages 13+)\$200
 Child (ages 5 to 12).....\$100
 Preschool (ages 2 to 4)..... \$25
 Infant/Toddler.....No charge

The registration fee includes the Thursday social, Friday breakfast & lunch, Saturday breakfast, lunch, & dinner, and Sunday breakfast & lunch.

Kid-a-Palooza

Fun, safe, and supervised activities for children ages one to completed fifth grade. Pre-registration required.

Discounted Hotel Rooms

Special room rate at the San Diego Marriott Mission Valley is \$129++ flat occupancy. Hotel has easy access to many great attractions—Old Town, Mission Bay, Rio Vista Trolley, SeaWorld®, Petco Park, plus more.

Stay Tuned In...

#FIRSTNC16



Registration opens November 1, 2015 at www.firstskinfoundation.org/conferences





Foundation for Ichthyosis & Related Skin Types, Inc.®
2016 National Conference - San Diego
Financial Aid Application



Application Deadline: February 1, 2016

Name: _____

Address: _____

City: _____ State: _____ Postal Code: _____

Province: _____ Country: _____

Home Phone: _____ Work Phone: _____

Cell Phone: _____ Email: _____

How many people will be attending the conference? _____

Name: _____ Age: _____ Type of Ichthyosis: _____

Have you attended a FIRST Family Conference before? Yes No If so, when? _____

How many persons are you applying for financial aid for? _____ Adults (13+) _____ Children (under 12)

Annual Family Income:	_____ Under \$20,000	_____ \$51,000 - \$60,000
(please include a copy of	_____ \$21,000 - \$35,000	_____ \$61,000 - \$75,000
Your most recent W-2)	_____ \$36,000 - \$50,000	_____ Over \$75,000

Financial Aid recipients are required to volunteer 4 hours at the National Conference

Scholarships are awarded for full and partial conference registration fees and hotel accommodations.
 Scholarships are not awarded for travel to/from the family conference.
 Funding is limited; full and/or partial awards are not guaranteed.

Please return this form to the FIRST office by February 1, 2016.

*Applications received after February 1 will not be considered.
 FIRST and its officials reserve the right to disqualify any application that is incomplete.*

Foundation for Ichthyosis & Related Skin Types, Inc.® • 2616 N. Broad Street • Colmar, PA 18915
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2016 National Conference – *San Diego!* June 24 - 26, 2016



Look for updates
on Twitter
#FIRSTNC16

*It's not too early to start planning
for the 2016 National Conference-San Diego!*

**Sneak Peek
inside on
page 14!**

Visit firstskinfoundation.org/financialaid
for a financial aid application
to the 2016 National Conference - San Diego.
The deadline for applications is February 1, 2016.
Application available on page 15.

*Registration information will be available in January 2016.
We'll continue to share updates throughout 2015 and 2016.*

San Diego Marriott Mission Valley
8757 Rio San Diego Drive, San Diego, CA 92108 619.692.3800

