FIRST
Foundation for Ichthyosis & Related Skin Types®
Educate • Inspire • Connect

Ichthyosis Focus

Summer 2014 *A Quarterly Journal for Friends of FIRST* *Volume 33, No. 2*

Connecting at the Crossroads ...and Beyond

The 18th Biennial FIRST National Family Conference took place in Indianapolis, from June 20-22. By all accounts, the three-day event, “Connecting at the Crossroads,” filled with workshops, panel discussions, entertainment, and special opportunities for connection, was an astonishing success, as well as our highest attended conference to date (407 attendees in total).

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Photo by: Rick Guidotti

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Collaboration, Connecting and a Family Conference Like No Other…

**Jean R. Pickford,
Executive Director**

This past spring has, by far, been the busiest season of the year, for the FIRST staff and community. Not only did our families step out and embrace Ichthyosis Awareness Month, with every conceivable ounce of gusto, but we prepared and executed the most highly attended National Family Conference on record! If you were unable to participate in IAM or to attend the conference, we dedicate this issue of the Focus to you! We are bringing you front row seats to the IAM selfie campaign, and the many unique and exciting grassroots events that took place throughout the month of May. Our hope is, simply put, to give you hope. Our wish is that you are inspired in the very same way we've been inspired, and that you read these messages and stories feeling as though you are part of a community whose voice is now more thunderous than ever before.

We bring you a conference wrap-up, including all of the sessions, highlights, and surprises! You'll meet a photographer turned "difference advocate" and a young man, with CIE, who skyped into the conference from his three-month hike across the Pacific Coast Trail. You'll read a research update from medical experts in the field of ichthyosis, collaborating tirelessly with one mission in mind: finding the best possible treatments, and an eventual cure. Plus you'll meet families from around the world and some who are new to FIRST and looking forward to building a life-long relationship with as many members as possible.

Most of all, we hope that you read these pages and feel the joy it brings to all of us in the FIRST office. We are proud to be a part of this extraordinary community and have a deep gratitude for each and every one of FIRST's members.

Enjoy!

Jean Pickford

Correspondence Corner

"Our first FIRST conference was amazing! *I felt like I was home being with all of you. I can say for the first time ever, I felt so comfortable sitting down in public to have a meal without all the stares and whispering comments behind our backs. I love my ichthyosis family!"*

Alicia Morales

Dear Jean,

We just wanted to write a quick note of appreciation to FIRST. Our son, Timothy, has lamellar ichthyosis. He is 14 years old and just graduated from 8th grade. My husband and I still remember when he was born and he received the diagnosis. Holy Cross Hospital put us in contact with FIRST and we attended the conference in Philadelphia.

Over the years, FIRST has put us in touch with other affected families. We even had the chance to meet a girl with lamellar ichthyosis who was visiting the Washington DC area from India. It was quite an experience.

We are so proud of Timmy. He was elected President of the Student Government this past year. He won two awards for Christian Sportsmanship and Service. He even wrote about his experience with lamellar ichthyosis for his high school entrance application.

Mary & Tim Harper
Kensington, Maryland

Dear SR Lotion,

My son Zeeshan was born with ichthyosis. We had been searching for a lotion that would help to lessen the build-up of scaly skin. Then we met a family with a child of the same condition. The family told us about SR lotion, and they called it "amazing." I call it "a miracle in a bottle." Skeptical as I am, I hesitated placing an order for the product not knowing whether it would work for us. The lotion arrived and we started using it straight from the bottle because the build-up of the skin was immense. Within a few days we started noticing that the skin had softened and in some areas dried and started flaking off. With a regime of SR lotion twice daily and a bath once a day, the skin after seven days was nearly clear. It is certainly a big turnaround for Zeeshan and has also changed our lives. I cannot recommend SR Lotion enough!

Nafis Younis

This information is provided as a service to patients and parents of patients who have ichthyosis. It is not intended to supplement appropriate medical care, but instead to complement that care with guidance in practical issues facing patients and parents. Neither FIRST, its Board of Directors, Medical & Scientific Advisory Board, Board of Medical Editors, nor Foundation staff, and officials endorse any treatments or products reported here. All issues pertaining to the care of patients with ichthyosis should be discussed with a dermatologist experienced in the treatment of their skin disorder.

Does Your Employer have a Matching Gift Program?

Employee Matching Gifts are contributions from a corporate employer that match contributions to a charitable organization by a corporate employee. More than 1,000 American companies have adopted corporate matching gift plans to help support nonprofit organizations. Usually, employer matching gifts are dollar-for-dollar, but some companies will give double or even triple the original donation. Some companies even match contributions made by retirees.

Please check with your Human Resources Department to see if your employer matches gifts. ***Contact Grassroots Development Coordinator Chris Wassel at cwassel@firstskinfoundation.org, for more information on matching gifts as well as any questions regarding grassroots fundraising.***

Ichthyosis Awareness Month

FIRST is so very appreciative of the generosity of the ichthyosis community. If this year's IAM told us anything, it's that we are surrounded by a community of loving, caring, and committed individuals. And although it is rather small numbers, our entire community makes great efforts, each and every day, to offer support, raise awareness, and connect. We'd like to express our gratitude for the outstanding fundraising efforts of our members and families, and to all those who participated in the amazing IAM "selfie" campaign (photos above from our online campaign).

Balloons for Brenna

This year IAM took on a life of its own, as families like the Westlakes, whose daughter Brenna is affected with harlequin ichthyosis, stepped out and raised awareness sky high! Initially, they set a goal of raising $3,000 with their online campaign, Balloons for Brenna. In the end, the Westlakes surpassed their goal, raising over $3,600! A big thank you to their family and community for their drive, passion, and commitment to raising awareness!

IAM Wine Tasting

A big thank you to the Cina family, whose daughter, Portia, and son, Myles, are affected with ichthyosis en confetti, for hosting their 7th Annual Wine Tasting event in their home on May 31. Portia even sang for the crowd while playing piano! It was a warm and festive way to wrap up IAM 2014. Plus, they raised over $2,800, including a donation from Sean's employer, Toyota. Thank you to the Cinas and their entire community for your unwavering support!

T-Shirt Fundraiser

The Fasciano family, whose son Evan is affected with harlequin ichthyosis, created a whimsical "fun in the tub" t-shirt, with the slogan "we're all in this together," specifically designed to raise awareness of ichthyosis, as well as funds for FIRST. The t-shirt was sold online and mom DeDe worked tirelessly at preparing, organizing, selling, and shipping, raising nearly $1,150! We are so grateful for their continued support and commitment and to their fantastic eye for a fun, meaningful, and creative design.

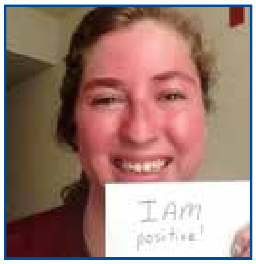
Cookie Sale

During IAM, Kimberly Cole, whose daughter Harper is affected with erythrokeratoderma variabilis (EKV), held a home-baked cookie fundraiser, raising $416! The next day her coworkers also jumped in on the action by giving an online donation of $100 for the "leftovers." It was a delicious day of fun and family! Thanks so much for all your efforts.

Stay tuned for the post-season MLB wrap up in the fall Focus!

Coin Collecting, Phantom Tea, Newsletter & More!

During IAM, long-time FIRST member and supporter, Nancy Osentoski, affected with lamellar ichthyosis, took “grassroots” awareness to a new level! Nancy reached out to her community in every way possible. Not only did she hand out educational materials, while collecting “coin” donations at a local retailer, but there was the feature story in her local church newsletter. At her church, she spoke about ichthyosis, FIRST, and our Phantom Tea Fundraising event (an event that she wholeheartedly participated in). Nancy raised $250.00 at her coin collection and $445.00 through the Phantom Tea promotion. We are so proud of Nancy for being such a strong self-advocate. She is role model and a very dear member of the FIRST family.



Social Media Campaigns

Bailey Pretak, affected with lamellar ichthyosis and Kalyn Clark, affected with congenital ichthyosiform erythroderma (CIE) turned their social media pages into full-blown awareness channels! Bailey explained about her ichthyosis on her Facebook page, encouraging her network to find out more and to donate to FIRST, as well as posting photos of her journey this year to meet several other FIRST members around the country. Kalyn embraced our IAM selfie campaign, by posting a selfie with an inspiring message every day of the month. Way to go girls!

Tune-in Radio Carly

Carly Findlay, affected with Netherton syndrome, once again posted a daily story reflecting “life with ichthyosis” (even while she traveled around the world). Carly has a knack for finding the most unique and special qualities in all the people she meets affected with ichthyosis. Her IAM blog series is an amazing tribute to them, their families, and the entire ichthyosis community. We are delighted to have been included in the line-up for the past two years! Thank you for your courage and commitment Carly!

Some ecards

Member Tara Orme-Latrielle, whose son Myles is affected with lamellar ichthyosis, designed an inspiring Someecard that truly expressed the essence of ichthyosis awareness month. Very creative, clever and thoughtful, Tara! Thank you kindly.

I understand you're not an Ichthyosis parent, so spreading awareness isn't a priority. But the day before my child was born I was not an Ichthyosis parent either.
www.firstskinfoundation.org
someecards

School Newsletter

The Robinson family’s daycare center dedicated a page of their May 2014 newsletter to their family, whose daughter Sienna is affected with epidermolytic ichthyosis (EI). They shared information about her particular disorder, and what her day-to-day life is like, as well as information about FIRST. What a wonderful way to raise awareness throughout the local community.

Apron Sale

Kitty Wall, grandmother of Joella and Addison, both of whom are affected with erythrokeratoderma variabilis (EKV), held an online Apron Sale. She handcrafted a selection of unique, one-of-a-kind aprons using varied patterns and materials (some were even vintage). There was truly an apron for every style. In fact, you can find Kitty’s Apron sale on her Facebook page. Thanks for sharing your wonderful skills and creativity Kitty!

Ace in the Hole, Beach Run-Walk

Ace in the Hole Foundation hosted its fifth annual Lido Beach Run/Walk at Lido West Beach on Long Island, New York. The event was held in honor of 1st Lt. Michael LiCalzi who died in action in Iraq on May 11, 2006, and whose twin brother, Greg LiCalzi Jr., is the President and Founder of Ace in the Hole Foundation, serves on the Board of Directors of FIRST and is affected with lamellar ichthyosis. This year’s event, attended by over 350 people, raised a new record of over $90,000. Proceeds from the fifth annual Run/Walk will support Marines and their family members from 2nd Tank Battalion, 2nd Marine Division; 1st Lt Michael LiCalzi Scholarship administered through Marine Corps Tankers Association for current and former Marine Tankers; Wounded Warrior Project; Huntington’s Disease Society of America; and FIRST. FIRST member, and Board of Directors member, Denise Benedetto, whose son Marc is affected with lamellar ichthyosis, attended the event with her family and wonderful friends. A sincere thanks to all who participated!

Connecting

Also of note, we were delighted that for the very first time, six families with children affected with harlequin ichthyosis had the rare opportunity to finally connect at the family conference.

The gathering unofficially began on Thursday night as attendees sprinkled into the Hilton Indianapolis, filling the hallways, lobby, and restaurants with an air of excitement and anticipation. A wonderful group of volunteers began ushering members who had registered for a clinical screening and/or genetic testing appointment with our volunteer team of physicians, to the designated screening area. Screenings continued again on Friday morning while the rest of the attendees registered in Monument Hall-each family greeted with an overflowing 30+ lb. bag of samples! Also, during registration, two Indianapolis Colts cheerleaders helped to create a warm and inviting atmosphere, as they assisted the FIRST staff in greeting our guests.

FIRST Board President, Mike Briggs and his grandson Adam Klafter, kicked off the conference with a warm welcome and called attention to the mission of FIRST, the returning families, and to all the new families in attendance (65 new families in total!). Members came from all corners of the world including families from Israel, Canada, Italy, Australia, and Japan!

> *"FIRST has been a lifeline for my family. I don't know where we'd be without them." -Bhugwant Sethi, Japan*

Our keynote speaker, Rick Guidotti, then took the stage, his energy permeating the room, as he explained his philosophy for "seeing the beauty in all of humanity," with regard to visual differences. He spoke of the beginnings of his foundation, Positive Exposure, and his recent connection to the ichthyosis community. But his time with us didn't end there. He co-moderated a teen open-discussion session in the early afternoon, and then spent the rest of the day generously photographing anyone who wished to be photographed, in none other than the parking garage, as the lighting was best suited for photos. Rick is an award-winning photographer and an admirable humanitarian that we are truly honored to call our friend. The smiles he inspired at the 2014 National Family Conference will not soon be forgotten.

> *"It's not about competing with the beauty standard set by Vogue; it's about setting our own beauty standard. People either stare or look way, and looking away can be more painful than stares. So we need to steady our gaze long enough to see the beauty in difference, to look around the diversity to see what we all share – humanity." –Rick Guidotti*

As the younger kids settled into a fun day of games and crafts at the onsite Kids Camp, parents and affected members chose from a selection of Disease Specific Type sessions.

Following the conference kick-off, and throughout the first two days, attendees also enjoyed participating in our first FIRST VIP media booth, where they were encouraged to share their personal stories, their impressions of the event, and their special takeaways regarding their Indy experience. Members from all backgrounds and all stages of life eagerly shared their thoughts. Some videos were quickly edited onsite and posted via social media, while others will be posted in upcoming weeks to FIRST's YouTube channel.

During lunch on Friday, attendees played a fun and interactive FIRST trivia game, and then viewed an uplifting "parody" video of members dancing and singing to the hit song, "Brave," by Sara Bariellas. Some even felt compelled to dance along! Following lunch, attendees had the option to attend workshops on skin management, genetics, or dealing with the emotional roller coaster of an ichthyosis diagnosis.

Meanwhile teens and siblings enjoyed a fun and lively open discussion session, moderated by Program Director, Moe Wenik, and Rick Guidotti (beach ball ice breaker included). Teens were able to truly let loose in a friendly, judgment-free setting.

On Friday afternoon, attendees had the choice of attending the Pediatric or Adult 'Ask the Experts' Panel, where our ichthyosis expert medical panel answered questions one-on-one, from the audience.

The day ended with a Fun-Raising Mocktail Party, led by Development Coordinator Chris Wassel, where attendees learned fun and easy ways to participate in grassroots fundraising. The Cossel, Klafter, Kocher and Robinson families, who have all had FIRST fundraising success, shared their stories, and answered questions on the best practices for holding events both live

at the Crossroads …and Beyond

... continued

in-person and online. After an amazing day of activities and connecting, everyone enjoyed a beautiful evening in downtown Indianapolis.

Day two started early, with a Board of Directors meeting. All board members were excited for the day ahead, and encouraged by what they had seen at the conference thus far. A recap of the conference preparation and public relations was discussed, and the group viewed a clip from WISH-TV, that aired on the local Indianapolis CBS affiliate on June 17. The clip featured the Swisher family, local FIRST members. And, Dr. Len Milstone presented an update to the latest news in ichthyosis research.

> *I met someone with CIE for the first time, and it was like 'Ah, I found my people!' It was so exciting!" -Anke Fronz*

After breakfast, the Kids Camp kicked off once again, and conference attendees eagerly dispersed into breakout sessions focused on the latest ichthyosis research, techniques for skin, eye and ear care, and a workshop focused on best practices for beating the heat. Meanwhile teens were invited to a session where they were free to discuss topics of a sensitive nature like relationships, dating, and more.

Lunch on Saturday was particularly riveting, as not only were the Volunteer of the Year Awards, Frances Bernsteil Awards, and Distinguished Services Awards given out to our amazing team of volunteers and fundraisers, but we also had the privilege of skyping with Brian Gass, a member affected with CIE. Brian is currently hiking the Pacific Coast Trail and spreading his message "do what you love and your skin will follow."

> *"FIRST has been instrumental in furthering the research of ichthyosis on many levels. Most importantly, the participation of the FIRST family members is unparalleled." – Dr. Amy Paller*

The teens had a blast that afternoon during a field trip to the mall, as other attendees had the options of learning about specific skin care products and techniques, attending an informative discussion regarding the bathing process, additives, and bath time habits, or gaining some tips for wellness and stress management.

The day ended with attendees gathering in groups that best suited them for supportive and honest discussion about life with ichthyosis. The groups included the Mom's, Dad's, Young Adults Group (YAWI), Women's, and Men's. There were even special groups for extended family, like the Grandparent's Group, and the Spouse's Group. Many reported enjoying a real and intimate connection with others that made them feel comfortable and understood. A big thank you to our long-time members who stepped up and offered their wisdom and support.

The Saturday Night Dance Party left few in their chairs, and many inspired by the sheer talent amongst our young members. Ema Hodgkinson performed a beautiful dance routine followed by some astonishing vocalists including, Abby Mast, Kaylee Brown, Taylor White, Jackson White, Treasure White, and Portia Cina, who also played the piano. A special duet was performed by Hunter Steinitz and Lydia Wilson. And of course who could forget the wonderful musical theatre pieces, choreographed by Bailey Pretak and Natalie Hann, performed by the kids and teens. Encore! Encore!

> *"It was nice to be around some of the new dads, and some of the veteran dads. It was very emotional, but very comforting. They made me feel hopeful for the future."*
> *- FIRST member*

A robust raffle, raising over $3,600, added to the fun. Thanks to volunteer and member Chrissy See, for her dedication and hard work in soliciting such top-notch prizes that added a little extra magic to a truly special evening. Dr. Bob Silverman added his own magic, as he was so inspired by Brian Gass earlier in the day, that he publicly pledged to match every dollar of $1,300.00, if collectively this amount was raised throughout the evening. His goal was to help Brian continue his journey (additionally, Brian's proceeds from his endeavor are being split with FIRST). Within minutes the $1,300.00 was raised!

Sunday, the final day of the conference, began with two back-to-back Teen Panels, where teens with ichthyosis and their siblings candidly answered questions from parents, other teens, and other affected adults, sharing an inside perspective on life with ichthyosis. (A brief summary of what they shared can be found on page 12.) Meanwhile, more breakout sessions were offered to help attendees learn how to turn negative emotions into positive ones, aging well with ichthyosis, prepare for the school year, and learn the best ways to handle a "bullying" situation.

The final sessions of the conference included an inside look at how to prepare for doctor's visits. During the conference Drs. Keith Choate and Philip Fleckman were interviewed about this very topic, both feeling strongly about the need to prepare before you sit down with a specialist, in order to get the absolute most out of your visit. Their clip will be available on FIRST's website in the coming weeks. Other sessions included a lively panel discussion of bloggers, tweeters and Facebook friends who took the stage for a Power of Social Media Q & A. Chris Wassel also met with anyone interested in holding a future fundraiser while other families learned about the summer and fall camps available for children with skin disorders, and the many benefits of attending.

Phew…lunch on Sunday was filled with lots of hugs, tears, number exchanges, and more. A particular highlight was the photo slideshow prepared by FIRST Public Relations Coordinator, Lisa Breuning. It was an uplifting presentation of the special "moments of the conference that melt your heart," and the absolute perfect ending to a spectacular three-day event.

In upcoming weeks we will share a more in-depth summary, including points of discussion, powerpoint presentations, video interviews, and articles regarding the sessions that took place during the conference. You can also search #FIRSTNFC on Twitter to see all the amazing photos and comments that have been posted by FIRST staff and conference attendees. We hope you've enjoyed the 18th Biennial FIRST National Family Conference recap. And hopefully we will meet even more families when we reunite in 2016!

Friday, June 20, Breakout Sessions:

- Autosomal Recessive Congenital Ichthyoses
- Epidermolytic Ichthyosis
- Netherton & Related Skin Types
- X-Linked Ichthyosis/Vulgaris
- Syndromes & Ultra-Rare Ichthyoses
- Your Skin: Inside & Out
- A Whole New World
- Genetics 101 session
- Panel Discussion: Pediatric & Adult

Saturday, June 21, Breakout Sessions:

- What's Up with Research
- Head to Toe
- It's Getting Hot in Here
- Stop, Look & Listen
- Relationships, Dating and more (teens)
- Everything but the Kitchen Sink
- Soak and Scrub
- Stressed Out
- Let's Get Real
- Unique Considerations for Women with ichthyosis

Sunday, June 22, Breakout Sessions:

- How Rude, Can You Believe They Said That?
- It's Elementary, Dear Watson
- Could it Happen to Me?
- Panel Discussions: Teens

Full program available at wwww.firstskinfoundation.org

Regional Support Network

Be more involved and connect with other FIRST members. The Regional Support Network (RSN) has many opportunities for member involvement. Is there an area that interests you?

Ambassadors are regional support volunteers, with an opportunity to be “specialists” in one of seven key topic areas. As an Ambassador, pick the area of interest in which you have knowledge, and be one of the lead support volunteers in that particular area. All Ambassadors will continue to be asked to connect with families or individuals by region and/or ichthyosis type as the need arises. Specialists are needed in School Resources, Health Insurance, Social Security/Disability, Physician Referrals, Fundraising/Awareness, Meeting Hosts, and General Support. If you are interested in becoming an Ambassador please contact Moureen Wenik, mwenik@firstskinfoundation.org, or call Moureen at 215-997-9400.

Are you the FIRST to Know?

Join in on the one-hour phone calls for members and talk to others. The calls are scheduled on Sunday evenings. The schedule for upcoming calls can be found on the FIRST website, www.firstskinfoundation.org.

Did you miss the 2014 Family Conference?

Patient Support Forums are smaller one-day meetings, and are held on the odd years when there is no national conference. The meetings consist of a medical lecture in the morning, which is followed by an opportunity to ask questions of the doctor(s). The afternoon program includes support networking, sharing advice with other families, and making connections. The 2015 meetings will be held in Canada, Florida, Arizona and Minnesota. Dates and locations will be announced by the end of the year. Most meetings are held in the late spring through early fall.

Upcoming Events

3rd 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 will, once again, host a spectacular concert including musicians, dancers and performers from around the world on Sunday, September 7, 2014. The event will take place at the Campbell Heritage Theater in Campbell, California. Tickets will be on sale soon through the Heritage Theater Box Office. Visit www.danesfriendsforfirst.com for ticket updates. ($40.00 Adult 13+, $25.00 Child,12 and under)

What's Up with Research?

Medical Experts Present Latest News in Ichthyosis Research at National Family Conference

Collaboration was by far the word-of-the-day, with regard to the current culture of the ichthyosis research community.

During the What's Up with Research session on Saturday morning, Dr. Leonard Milstone began by calling attention to the precise goals of ichthyosis research: understanding the medical and social issues, discovering ways to intervene to improve outcomes, and to effectively disseminate new knowledge. He also mentioned the critical importance of advocacy groups to stay involved, be a non-negotiable step in the process, and to continue to create opportunities for affected families and doctors to connect and learn from each other. With regard to the current state of research, Dr. Milstone said, "Advances in technology have led to more rapid, more informative, and more precise information and discoveries than imagined even 25 years ago." Yet, Milstone also noted, "This new technology, which is a direct result of investments in research, is expensive." And with the research expense rising as government support is decreasing, Milstone further emphasized that large-scale collaborations and private foundations will play an increasingly important role in supporting research.

Another key focus of the session was the call for worldwide collaboration. Dr. Bill Rizzo introduced the STAIR Consortium, an international multi-center, collaborative research project focusing on genetic diseases that are caused by defects in Sterol (cholesterol) And IsopRenoid metabolism. The STAIR Consortium was created and funded by the NIH and NCATS. Its goal is to establish the natural history of rare diseases, identify biomarkers for future therapy studies, investigate new treatments, discover new diseases, and to train new physicians/researchers to work on rare diseases. Rizzo, one of the world's leading researchers of Sjögren-Larsson syndrome, explained, "Access to biological data from as many patients as possible is critical for understanding the disease." He further emphasized that the input from patient advocacy groups is a necessary part of this type of collaboration. STAIR is currently working with seven patient advocacy groups worldwide, including FIRST.

Dr. Choate provided the conference attendees with an update about the promising progress he and his team at Yale have made on the Gene Discovery Project. He mentioned that the Gene Discovery Project began at a FIRST family conference, in one small room, at the 2010 conference in Orlando, Florida. However since then, the research incurred tremendous growth. Including the 57 families recruited in Indianapolis this year, they've recruited 375 total families and so far, they've been able to determine a genetic diagnosis for 247 of those families. Since the Denver conference in 2012, they have also identified three new genes which cause ichthyosis. Choate also noted that advances in genetic sequencing technology has made genetic diagnoses faster and much less expensive. Of the 247 families who were able to obtain a genetic diagnosis from Dr. Choate and his team, 80% of them were able to get that diagnosis through their "pre-screening" process, which looks at the 11 most common genes that cause ichthyosis. This "pre-screening" test now costs the Yale lab between $30 and $50, which is a huge drop in costs from a decade ago. "Learning more about the specific genetic causes of ichthyosis will enable future research to develop effective therapeutic pathways for treating ichthyosis," Choate added.

Dr. Brittany Craiglow introduced a prospective evaluation of infants and children with congenital ichthyosis, discussing the importance of further investigation into the relationship of the phenotype (the way a disease presents itself) and genotype (the way a disease is caused)of ichthyosis. Craiglow's evaluation process predicts that mass observation of infants can assist doctors and families in understanding and preparing for issues in growth and development. Specific medical issues observed include electrolyte disturbances, infections, and possible other medical complications, such as loss or obstruction of hearing or eyesight from birth through early childhood. Again, Craiglow also emphasized the need for a collaborative effort between doctors, patients, and patient advocacy groups so that proper management protocols for these medical issues can be established as efficiently and effectively as possible.

Dr. Phil Fleckman spoke about health related quality of life and patient reported outcomes from enrollees in the Ichthyosis Registry. The registry, which collected data directly from patients from 1994-2004, was a collaboration of FIRST's MSAB (Medical & Scientific Advisory Board) and was funded by the NIH. In addition to a clinical diagnosis, this type of doctor-patient collaboration has offered doctors critical information regarding the "real life" impact of the disease and opening a window into the day-to-day physical and emotional challenges that often accompany ichthyosis. He hopes to extend these studies to determine how quality of life changes as participants age, to include those enrolled in Keith Choate's study, and to add newer ways to assess the impact of ichthyosis on those affected and their families.

Judging by the close, supportive, and collaborative nature between our doctors, patients, and FIRST, we are poised for great strides in ichthyosis research.

Inspire

Do what you love and your skin will follow.

As many of you affected with ichthyosis already know, at times this condition can present enormous challenges. And yet, as many of you also know there are still other times when ichthyosis is simply a background hum to the music of life. Member Brian Gass, affected with congenital ichthyosiform erythroderma (CIE), is living, walking, and hiking proof that, although his ichthyosis is a part of his life's journey, it follows his lead, trailing far behind his pursuit of passions, dreams, and interests. Recently Brian contacted us to let us know he'd be doing a little traveling this summer. Well, actually a lot of traveling – 2,650 miles up the spine of the Pacific Coast Trail from Mexico to Canada, to be exact. Although he is an avid hiker, racking up "over a thousand trail miles on three continents," this journey will prove to be the journey of his lifetime. And for the benefit of others affected by ichthyosis who share in his love of the outdoors, periodically throughout the summer he will be reporting back to FIRST and on his blog: (http://hikeonthegoodfoot.blogspot.com/). Not only will Brian be sharing an up-close view of the most breathtaking terrain, but he will be sharing everything he learns and experiences about the care and safety of his skin along the way.

At this year's National Family Conference, Brian took the time to not only find a Wi-Fi connection in the "wilds," but to skype in and say hello! The audience was thrilled and one of our doctors was so inspired, he presented a $1,300 match for fundraising efforts for Brian's cause. (Brian is splitting his proceeds with FIRST).

We are happy to share Brian's mission and his message: do what you love first and your skin will follow.

Why is my skin red? 'Cause blue is taken!"

Teen Panel a Smashing Success at FIRST National Family Conference!

Two open and candid teen panel discussions, moderated by Program Director Moureen Wenik, took place on the final day of the National Family Conference. Nearly every seat full, it took only a minute for parents, siblings, and other affected members to enthusiastically ask questions, jot notes, and ultimately discover that this was as rare and unique an opportunity as any – getting inside the minds of teens! From how to keep their cool when strangers stare, to the pros and cons of parents "picking at their skin," these teens opened up and let the audience explore their situation, from their eyes; in their shoes; in their skin. Additionally, not only did the panel consist of those teens affected, but also included non-affected teen siblings for an even broader family member perspective on life with ichthyosis.

Some key takeaways from the discussion included:

Silence Isn't Always a Bad Thing: The teens seemed to agree that sometimes they are "quiet" about their situation because they are coming to terms with it themselves. "We don't always want to talk about what's happening every day. Trust that if it's serious enough, we will come to you," said one teen girl.

Listening is Key: Many teens encouraged parents to listen as carefully as possible. One teen remarked, "If you put a cream on me and I say it hurts, please listen to me and don't force the issue. Even if you've heard it works for lots of other people, it may not work for me."

Follow Our Lead: One teen remarked, "If I don't want my skin showing, I don't want it showing. If I want to wear leggings, I should be able to do so." Ultimately she encouraged parents not to worry, and to follow the emotional lead of their children. "If I'm happy and comfortable with how I look, or what I'm wearing, my parents should be happy too."

Public Grooming/Dusting: Parents were curious as to how the teens felt about them constantly picking at them or "dusting them off." Most teens agreed that they were, in fact, used to it and that the constant fussing did not greatly upset them. However, they also encouraged parents, that if it was not too much skin, perhaps they could wait until they got home. Another teen remarked that ultimately, "Parents should teach kids to check themselves, and make it a lifelong habit."

Leaving Home: Teens that are preparing to leave for college shared some concerns that they are currently addressing, including air conditioning, securing a private shower, and informing others of their condition ("The College Survival Guide," is available FIRST's blog, blog.firstskinfoundation.org). One teen leaving for college this fall remarked, "I worried about what my roommate would think, because I can't change my skin. But then I explained everything to her, and she said – no big deal. I have ADHD, does that matter to you?!" Another young adult from the audience offered advice based on her own college experience. "Talk to them, be honest and upfront with your roommates. It will also help by letting them know, so that they can support you, in case there is a medical issue – someone around you should know about your condition, particularly if you do not have family close by."

Photo by: Rick Guidotti

Overprotective Siblings: From the sibling perspective, it seemed that most of them had more of a difficult time dealing with the skin condition than the affected individuals. A few of them commented that they feel very overly protective of their sibling, and when people make comments or stare, they "lose their cool," and tend to want to react in an angry and aggressive manner. "I think it's normal to get upset for your sibling. However resorting to violent comments and behavior is never a good thing. Just try to explain the situation to them, and also, if it's a younger sibling, you don't want them to see you getting angry. It's not a good example," said one teen sibling.

Transitioning from a Small to Large School, or Starting School in General: The consensus was that having the parents, along with the affected child, go into classroom and inform people about their skin condition was a positive experience. However, one teen strongly suggested, "Make sure that the affected person is prepared to answer the questions themselves, even beyond when the parent is there. Make sure they really know their condition, and how it affects them, so they don't feel badly for not knowing what to say."

Speak for Yourself: For younger children, one teen suggested that maybe it's not one hundred percent necessary for them to always use the medical terms to discuss their condition. Perhaps if they use their own words to describe their skin, like severely dry, rather than a medical term, it would make the situation more relatable.

Using Your Sixth Sense: Humor – Sometimes turning an uncomfortable question or conversation on its head with a little wit, may be a great way to show peers there is more to you than your skin. One teen commented that whenever he is asked why his skin is red, he replies, "'Cause blue was taken!" Although this is not a solution in its entirety, it can really break the ice and lead to a more informative conversation.

We are enormously grateful to our two amazing teen panels for their courage and willingness to share an inside perspective on life as a teen with ichthyosis, and we wish them all the best of luck in all they do!

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Diya & Aliya's Friends (DAF)

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.

To apply for an award, please complete the DAF application form. All forms must be completed in English and submitted to the FIRST office. Individual awards will not exceed $250.00. Applications will be awarded two times per year; all applications must be received by April 30 or October 31 each year to be considered for each cycle. For non-US residents, the grant award will be sent via Western Union; **it is the applicant's responsibility to locate the nearest Western Union office to receive the award.** Applicants will be eligible to receive one award every two years.

This fund is available to affected children from around the world. 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. You will be contacted by the FIRST office if you have been awarded funding.

The application can be downloaded from FIRST's website at www.firstskinfoundation.org, and emailed to 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

The deadline to apply for funds is October 31, 2014.

Donations to Diya & Aliya's Friends (DAF) Fund are always appreciated and enable FIRST to make this fund available to more deserving families. Donations can be made at www.firstskinfoundation.org.

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