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

Ichthyosis Focus

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FIRST Turns 35!

An interview with FIRST's CEO - Jean Pickford

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The editor invites your correspondence. We welcome your comments, observations and suggestions. Please send your letters to Ichthyosis Focus at the address listed above.

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Join the Celebration!

January 2, 2016, marked a very special milestone for FIRST as we celebrated our 35th anniversary. In this issue, you'll discover how FIRST has grown and evolved since 1981 and why I am so honored to have been a part of this incredible journey. Plus, you'll find all the latest news and information for the upcoming 2016 National Conference - San Diego, June 24-26, including the program, activities and registration form. You'll learn how our UFIRST Scholarship program has inspired and supported our young adult members to reach their fullest academic potential. You'll also learn why one inspiring family feels so passionate about genetic testing.

Additionally, this issue's healthy living feature is a very hot topic, as it offers tips and information regarding cyberbullying, an online offense that some of our members have recently become victims. As always, when facing discrimination or harassment, FIRST encourages self-advocacy and the promotion of positive messages. We are behind you every step of the way, in times that are good, as well as those that are challenging.

Best wishes for the year ahead!

Jean R. Pickford

Chief Executive Officer, FIRST

2016 National Conference *San Diego!* June 24 - 26, 2016
Registration Forms Inside! Pages 13 & 14
Use #FIRSTNC16 for Conference Updates!

Correspondence Corner

Dear FIRST Foundation,

"Tomorrow, I celebrate my son's 29th birthday, and the year I joined the FIRST community. Giving birth to a child with congenital ichthyosis was a difficult time in my life, but because of FIRST, our lives were blessed because of all their help and support. Thank you and congratulations on celebrating 35 years."

Peggy Neilson

"Thank you so very much for being the bearer of such wonderful news. We are overwhelmed and greatly thankful to FIRST as well as the parents of Diya & Aliya for making things more easy for us. God bless you all."

Victoria Khing

"I have given your email address to some of the newest FIRST parents to help assist them in talking to Dr. Craiglow for answers about genetic testing, etc. You all have been such a huge help to me! Thank you so much! I feel light years ahead already and the FIRST parents' group is amazing!"

Rose Bullington

FIRST ADVOCATES

Get informed. Stay involved.

President Barack Obama signed into law a $2 billion funding increase to the National Institutes of Health, a big boost that could turn around the agency's fortunes after years of stagnant budgets. It's the first time the NIH budget would get such a large raise in more than 12 years. The bill gives $200 million to the Obama administration's Precision Medicine Initiative — an effort to find treatments that can be targeted to an individual's genetic makeup, a $350 million increase for research on Alzheimer's disease, an amount that could boost efforts to find an effective treatment by 2025. It also includes an $85 million increase for the BRAIN Initiative, the project to map the human brain. Follow developing story at: http://www.nih.gov

Rare Disease Day 2016 State House Events

How can I celebrate Rare Disease Day (February 29) and raise awareness for my condition?

State House events were established to educate state legislators and their staff members about rare diseases and Rare Disease Day. This year, there are number of Rare Disease Day State House Events being planned throughout the United States. We encourage you to participate in your home state event. Below is a list of current states where an event is being planned, and more states are being added daily. You can find updates at rarediseaseday.org.

RAREDISEASEDAY.ORG

Current list of states hosting State House Events on Rare Disease Day:

Alabama	Illinois	Minnesota	Oklahoma
California	Indiana	Missouri	Oregon
Colorado	Iowa	Nevada	Pennsylvania
Connecticut	Kansas	New Hampshire	South Carolina
Delaware	Maine	New Jersey	Texas
Florida	Maryland	New Mexico	Utah
Georgia	Massachusetts	New York	Virginia
Hawaii	Michigan	Ohio	Washington

FIRST will be joining the Rare Disease Day celebration all day on social media! An easy, but impactful way to get involved is to simply join us online:

- Go to rarediseaseday.org and download the Rare Disease Day "hand" symbol for your photo.
- Take an RDD selfie and share it on our Facebook page, in a tweet, on Instagram or in any other social network you belong to.

Use hashtags #raredisease and #ichthyosis, and FIRST will be sure to share it too.

Our individual voices are strong, but together we are unstoppable.

Science, Innovation and Research
in Ichthyosis & Related Skin Types

From Difficult Case to a New Syndrome

Mo Neville from FIRST interviews Keith Choate, MD, PhD, and FIRST Members, Suzanne and Eric Phelps.

When Keith Choate, MD, speaks about his research program to identify and understand new genetic causes of ichthyosis, he always begins by discussing the importance of genetics to medicine. He notes that it has the power to provide genetic diagnoses, to identify new genes for novel disorders, and to identify pathways which could be therapeutically relevant. Behind all this though, he says is a motivation "to do something meaningful" for families with ichthyosis. I interviewed Dr. Choate and one family particularly touched by his research to learn more about the scientific and personal impact behind finding new genetic causes of ichthyosis.

The story begins when Suzanne and Eric Phelps welcomed a beautiful baby boy to their family on December 21, 2004. His name was Dane Christian Phelps, and by all accounts he was as healthy as can be. "He was such a joyful child, right from the beginning. Such a happy baby," said Suzanne. At that time, worries were scarce for the Phelpses, a kind and loving family of five from San Jose, California. They took Dane home with great anticipation of watching their young boy grow.

"It wasn't until Dane was about four to six weeks old that he started showing any symptoms," said Suzanne.

A seemingly healthy baby, Dane began to present with a relentless skin condition. His skin grew extremely red, dry and flaky. His feet became thickened with skin and burdened with deep cracks. He was constantly shedding and his skin was becoming more and more fragile. The slightest touch from a fingernail or ring would leave a cut, making his bath time all the more uncomfortable. He had issues with overheating and on days when he was itching more than usual, he required additional baths, additional skincare products, and oral antihistamines and medications. He'd wake in the early morning hours thrashing terribly due to the intense itching and discomfort.

"Even with all he had to go through, this little child was always smiling. He had such a soft spirit about him. And he was empathetic to others who were hurt or suffering. He was such an old soul," said Suzanne. To this day, friends and family still remember Dane for his love and enthusiasm for life.

"His gracious spirit and attitude were truly inspiring," Suzanne said.

Although he was a joyous child, there was no mistake that his health was continuing to suffer, and the Phelps family grew more and more desperate to find the cause. "We had many types of medical and genetic testing done and they all came up negative and/or inconclusive," said Suzanne.

Dane Christian Phelps

"When Dane was 2 years old," she continued, "my aunt found FIRST online and also contacted one of their members. It was becoming clearer that the descriptions of those with ichthyosis were matching many of Dane's symptoms. But, at the time I was in a real state of denial, and I myself didn't contact FIRST at that point. I was still in a 'fairy tale land.' Since there was not a diagnosis, I did not believe nor was I ready to accept that it was a chronic condition as rare as any of the disorders that fell into the ichthyosis category."

After two more years of genetic testing, it became apparent that, despite their best efforts, the medical community could not offer any answers about what was causing Dane's condition.

As the Phelps family continued on this journey, their desperation worsened and their frustrations grew. "Nothing is more frustrating than having people ask you if you have tried using sunscreen for your child when they saw how red Dane was. As if I would never have thought of that! And it was even more frustrating to not be able to explain his condition, because we didn't know what it was. I think the human spirit can prevail, no matter what situation it is given. The problem was, though, that we didn't know what we were dealing with."

With no other options, the Phelpses continued to bring Dane for many more tests and visits to the doctors, especially as he started to lose his hair and his teeth began to break down. It also became clear that he was not growing properly.

"It was so hard to make the decisions to keep bringing him, to keep causing him discomfort and sometimes pain with all the testing and biopsies. If we had known what the condition was, even if it was a life-threatening diagnosis, he could have just been living his life, just being a kid going to the beach like he loved, but we were so desperate for an answer. This was the burden, the decision to keep searching. A heavy burden for so long."

Months later, Suzanne finally contacted FIRST herself in 2007 when Dane was a little over 2 years old. "I contacted Jean Pickford regarding a medical grant from a foundation associated with my family that FIRST might have the opportunity to receive. I thought, *"if we're not going to have an answer, at least we can DO something."*

It was around this time that Dane was diagnosed with a heart murmur. “We didn’t know that he had heart issues other than the murmur, which we were told was normal for someone with a chronic skin condition.”

Suzanne could see a change in what would be the last month of Dane’s life, as he became more tired and lethargic. “He was a little edgy, which was not like him,” Suzanne said. After his death, they would come to know that these were the beginning signs of heart failure. “Again, not knowing about the heart condition, not having an accurate diagnosis, and not being informed of what to expect, there was nothing we could have done.”

Dane passed away in the early morning hours of June 25, 2008.

“My prayer from that day since has been, please God, in our lifetime, could we find out what it was.”

The Phelpses had become convinced that it had to be some form of ichthyosis as the similarities were uncanny.

“We decided to go to the next FIRST conference after Dane’s death and as soon as I walked in the room, I felt like I was surrounded by him. There was such a similarity in their spirits and their skin presentation. It really felt like he was all around me. It was meant to be for us to have this experience, this ‘confirmation.’

The Phelps family would have the opportunity to share information about Dane with the ichthyosis medical experts at the conference, who also agreed it might have been some form of ichthyosis, perhaps so rare that he was the only one with the mutation.

In 2015, seven years after Dane’s passing, the Phelpses received a message from Dr. Choate, who they’d met at FIRST family conferences. He told them that that he’d been studying other families who had children who looked like Dane, and who had heart problems. He asked if they were interested in participating in his team’s research efforts, and had a very specific request – he needed to find something that had Dane’s DNA. He specifically asked if Dane had ever had a skin biopsy.

It turns out that shortly before Dane’s death, Sheilagh Maguiness, MD, a dermatology fellow/resident at University of California, San FranciscoCSF, suggested that they do a skin biopsy. After all Dane had been through, this was an anguishing thing consider, but the Phelpses agreed, hoping for an answer. Dr. Choate was able to request this biopsy tissue from UCSF, and within days had an answer.

Dr. Choate’s team discovered that Dane had a mutation which had arisen spontaneously in his cells very early in the development in the gene which encodes a protein called desmoplakin which is essential for normal heart and skin function. He and his team would name Dane’s disorder erythrokeratodermia-cardiomyopathy syndrome and had identified two other children with the disorder, one who had an undetected cardiomyopathy. Suzanne recalled that when Dr. Choate called with the news, he said “I want you to know Dane’s story doesn’t stop here. His story is going to change how we think about children with ichthyosis, and now we know that others with his condition will need cardiac evaluation. We know this because of Dane.”

“It was an overwhelming sense of relief,” said Suzanne. “I cannot express the gratitude I feel toward Dr. Choate. If I had to lose my own son, I could at least now know that maybe I could help someone else’s child. Maybe that’s what Dane’s life was about. Maybe this diagnosis would save another life, maybe even many.”

When asked about her thoughts on genetic testing and diagnosis in general, Suzanne said, “An answer gives you a game plan, so your mind doesn’t go crazy. So you don’t have to waste so much energy constantly searching. I cannot emphasize enough, whether the condition is chronic or life-threatening, or not, having peace of mind about what the condition is, and being able to just cope with it…and just live… is truly a gift.”

Dr. Choate says that the Phelpses are not alone – up to 20 percent of ichthyosis cases do not have mutations in currently known genes. He has partnered with FIRST and physicians across the country and around the world to identify families with ichthyosis who are seeking answers about their diagnosis. He told me “behind every new discovery are families who are willing to continue to engage in our common goal of finding answers. We are deeply grateful to families like the Phelpses and many others who have been so generous in sharing their stories and participating in research.” Dr. Choate’s team has recently discovered three new genes which cause ichthyosis and tells us that more are on the way. He says he hopes “that no child will go undiagnosed, and that we can make discoveries that are ultimately relevant to cures.”

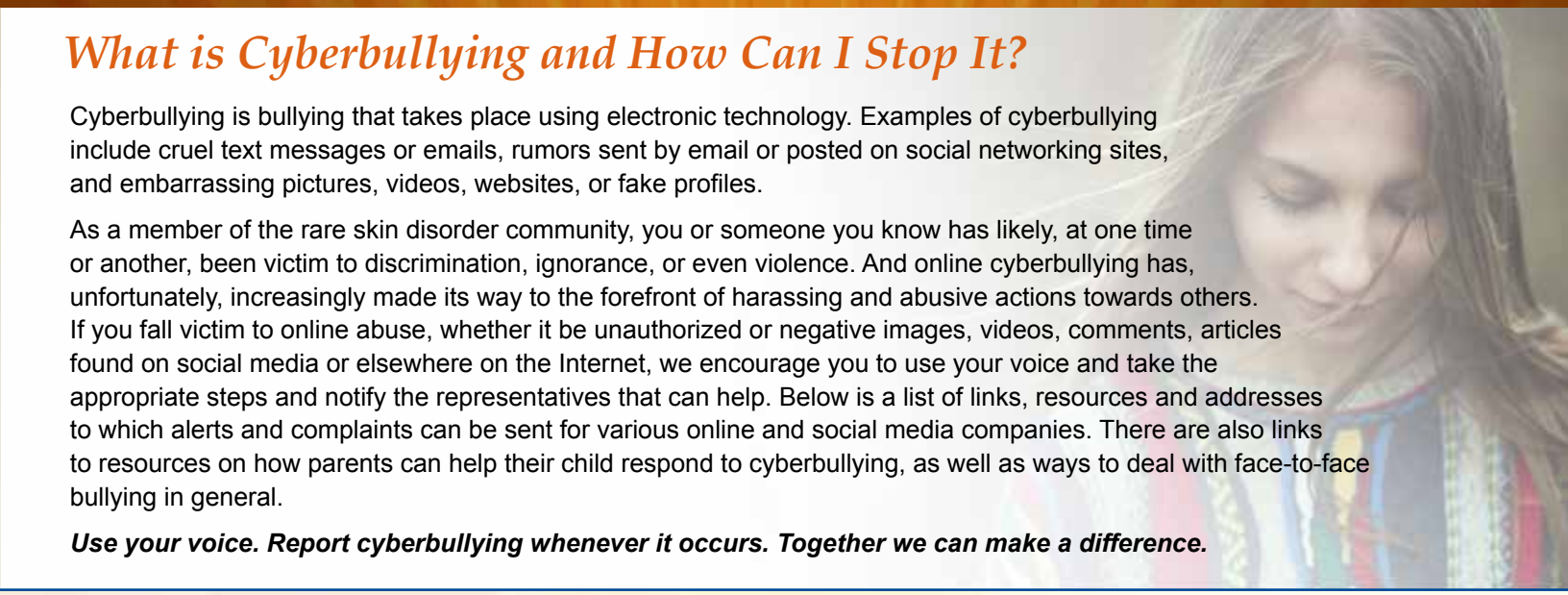
The Phelpses have supported the mission of FIRST each and every year since first connecting with the organization. Since Dane’s passing, over $800,000 has been raised for FIRST in his memory. We share their story in loving memory of Dane, in gratitude to their family and community, and with hope for a better future for all those with ichthyosis and related skin types.

The article about Dane’s condition, Erythrokeratodermia-Cardiomyopathy syndrome, appeared in the January 16, 2016 issue of Human Molecular Genetics. FIRST Medical and Scientific Advisory Board members Brittany Craiglow, Erin Mathes, Mary Williams, and Peter Elias were contributors. Reference: Boyden LM, Kam CY, Hernández-Martín A, Zhou J, Craiglow BG, Sidbury R, Mathes EF, Maguiness SM, Crumrine DA, Williams ML, Hu R, Lifton RP, Elias PM, Green KJ, Choate KA. Dominant de novo DSP mutations cause erythrokeratodermia-cardiomyopathy syndrome. Hum Mol Genet. 25(2):348-57.

If you would like to participate in Dr. Choate’s research on the genetic causes of ichthyosis, please e-mail maryann.ackerman@yale.edu with your contact information to learn more.

Living Well With Ichthyosis

What is Cyberbullying and How Can I Stop It?



Cyberbullying is bullying that takes place using electronic technology. Examples of cyberbullying include cruel text messages or emails, rumors sent by email or posted on social networking sites, and embarrassing pictures, videos, websites, or fake profiles.

As a member of the rare skin disorder community, you or someone you know has likely, at one time or another, been victim to discrimination, ignorance, or even violence. And online cyberbullying has, unfortunately, increasingly made its way to the forefront of harassing and abusive actions towards others. If you fall victim to online abuse, whether it be unauthorized or negative images, videos, comments, articles found on social media or elsewhere on the Internet, we encourage you to use your voice and take the appropriate steps and notify the representatives that can help. Below is a list of links, resources and addresses to which alerts and complaints can be sent for various online and social media companies. There are also links to resources on how parents can help their child respond to cyberbullying, as well as ways to deal with face-to-face bullying in general.

Use your voice. Report cyberbullying whenever it occurs. Together we can make a difference.

Advice from U.S. Health Resources and Services Administration:

The U.S. Health Resources and Services Administration advises parents to encourage children to tell them immediately if they are victims of cyberbullying or other troublesome online behaviors. The agency also lists a number of steps that parents can take to help prevent cyber-bullying and how to respond to it at stopbullying.gov. The site also includes extensive information on preventing and dealing with traditional forms of bullying. The Centers for Disease Control and Preventionalso provides information on electronic aggression for parents, educators, and researchers at: cdc.gov/ViolencePrevention/youthviolence/electronicaggression

How to report abusive posts on Facebook:

Facebook removes things that don't follow the Facebook Terms (ex: nudity, bullying, graphic violence, spam). If you come across something on Facebook that doesn't follow the Facebook Terms, use the report link near the post or photo to submit a report.

Other tools for addressing abuse:
It's possible that you might see something you don't like on Facebook that doesn't actually violate the Facebook Terms. If you come across something you'd rather not see, you can:

- Hide it from your News Feed
- Send a message to the person responsible for posting whatever is bothering you and ask them to take it down
- Unfriend or block the person responsible

For information about what is and is not allowed on Facebook, please read the Facebook Community Standards on facebook.com.

How to report harassing or abusive images and videos on YouTube:

You can report abusive behavior on YouTube directly from their site at support.google.com/youtube/answer/2802008

You can also contact YouTube at the address below:

YouTube, LLC,
901 Cherry Ave.
San Bruno, CA 94066 USA
Fax: +1 650-253-0001 YouTube, LLC

You can also create an online petition and circulate it to your social media network. The more attention is drawn to a particular situation, the more likely it will be addressed. There are several online petition websites available.

FIRST Celebrates 35 Years!

Interview with CEO Jean Pickford

When did you join FIRST and what was your position?

I was hired in June of 1999, which was 16 years ago. Wow! Time goes too fast. It doesn't feel like it's been that long. I was hired as the organization's first full-time Executive Director, replacing part-time Executive Director, Elena Levitan. The staff only included one part-time high school volunteer and the office was two tiny rooms above a pizza shop in Havertown, Pennsylvania. After my first three months, the Board of Directors authorized a move to the Lansdale/Colmar area, where we've been ever since.

What are the most significant areas of growth and transformation you have seen in the past 16 years?

There are so many things that come to mind. I guess I can narrow it down to four specific areas: membership, commitment, fundraising, and research. Our membership has grown exponentially because of better communication tools. Obviously, the onset of the Internet and continuous electronic communication has evolved the organization in ways we couldn't have previously imagined. The commitment of our staff, board, volunteers and member families is astounding. So many people want to make a difference and help. Dedication and volunteer involvement has increased dramatically. The time and expertise that is offered to our organization inspires me every day. And, as a result of our growing membership base and determined commitment, FIRST has seen solid financial growth, from increased donations and grassroots fundraisers to major gift donors and industry partnerships. It seems the more people that know about the work of FIRST, the more support we receive.

And research...it is moving so fast, especially in genetic discovery and targeted-based therapies. It's very exciting. As genetic research advances and knowledge about specific gene mutations evolves, FIRST continues to be poised for great things. Since most types of ichthyosis are caused by single - cell mutations, this set of diseases is an excellent model for investigators to study to find better therapies, treatments and, one day, a cure. The research pathway for ichthyosis and the related skin types may also lead to discoveries in other more common diseases, which could be tremendous.The future for genetic research is very promising.

Tell us something about FIRST that most people don't know, but would find intriguing.

Something that I always think is fascinating is that everyone on staff, including me, had never even heard of the skin disorder or met anyone with ichthyosis before working here. When I applied for this job, the employment ad said FIRST, not Foundation for Ichthyosis & Related Skin Types. I sent my resume not even knowing what FIRST stood for! It's really quite amazing. Everyone just falls in love with our mission, the families we serve, and the people we work with. Another interesting fact is that in the first 10 years of my employment, I moved the office five times to meet our rapid growth. Packing and moving is never a fun thing, but it made it easier knowing the moves were always for a positive change. One last interesting anecdote is how FIRST began. I love to hear Dr. Mary Williams tell the story and find it inspiring. In her waiting room, ichthyosis families who were participating in a clinical trial, would gather once a month to check-in with their progress. Dr. Williams would hear the conversations between the parents and kids and encouraged the group to schedule time to get together, beyond the waiting room, for support and advice. A few people jumped in, took the reins, and started to formalize the group. Other ichthyosis patients and their families joined in, and the rest is history, as they say.

Please share a particularly memorable moment at FIRST that had an effect on you.

There are several moments that come to mind, all of which I think of often. I was only working at FIRST for a short time when I found myself riding in an elevator with a very sweet, funny, young girl who had a severe form of ichthyosis. As we stopped at different floors, I watched how the others getting on the elevator reacted to her. Some stared, some looked away, and others moved to the other side. It was the first time I had the chance to really witness what going out in public must be like for those who were "different." I remember my commitment deepening even more after that experience.

Another moment was at the Seattle National Conference in 2002. On the closing day and after the final speaker, I actually broke down in tears. I was just so overwhelmed with all of the connecting and warmth and friendships that were developing right before my eyes. I experienced this same feeling in Orlando at the 2010 National Conference while watching Cinderella come out onto the dance floor and the little girls just in awe and giddy with excitement; it was magical. In those moments, it reinforced, at least for me, that it doesn't matter what you look like, or what your skin looks like. It matters what you feel inside, your relationships with others, and your own personal confidence. It's something we all know, but when you see it unfolding right before your eyes, it really hits home.

What is the motivation behind your long-time commitment to FIRST and its mission?

That's a good question and I don't think there is just "one" answer. It's who I am. My passion is helping others. I also enjoy the non-profit business environment, which encourages building relationships, seeking new opportunities for development, and marketing our message. Of course, the families and children are a huge part of my love for FIRST! They are so kind, so courageous. And the dedication of the Board of Directors is truly remarkable. I'm inspired all the time and learn so much from them. And, speaking of dedication, I can't say enough about our Medical & Scientific Advisory Board. They care so much about helping our members and their families, that it just makes me want to be a part of it, too. As FIRST continues to grow, almost every day brings new challenges, new opportunities, and ideas are floating around all the time. The potential of FIRST is so evident to me. It excites me. I want to be a part of this remarkable journey and I'm so proud of all we've accomplished together. Can't wait to see what's in store for the next 35 years!

Where do you envision FIRST in the next five years? 10 years?

I am very confident that FIRST will remain ahead of the curve as far as meeting the needs of our growing population. We'll continue to strive to reach all those affected with ichthyosis and related skin types. Whether they want to become engaged with FIRST or not, it is our mission to let them know FIRST is there for them, whenever they need us. I also hope in 10 years, that the investigators we have funded and others working to find a cure, will have benefitted from the rapid evolution in genetics to find better treatments and techniques to alter the faulty genes that cause these diseases. Sustained funding to keep the research moving forward combined with technology is the key. We live in fascinating times and the future looks bright, indeed.

Members Join The Celebration!

Tracie and Bailey Pretak support members, door-to-door

Tracie and Bailey Pretak, long-time members of FIRST and tireless self-advocates, took to the road to celebrate FIRST's 35th anniversary! First stop was Toronto, Canada to surprise another affected member, Ema Hodgkinson. It was Ema's first time to the professional ballet, and as a surprise, her mother bought tickets for the Pretaks to meet her at the show. "My mom and I got there before the Hodgkinsons. It was hilarious because Ema walked right by me. Her mom called out her name and when she turned around I said 'hi' and it still took a few more seconds for her to register that she knew me. But then she was so excited!" said Bailey regarding the surprise reunion. On their way home, the Pretaks made yet another stop in Buffalo, New York, to connect with FIRST members Brianne Wopperer and Andrew Constantino. Angelo Mantione joined them, as well, and they had a great time of catching up over several hours. As a final stop on their whirlwind weekend of connecting, Tracie went to meet up with Hunter and Mark Steinitz in Pittsburgh as Bailey made her way back home to work. "How cool is that? Three days in a row of ichthyosis families getting together. That is what FIRST does best...connects us. Thank you!" said Tracie and Bailey.

See more information on page 15 about the concert tour, hosted by the Pretaks and other members of the FIRST community.

Educate. Inspire. Connect

Learn about your condition, discover new skin tips and get to know the FIRST Community with FIRST to Know Calls

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. Each call is centered on a topic or subject, and lasts for one hour. You can decide which calls are interesting to you and phone in. You can choose to be an active participant, or just listen to what others are saying. All calls are held at 8 pm Eastern Time.

To participate on a call, simply dial: 267-507-0420. When prompted, enter the pin# 261618915.

February 28 – Harlequin Ichthyosis: Sharing Information
March 20 – Babies and Skin Care: Tips to Make Care "Easier"
April 24 – Netherton Syndrome: Sharing Information
May 22 – Understanding Occupational and Physical Therapy
June 19 – Erythrokeratoderma Variabilis (EKV): Sharing Information
July 24 – Grandparents: Helping Your Grandchild and Your Adult Children
August 28 – Sjögren-Larsson Syndrome: Sharing Information
September 25 – Building a Stronger Network in Canada
October 23 – Lamellar: Sharing Information
November 27 – How to Work with Your Insurance Company
December 18 – Palmoplantar Keratodermas (PPK): Sharing Information

UFIRST Scholarship – Enrollment Now Open!

Meet 2015 UFIRST Scholarship Recipient, Quincy Harrison

FIRST is now accepting UFIRST Scholarship applications for affected members looking to continue their post-secondary education. Apply at firstskinfoundation.org. The deadline is March 31 and recipients will be notified of grant awards in May.

We asked our UFIRST scholarship recipients just how they felt about preparing for college, and whether or not having ichthyosis factored into their planning or decision - making process. The responses varied greatly, and we're excited to share an interview from UFIRST scholarship recipient Quincy Harrison, affected with X-linked ichthyosis. Discover how Quincy overcame his doubts about attending college and how he's been raising awareness for genetic diseases at Columbia University.

How did (or didn't) ichthyosis affect your decision to attend college?

For a long time, I was embarrassed by my skin condition. As a result of that, I wondered how I was going to survive in college environments where my dorm roommate and team club members had the potential of seeing my skin. Even though I understand the general curiosity, no one wants to constantly answer questions regarding the appearance of their skin. I also did not want others to judge me solely based on my ichthyosis. Thus, I actually thought about not attending college at all. However, my thinking changed as I grew older. I realized that the best friends and people that I meet in college will accept me exactly as I am, unconditionally.

What can you share with our teens, or parents of teens regarding college?

As an incoming freshman to college, the best piece of advice I can give both parents and students is to manage their time wisely. For students, time management prevents procrastination and allows more study time for tests and to do homework. In this way they will be able to utilize all of their potential while minimizing stress. Parents should also manage their time and ensure that their children have all of their dorm furniture and legal forms taken care of well before the move-in date.

What do you wish you had known about the process that you would like to share with teens?

I wish someone had told me beforehand how agonizing the process can be while waiting for college decision acceptances. Waiting for acceptance to your preferred school can be very nerve-wracking! Part of my stress level would have been alleviated if someone had told me that regardless of the decision a college gave me, I still had a bright future and many options available to me.

How do you plan on sharing about your ichthyosis while at college?

At Columbia, there are a lot of opportunities to spread awareness about different topics. One topic that I would like to highlight is genetic diseases and how it could potentially impact the life of an individual. This would afford me the opportunity to talk about X-linked ichthyosis.

Surf's Up! for the 2016 National Conference
June 24 - 26 • San Diego Marriott Mission Valley

Why Attend the National Conference?

FIRST member, Denise Eiser, gives us her top ten reasons! #FIRSTNC16

I have attended four FIRST National conferences, with my parents in the '90s and now my own family. Each time I learn something new, make new friends, and leave the conference bursting with hope for the future of our rare disease. If you or a family member is affected with ichthyosis or a related skin type, this is an absolute "don't miss" event. Here's why…

Meet the Medical Experts - The National Conference offers the rare opportunity to learn from ichthyosis & related skin type experts. ***Experts.*** One-on-one clinical appointments available.

Surround Yourself with Affected Families & Individuals - For once, ichthyosis is the majority. You'll see people with your type of ichthyosis everywhere. Through casual encounters, formal presentations, and in-depth conversations, you will feel it and see it: you are not alone. This, by itself, is a life-changing experience.

Program

(subject to change)

Thursday, June 23

7 - 8 pm……..Early Bird Registration

7 - 10 pm……..Evening Social

Friday, June 24

8 - 9:30 am…...……..Breakfast & Registration

9:45 - 12 pm…..Types of Ichthyosis Breakouts

12 - 1 pm..……..Lunch

1:15 - 4:30 pm……...……...Breakouts

1:15 - 4:30 pm…....Teen Session & Pool Party

6 pm…..……Pizza & Trolley Tour (optional)

Saturday, June 25

7:30 - 8 am……....Light Yoga Stretch (optional)

8 - 9:30 am……..……Breakfast

9:45 - 10:45 am….Life with a visible difference

11 - 12:15 pm…….Teens & Siblings Panel

12:15 - 1:15 pm…..……Lunch

1:30 - 2:45 pm……. Research Panel and Q & A

2:45 - 3:15 pm……..Let's RAISE the Bar

3:30 - 5:00 pm……..….Private support sessions

6:30 - 10 pm…...Beach party, awards, dancing

Sunday, June 26

7:30 - 8 am……...….Light Yoga Stretch (optional)

8 - 9:30 am……...……..……Breakfast

9:45 - 11:45 am……...Breakouts

9:45—11:45 am……....Teen Session

12:00 - 12:30 pm…....…..Conference Wrap-Up

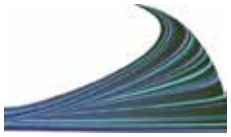
12:30 - 2 pm……....Farewell Lunch

Kid-a-Palooza

A supervised kid's camp for ages one to completed fifth grade will be offered concurrently with all educational sessions for little ones to play, laugh, and have fun while parents attend lectures and breakouts. Your child(ren) will rejoin you for all meal functions. A licensed childcare company will be hired. A nominal fee is required so FIRST can confirm how many are planning to use this service and the appropriate number of childcare providers are hired for your child's safety.

Tweens & Teens

Interactive and educational breakouts. Plenty of opportunities to attend general sessions, hangout time, enjoy the pool together, plus more!



Make Friends that Last a Lifetime - Many parents feel overwhelmed with everything that comes along with an ichthyosis diagnosis, and the "ichthyosis family" is a support network that runs far and wide. You will no doubt spark connections for a lifetime.

Get ideas - Did you know that some people use a Dremel drill for their feet? That sleeping with surgical gloves can help your cream work? Some of the most effective treatments I've found have been from suggestions at the conference.

Stay In-the-Know – You'll hear all the latest in research, from the scientists themselves! You'll learn what's new with FIRST, and how to get involved.

See Your Future – New parents with affected toddlers can meet happy and adjusted teens with ichthyosis. Young adults can talk with 30-somethings and adults can visit with seniors to find out what issues and solutions they've found for aging with ichthyosis.

Inspire Others - I'll never forget how strong I felt when I lifted up a room full of parents just by sharing my own story. Your strength will empower you and inspire others.

Have fun! - From dawn till dusk, and beyond, the positive energy of the conference is contagious. Plus it all wraps up with a Saturday night dance party and talent show!

Meet the FIRST staff - Did you know Jean Pickford has been with FIRST for more than 15 years? Meet all our staff members who are committed to the mission of FIRST! You'll have a chance to get encourage them in the work they're doing.

Score Free Samples - Generous sponsors and companies that are working on products just for ichthyosis contribute massive amounts of freebies. The "swag bag" is VIP all the way.

Surf's Up! for the 2016 National Conference
June 24 - 26 • San Diego Marriott Mission Valley

Hotel room reservations must be made on your own and are separate from your conference registration. See below to book your stay with FIRST's discounted room rate.

Making Hotel Room Reservations

FIRST's discounted group rate at the Marriott Mission Valley is $129 ++ per night, which is available from June 23 through June 27. The discounted guestroom internet fee is $6 per day. Self parking is $12 per day. All attendees must make their own hotel reservations in one of two ways:

1. **Online Reservations** - A dedicated booking website has been created just for our conference to make, modify and cancel their hotel reservations online. Visit their website—https://resweb.passkey.com/Resweb.do?mode=welcome_ei_new&eventID=14107342
2. **Phone** - Please use the following numbers to make your reservation by phone. When making your reservation, be sure to reference the "Foundation for Ichthyosis" to book within our group room block and receive the discounted rate. Reservations toll free: 877-622-3056 or reservations local phone: 619-692-3800.

For general questions about the hotel, driving directions, amenities, etc., contact the hotel directly at 619.692.380 or visit their website at http://www.marriott.com/hotels/travel/sanmv-san-diego-marriott-mission-valley/.

Airport & Shuttle Information

San Diego International Airport (SAN) is the major airport for the San Diego area and is about eight miles from the hotel. 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.

There are several travel options between the airport and hotel:

Supershuttle: 1(800)BLU-EVAN—supershuttle.com
$12.00 per person to/from airport

Yellow Cab: (619)444-4444—sandiego.driveu.com/taxi.php
$25—$30 per cab one way (fits up to 4 persons)

Town Car/Limo Service: SanLimo Transportation
(858)752-7291—sanlimo.com—san.limo@yahoo.com
Contact: Harry Sharifi—$28 flat rate one way (up to 4 persons)

Uber: Available to pick up and drop off to/from the airport for around $19—$25. Contact the hotel for discount codes up to $20 off for those who have never used Uber before.

Friday Pizza & Trolley Tour (Optional)

This optional activity features a casual pizza get-together at the hotel before embarking on a two-hour trolley tour of beautiful San Diego. Sights include Old Town, San Diego Harbor and Embarcadero, Seaport Village, Horton Plaza, Historic Gaslamp Quarter, Coronado, Balboa Park and Little Italy. All trollies will stop midway through the tour at Coronado Beach for a bathroom break and leg stretch. Sign-up on the registration form to reserve your spot(s).

Please note: The trolleys are not air-conditioned but have open windows and water on board.

Dress Code, Meals, Attractions

The conference attire is casual. Your registration fee includes Friday breakfast & lunch, Saturday breakfast, lunch & dinner, and Sunday breakfast & lunch. The San Diego Marriott Mission Valley provides easy access to popular attractions including Old Town, Mission Bay, the Rio Vista Trolley, SeaWorld® San Diego, Qualcomm Stadium, home of the San Diego Chargers, and Petco Park, home of the San Diego Padres. For more information on area attractions, go to www.sandiego.org/plan-your-trip/travel-guides or access special offers and coupons by visiting www.sandiego.org/coupons.

FIRST's Got Talent (Optional)

Back for its fifth conference! This is a popular and heartwarming experience for kids, ages 5—17, to showcase their talents. Performances are on Saturday evening after dinner. Speakers and microphone will be provided; bring your own music, costume, props, etc. Performances will be limited to a max of two minutes. Sign-up on the registration form.

Stay Tuned In… #FIRSTNC16

Surf's Up! for the 2016 National Conference
Registration Form

Registration can be submitted by completing this form or registering online at www.firstskinfoundation.org/conferences. All registrations must be received by June 8th. Registrations with missing information or payment will not be considered. Cancellations received prior to June 8th will be refunded, less a $25 per person administrative fee. No refunds issued after June 8th.

Family Registration, Contact Info, and Permissions

Family Last Name: _____ Contact Person:_____

Address: _____

City/Town :_____State/Province: _____ Zip/Postal Code:_____

Country: _____ Home Phone:_____

Cell: _____ Email:_____

Type of Ichthyosis: _____

❑ I give FIRST permission to publish names, contact, and type of ichthyosis in the conference roster, which will be distributed to attendees, vendors & faculty attending the event.

❑ I give FIRST permission to use and distribute any photos or videos taken at the conference, in which I, or my family, may be a part, including but not limited to use in newsletters, appeals, social media, website and reports.

Who's Attending?

	First Name	Last Name	Date of Birth	Age	Affected with ichthyosis or a related skin type?	Relationship to person affected? *(mom, brother, uncle, friend, etc.)*	Participating in Kid-a-Palooza?	Participating in FIRST's Got Talent Show?	T-Shirt Size
1)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	Provide address if different than above								
2)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	Provide address if different than above								
3)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	Provide address if different than above								
4)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	Provide address if different than above								
5)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	Provide address if different than above								
6)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	Provide address if different than above								

Surf's Up! for the 2016 National Conference
Registration Form

Clinical Appointments & Yale Registry

All appointments will be scheduled for Saturday, June 25

This unique opportunity is offered to any affected member(s) and families to meet with expert dermatologists and researchers from Yale University. Please check which option you are interested in:

❑ Option 1—A 15 minute appointment with experts in ichthyosis to discuss your/your child diagnosis. This option does not involve participation in any research studies.

❑ Option 2—A more in-depth, longer appointment to enroll in the Yale Registry for research studies. This option also includes a 15 minute appointment with expert dermatologists as well. For new enrollees, the study will involve providing a saliva sample, photographs, and completing a questionnaire.

❑ Option 3—For those already enrolled in the Yale Registry, you are encouraged to still sign up, as there will be an opportunity to update information, ask any questions, and participate in continued Registry activities.

Name	Age	Type
_____	_____	_____
_____	_____	_____

A packet will be mailed to you from Yale which will contain necessary paperwork and confirmation of your scheduled appointment time.

Registration & Payment

Registrant	Number		Fee Per Person		Total
Adult (ages 13+)		x	$200 per person	=	$
Child (ages 5 to 12)		x	$100 per person	=	$
Preschool (ages 2 to 4)		x	$25 per person	=	$
Infant/Toddler		x	No Charge	=	$
Optional Add-Ons					
Kid-a-Palooza (ages 1 to completed fifth grade)		x	$10 per child	=	$
Friday Night Pizza & Trolley Tour					
Adult: Ages 13+		x	$35 per person	=	$
Child: Ages 4 to 12		x	$21 per person	=	$
Toddler: Ages 3 and under		x	$3 per person	=	$
Celebrate FIRST's 35th anniversary with a $35 gift to support the Conference Scholarship Fund—helping those who need it most…				=	$
			Grand Total		**$**

❑ Enclosed is a check in the amount of $_____, payable to FIRST, Inc.

❑ Please charge my credit card for $_____(Visa, Mastercard, American Express, Discover)

_____ Credit Card Number

_____ Exp. Date

_____ Signature

_____ Date

Waiver

In consideration of the acceptance of this registration entry, I/we the undersigned, assume full responsibility for any injury or accident which may occur while I/we am/are attending this conference. I/we hereby release and hold harmless the sponsors, promoters, and all other persons and entities associated with this event from any and all personal injury or damage, whether it be caused by the negligence of the sponsors, promoters or other persons or entity. Applications for minors will be accepted only if signed by a parent or guardian.

_____ Signature

_____ Date

See You In San Diego!

Grassroots Fundraising from Coast to Coast

Iott Pumpkin Paint

The Iott family held their 8th Annual Pumpkin Paint and Bake Sale on October 17 at the William Janklow Community Center in Flandreau, South Dakota. Pumpkins were donated by Iotts Greenhouse, whose owners are the grandparents of Rylee, who is affected with ARCI-CIE. Participants painted pumpkins and enjoyed sweet goods with friends and family. The event raised more than $1,900 for FIRST. Thank you for your commitment to FIRST!

Orange County Ichthyosis Benefit

Chrissy See and friends organized the Orange County Ichthyosis Benefit on November 5 in Costa Mesa, California. Guests enjoyed live music, a pool tournament, silent auction and more! Chrissy organized the event in honor of her sister and nephews, who are affected with ichthyosis en confetti. Throughout her event promotion, Chrissy said, “There is beauty in our differences and underneath the skin we are all the same.” Joining Chrissy at the event were Roland and Lani Coates, whose daughter, Sophia, has epidermolytic ichthyosis.The evening raised $3,500. Thank you to Chrissy See!

Release the Butterfly Tour Stop #3/ Premier Design Party

The magic of the Release the Butterfly Tour continued to its third location, Johnsonburg, Pennsylvania, on October 17. Hosted by FIRST members Tracie and Bailey Pretak, there were over 80 people in attendance, including eight affected families. The evening raised over $2,500 from a love offering and auction and the Pretaks continued their fundraising streak by also holding a Premier Party Design raising over $185! Thank you for your enthusiasm! (more concert details online at www.firstskinfoundation.org) #releasethebutterflytour.

Dig Blue for Liam

The 3rd Annual Dig Blue for Liam Volleyball Tournament was held at Vestal High School in Vestal, New York on November 15. The tournament, held in honor of Liam Ewing, raised over $1,300 this year. Thank you to the club adviser, Susan Darpino, and students for your fundraising efforts!

Johnson Monster Dash

A little rain didn’t stop the community of Friendswood, Texas, from participating in this year’s 14th Annual Monster Dash Fun Run on November 7, 2015. Dawn Johnson and her daughter, Jordan, who is affected with epidermolytic ichthyosis, have hosted the fun run each year to raise awareness and money for FIRST. Thanks to the generosity of friends, neighbors and family, the Monster Dash raised $9,600. Over the 14 years that the Johnsons have organized this event, it has raised over $156,000 for FIRST! Your commitment and generosity has made a difference in the lives of so many. Thank you.

Dance Palooza at MSU

Kelly Benford who was diagnosed with lamellar ichthyosis, held a Dance Palooza at the Mississippi University for Women on December 2. The event, hosted by Audacity Dance Team, the Young Black Leadership Association and Phi Beta Sigma featured many talented performers and raised over $500 for FIRST’s programs and services. In addition, Kelly was interviewed by the local CBS affiliate, WCBI, and her college newspaper. Thank you Kelly for being a strong advocate on your college campus!

Bead for a Cure

The Mayone family hosted the 9th Annual Bead for a Cure at Caravan Beads in Portland, Maine on December 1. The event is held in honor of Mark and Kim’s son, Evan, who is affected with epidermolytic ichthyosis. Family and friends came out for a fun night of crafting and raised over $335 for FIRST. Thanks Mayone family for your continued support!

Mangus Dinner

Aaron Fisher and his friends gathered for a delicious dinner in New York City on December 18. In addition to great food and good company, Aaron spoke to his friends about ichthyosis and about his brother, Ryan, who is affected with ichthyosis vulgaris. Aaron asked each of his friends to make a donation to FIRST and the event raised $1,745. Thank you to Aaron Fisher, Mike Hammond, Greg Hammond, Kevin Mulcahy, and Pat McNamara for organizing the Mangus Dinner in support of FIRST.

Special Thanks

Special thank you to Schenck SC office in Green Bay, Wisconsin; Goshen Center School in Goshen, Connecticut; and TWWC, Inc., in Buffalo, New York for hosting a FIRST fundraiser at your workplace and raising $1,600 for FIRST. FIRST greatly appreciates your support!

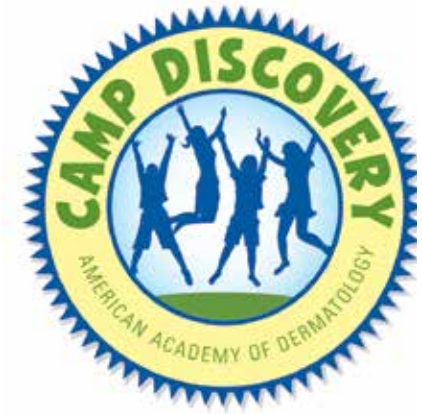
Contact Development Director Madeline Bergman mbergman@firstskinfoundation.org for assistance with all your grassroots events.

FIRST
Foundation for Ichthyosis & Related Skin Types®
Educate • Inspire • Connect
2616 N. Broad Street • Colmar, PA 18915

2016 National Conference *San Diego!* June 24 - 26, 2016

Registration Forms Inside! Pages 13 & 14

Use #FIRSTNC16 for Conference Updates!



The American Academy of Dermatology's (AAD) Camp Discovery program is for children ages 8-16 who have a chronic skin disease.

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

June 19-24:	Camp Little Pine in Crosslake, Minnesota (ages 10 – 14)	**August 7-12:**	Camp Dermadillo, Burton, Texas (ages 9 – 15)
June 20-24:	Camp Reflection in Carnation, Washington (ages 8 – 16)	**August 7-13:**	Camp Liberty in Andover, Connecticut (ages 8 – 16)
July 3-8:	Camp Big Trout in Crosslake, Minnesota (ages 14 – 16)	**August 13-19:**	Camp Horizon in Millville, Pennsylvania (ages 8-13)

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