

# National Conference 2016 Breaks New Record!

*The FIRST 2016 National Conference was as remarkable, meaningful and memorable as ever. FIRST staff is still reeling from the excitement!*

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*Ichthyosis Focus* is published quarterly  
by the Foundation for Ichthyosis &  
Related Skin Types, Inc.®

Requests to reprint information  
contained in the *Ichthyosis Focus*  
should be directed to the editor.

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"This was my ninth conference for FIRST...wow! It is the most absolute favorite part of my job. Without a doubt. I remember some of these kids when they were babies, and now they are grown up and knocking it out-of-the-park. Every year our attendance grows, which makes me happy. This means that more and more members are experiencing the warmth, support, and friendships within our special community. To quote a phrase I heard many times throughout the weekend, "It feels like one big, happy family when we are all together!"

-Jean Pickford, CEO, FIRST  
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# Look What's NEW at FIRST!

## *FIRST's website gets a new mobile-friendly look*

Have you heard? We're getting a bit of a facelift. Our newly designed website will still house all of the important resources you need to understand the medical aspects of your condition and cope with symptoms in the best way possible. And, of course, you'll still be notified about all the great ways to connect. But now, hopefully, it's a little easier to find. Plus we've added a "Voices in the Community" feature that will host inspirational stories, tips, and ideas, from affected families, individuals and ichthyosis specialists themselves. It will also feature an automated physician search, so finding a medical practitioner in your region should be a little easier. Last, but not least, the new design is mobile-friendly! A big thank you to Allergan for their grant to support our new website design and provide our community with the most relevant information in the most engaging and easy-to-use platform possible. The new design will launch in late summer of 2016. Drop us a note and let us know what you think.

[mneville@firstskinfoundation.org](mailto:mneville@firstskinfoundation.org)



"Hello, FIRST members! I'm more excited each year to be a part of this wonderful, big family at FIRST! I'm honored to share your amazing stories, advice, and experiences...every step of the way. (By the way, story ideas are always welcome! Drop me a line. I would love to hear from you!)" - Mo Neville, Senior Director, Marketing & Communications, FIRST ([mneville@firstskinfoundation.org](mailto:mneville@firstskinfoundation.org))

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# Attendance Record Officially Broken

*"You are not going to be the best person you can be until you get out of your own way. Love who you are and embrace the impact you can make on the lives of others."*

*- Chad Porter, keynote speaker, FIRST National Conference 2016*

From the warm moments of reconnecting at the welcome gathering on Thursday evening, to the inspired words of Chad Porter and Kaelin Ball, to the tip sharing, teen panel, dancing like there's no tomorrow and the rare look into the minds of the world's leading ichthyosis investigators, the FIRST 2016 National Conference was as remarkable, meaningful and memorable as ever. FIRST staff is still reeling from the excitement and, as always, we are honored and grateful to be a part of this BIG, loving, compassionate, and committed family. Thank you for being a part of it, too.



"They say in life that we all are a part of something. I couldn't think of a better something to be a part of. I just wanted to let you and FIRST know how moving this weekend was for me. It gives me the strength I need to continue to give Mason the care and support he needs from me. It has been a life-changing eye opener! Thank you for organizing something so amazing!! My heart feels whole!"

**-Jamie Logan**



"First of all, it was such a pleasure to finally meet you and your great staff after all of these years! The work that all of you do is beyond any words that I can say - I have seen it first hand over the years how much you all have supported Mark and his family and at the conference I also saw it at so many of the other families. I was just overwhelmed! And, second of all, as a first-timer I learned so much about EI - more than I ever thought I could and I learned how I could support Mark, Emma and their family more. You and your staff did a great job planning the conference - a job very well done! Thanks for all that you do!" - **Margot Klima**

"Thank you for all of your efforts in making the conference so fulfilling for all of us! Our best from us to all of you! Thanks so much!" - **Mark Steinitz**

"I just wanted to thank you so much for the amazing job you did in planning, organizing and pulling off yet another super successful National Conference! We were blown away by all you accomplished, as there were so many parts and subparts that you had to arrange to make it all happen. Our family always leaves feeling so inspired and connected, yet we always feel this void, as we feel like we leave a part of hearts the minute we leave. It's so hard to explain the deep emotional ties we have to all of you at FIRST. There is something truly divine that we experience while we are there, and that is largely because of all you do to make the conference so special." - **Suzanne Phelps**

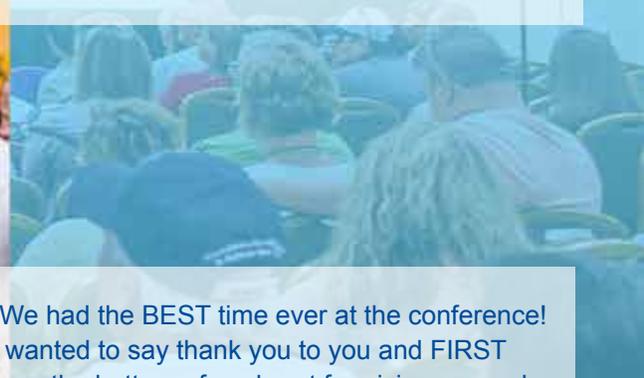


# at FIRST National Conference (473)!

"We were really impressed by what you all put together - obviously a lot of work! And it was so helpful to each of us in so many ways! I'm delighted our kids made friends and are communicating with them. It was great to reconnect with families we've met at the regional meetings. All the medical research news was fascinating and encouraging. The doctors you bring to the organization are truly outstanding. And I think I might cry every time I hear *Fight Song* from now on - Portia's performance was truly amazing! Thanks for all you do and we look forward to the next one!" - **Jennifer Bartlett**



"I am writing to extend our sincere gratitude to each of you for providing us such an awesome conference, and for your generous help for our family. A big congratulations to FIRST staff, keynote speakers, medical faculty, volunteers, and all FIRST family members, the 2016 conference has undoubtedly been a success. For our family, it was awesome. The wonderful physician volunteers have shared their valuable expertise and research achievements with us. We made many new friends, and all FIRST family members are so nice, which makes us feel that we are not alone and we are in a great family. The hot dance party, beautiful songs from our members, delicious food, samples from generous sponsors and companies, and all beautiful things on the conferences, will be good memories for us. As the only Chinese family, it is really a life-changing experience for us, and it will not be the only one for the future. Even though we return to China this year, we will remember FIRST forever, and we will do our best to contribute to our family in the future, just as all members have done!" - **Yanbin Yao**



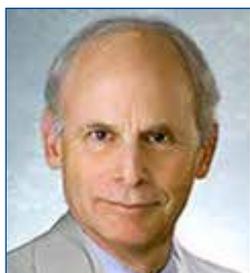
"We had the BEST time ever at the conference! I wanted to say thank you to you and FIRST from the bottom of my heart for giving me and my son the opportunity to attend the conference for the first time. We won't miss another one going forward. I was very excited, but to see the smile on my son's face, which didn't come off the entire time; that was priceless!" - **Angela Vance**

# Doctors Collaborate on Groundbreaking Ear Reconstruction for Patient with Harlequin Ichthyosis

*“We are being pushed to do things we haven’t had good answers for – and yes, it’s a challenge but this is how we all learn.” – Dr. Bruce Bauer*



Dr. Amy Paller



Dr. Bruce Bauer

It is the rare occasion when doctors are given the opportunity to collaborate on unique cases and perform procedures that are not only challenging, but will break new ground for all those that will follow. This was the case with FIRST’s MSAB and Board Member Emeritus, Dr. Amy Paller, Chair of Dermatology at Northwestern University and Dr. Bruce Bauer, Director of Pediatric Plastic Surgery at North Shore University Health System in Chicago. Having worked with Dr. Paller for many years, Dr. Bauer said, “I have been a pediatric plastic surgeon my whole career and throughout my career have collaborated closely with my pediatric dermatology colleagues

including Dr. Paller. For more than three decades it has not been uncommon for Dr. Paller and her colleagues to send me cases for which there have been limited or optimal medical answers.”

Recently, FIRST had the opportunity to speak with both doctors about one such collaboration - a procedure performed nearly four months ago, to reconstruct the ears on a seven year old boy with Harlequin ichthyosis.

## Can you briefly explain the characteristics of harlequin ichthyosis?

**AP:** Harlequin ichthyosis is the most severe form of ichthyosis. Babies are born with a thick “armor” of scale that has characteristic cracks or fissures that are patterned and somewhat resemble a harlequin print. Ectropion (turning out of the eyelids) and eclabium (turning out of the lips) are much more extreme than in collodion babies, and the markedly tightened skin leads to severe deformities/ reduction of the fingers, toes and ears.

## How did the family first find you? Who is affected and how old are they?

**AP:** The young boy I am highlighting is John, who has severe manifestations of Harlequin ichthyosis. Given our Center of Excellence for Ichthyosis at Northwestern/ Lurie Children’s of Chicago, it is common for babies born with ichthyosis in this area to be referred to our hospital. John was born at a hospital in Chicago and, after a 2-month

hospitalization during which he received excellent supportive care (and no retinoids), he was discharged for my continuing care.

John was born to young parents who did not feel capable of providing continuous care to him, and he became a ward of the State of Illinois. He could not have been more fortunate to have Laura become his foster mom. A common-sense, incredibly strong woman, Laura has raised John (now for about 6 years) as her own, providing fantastic support in all ways. John is now 7 years old and has grown to be an outgoing, witty, charming young boy despite his severe disfigurement and other issues (especially itchy skin and joint pain) from his Harlequin ichthyosis. My heart almost broke recently when he told me that he was being teased a lot by the other boys his age in school -- about his ears -- and how much this teasing bothered him. He wished he had different ears. John had virtually no ears – little more than openings in the side of his head – as severe an ear deformity as can be seen in Harlequin ichthyosis and much worse than in individuals with ichthyosis born as collodion babies.

I thought immediately of my colleague and long-time friend, Dr. Bruce Bauer, a pediatric plastic surgeon who is internationally recognized for his artistry in ear reconstruction.

## What was your approach to the surgery?

**BB:** I knew nothing about HI before meeting John, so needless to say this was a “first time” surgery of this kind. John’s ear deformity was the reason for his referral. He had what appeared in photographs to be similar to a congenital ear deformity known as cryptotia or “covered ear.” The approach was to release the ear from the side of the head and reshape the cartilage and re-drape the adjacent skin over the corrected cartilage deformity. Interestingly, looking back at the history of HI, the belief was that the patients actually did not have ears, but based on what we could see at surgery, the soft ear cartilage is partly collapsed under the abnormal skin “envelope.” The approach of the surgery was to release the ears, restructure the cartilage and create the space behind the ear. His skin was not flexible enough to move the way we normally do, so we needed to take a skin graft and we didn’t know if it would heal in that setting and how that graft would change. However, we got the ear separated, we lifted the skin off the ear and borrowed cartilage from the concha or bowl shaped part of the ear adjacent to the ear canal to reshape and add height to his ear.

**Would you consider the outcome a success?**

**BB:** It healed quite well initially. It has been 4 months and he has since lost some depth behind the ear. It is, however, enough of a correction that it now looks like he has ears, and his glasses stay on better. But most importantly, we learned something in the process. For instance, we may need to thin the full thickness skin graft used to cover the space behind the ear, more than normal, and use a splint to maintain that space for a period of months after surgery the next time. The approach was definitely the right one, but we are learning how it can be better. So it's a "work-in-progress" through the combination of having experience with a lot "odd ball" types of procedures, including with rare dermatologic disorders, and being pushed to do things we haven't had good answers for. It's a challenge but we all learn.

**AP:** I was so pleased with the result. John has real EARS! I have seen him in follow-up twice since the procedures and he's so happy.

**Is this a surgery you have recommended before for your patients with ichthyosis?**

**AP:** This is the first time I have recommended ear reconstructive surgery for ichthyosis -- and it is based on the severity of John's ear deformity and the impact that it was having on his psyche. However, given the outstanding results, I would consider it for children (or adults) with lesser

deformities that have impacted how they are perceived by others and feel about themselves.

**In what ways are you hoping this will change his story/ life experience?**

**AP:** This is the first time I have recommended ear reconstructive surgery for ichthyosis -- and it is based on the severity of John's ear deformity and the impact that it was having on his psyche. However, given the outstanding results, I would consider it for children (or adults) with lesser deformities that have impacted how they are perceived by others and feel about themselves.



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# We Support Research And So Do You

## Investigators discuss patient participation in research at FIRST National Conference

In addition to all of the friendly support, product sampling, tip sharing, and dancing, was the highly anticipated medical research session, where the leading ichthyosis investigators took center stage to report on the advancements in ichthyosis research. What was their prevailing message this year? A big “thank you” to the patients for providing the means to dive more deeply than ever before into the medical investigation of treatments and cures for this particular set of rare dermatologic disorders.

**FIRST Board and Medical & Scientific Advisory Board (MSAB) member Dr. Keith Choate, of the Department of Dermatology at Yale University**, opened the session with a passionate explanation of the importance of the National Registry for Ichthyosis & Related Skin Disorders, stating, “We don’t fully understand ichthyosis as a condition and its life cycle. The Registry will help us uncover more of what we need to know.” (See page 10 for more information on the Registry). In addition to managing the Registry, Dr. Choate’s team has also conducted the Gene Discovery Project from Yale University, a study seeking to comprehensively understand the genetics of ichthyosis and the biological implications of mutations in these genes. As presented by Dr. Choate, “We have discovered 608 genetic diagnoses, identified a novel cause of ichthyosis with confetti and two new syndromes.” He ended his presentation with an insightful message to the audience, saying, “Research is happening and you are all making it happen.”

**FIRST Board and MSAB member, Dr. William Rizzo of the University of Nebraska Medical Center**, followed with an overview of his specialized research into the very rare condition of Sjögren-Larsson syndrome (SLS). He explained how a collaborative approach to research could enhance and extend the research of others and commented, “We are looking for objective biomarkers that correlate with severity of clinical symptoms for drug treatment studies and to establish a place where other researchers can find the information.”

He continued his explanation of the importance of this collaboration stating, “Clinical variation and natural history of SLS is being uncovered and a wealth of ‘potential’ biomarkers for SLS likely exists. A bioregistry containing SLS specimens for all researchers to access is now available.”

*“Research is happening and you are all making it happen”*

*- Dr. Keith Choate, Yale University  
Department of Dermatology*

FIRST Board and MSAB member, Dr. Amy Paller of Northwestern University Skin Disease Research Center, who was also conducting onsite research at the conference, presented updates on her research regarding why skin is so red in many with ichthyosis. “If we can better understand the why then we can think about the possibility of new treatments for the redness.” Dr. Paller and her team have found that the immune system is skewed in the same way as another inflammatory, scaling skin problem called psoriasis -- and the more the redness, the greater the skewing, regardless of type of ichthyosis (lamellar ichthyosis, congenital ichthyosiform erythroderma(CIE), Netherton and epidermolytic ichthyosis were studied). She further noted, “Therapies that target precisely this arm of the immune system in psoriasis (anti-interleukin 17 biologics) have revolutionized the care of affected individuals,” showing greater effectiveness and fewer potential side effects than nonspecific anti-inflammatory therapies. Dr. Paller and her team plan to start the first research trial (Chicago and New York) to test the effectiveness of this anti-interleukin 17 medication in improving ichthyosis in adults within the next few months. For information about joining the study, contact Dr. Paller at [apaller@northwestern.edu](mailto:apaller@northwestern.edu).

**Dr. Nareh Marukian of Yale University** provided an intriguing presentation, “Developing Clinical Assessment Tools for Rating Ichthyosis Severity.” She again noted that patient participation in the development of projects will benefit the entire field of treatment for ichthyosis. Dr. Marukian explained that the new rating tool “will ensure that everyone speaks the same language when assessing efficacy of new treatments, and that the program will grade the severity of ichthyosis due to mutations in different genes, further assisting in diagnosis and treatment.”



**FIRST MSAB member Dr. Dennis Roop of the Gates Center for Regenerative Medicine at the University of Colorado** gave a fascinating view of the world of regenerative medicine, and the process of regenerating induced or “reprogrammed” pluripotent stem (iPS) cells from adult cells. Dr. Roop also discussed his work currently underway at the recently opened Charles C. Gates Biomanufacturing Facility (GBF), a 14,000 square-foot, state-of-the art manufacturing facility, just steps away from Dr. Roop’s research lab at the Gates Center for Regenerative Medicine, University of Colorado, Anschutz Medical Campus.

FIRST MSAB member Dr. Jennifer Hand of the Mayo Clinic introduced a methodology being used to improve FIRST’s Tele-Ichthyosis program. The effort includes surveying former

users, both ichthyosis experts and the medical professionals, who have submitted cases to the program. In regard to the importance of this effort, Dr. Hand stated, “Fine-tuning FIRST’s online Tele-Ichthyosis program will provide more efficient and effective solutions for both doctors and patients coping with these disorders.”

As noted by all of the medical investigators, patients are playing a more critical role in the research process than ever before. Check FIRST’s website for ways to participate in research, updates on research, and published articles regarding research news in the field of ichthyosis or related skin types.

# Your Energy Your Health



## Sandy Silverman shares tips for energy balancing & wellness at the 2016 FIRST National Conference

An intriguing and popular addition to the conference this year was speaker and energy healer Sandy Silverman. Sandy is an Eden Energy Medicine Clinical Practitioner (EEM-CLP), and her insightful breakout session explored the world of an alternative practice for wellness known as “energy medicine.”

The breakout session also included an interactive demonstration of exercises and techniques for moving blocked energy and “rebooting” your frame of mind. As energy medicine is a subject that is forging new frontiers in the field of healthcare, FIRST was honored to embrace and share Sandy’s expertise, and delighted that our members seemed to share our same enthusiasm. We had the opportunity to interview Sandy about her work, and her connection to the ichthyosis community

### What made you pursue a career in energy medicine?

I think my interest in energy medicine was initially curiosity. My first experience using acupressure points started me on a journey to learn more about ancient healing and how the body can heal and repair in such a simple and natural way. A few years ago, I was fortunate to attend a workshop presented by an Eden Energy Medicine practitioner. Then a few weeks later, I signed up for the foundation’s program. Now, after earning the designation of Eden Energy Medicine Clinical Practitioner (EEM-CLP), I simply want to share what I’ve learned with others.

**What do you hope the practice of energy medicine will bring to the ichthyosis community?** What I hope this practice brings to the ichthyosis community is empowerment. I believe eastern-based energy medicine as a support to western medicine makes a great marriage.



**Can anyone do it?** Absolutely! Working with your energies is your birthright! Students of energy medicine come from all walks of life - from ordinary people with no experience in self-healing or healing others, to healthcare professionals hoping to learn new ways for healing and to enhance their practices.

Watch video clips from Sandy’s session on FIRST’s Youtube channel for easy, practical techniques to work with your own energy for improved wellness.

**What is Energy Medicine?** Energy Medicine utilizes techniques from time-honored traditions such as acupuncture, yoga, kinesiology, and qi gong. Flow, balance, and harmony can be non-invasively restored and maintained within an energy system by tapping, massaging, pinching, twisting, or connecting specific energy points (acupoints) on the skin; by tracing or swirling the hand over the skin along specific energy pathways; through exercises or postures designed for specific energetic effects; by focused use of the mind to move specific energies; and/or by surrounding an area with healing energies.\*

\*www.innersource.net

# Join the New GENERation

## Have you received a genetic diagnosis?

Now is the time to GET DIAGNOSED and join FIRST in playing an important role in ichthyosis research. FIRST is co-sponsoring a transformational scientific endeavor with one of the world's leading institutions in ichthyosis research, Yale University. We encourage you to take part. The National Registry for Ichthyosis & Related Skin Disorders, is available to investigators worldwide, and is the largest host of ichthyosis patient information – critical data that holds the key to better, more targeted treatments, and eventual cures. The Registry, co-sponsored by FIRST, is the next evolution of ichthyosis research. Now is the time to get diagnosed, join the Registry and the new GENERation, and play your part in unlocking the future of ichthyosis research.

**What is a registry?** People living with a rare disease are a critical component of the research process. Without patients and families voluntarily providing detailed insights into their rare disease, researchers may be missing information that is vital to unlocking scientific puzzles that may lead to new treatments. In the rare disease community, patient registries are especially valuable to gather this critical information because, in most cases, very little is known about a particular condition.

The purpose of the Registry is to enroll people with ichthyosis, to characterize their specific type of ichthyosis using defined descriptions, and to collect information about enrollees in order to advance understanding of the diagnosis, causes, and treatment of the disorders.

**How is FIRST involved?** FIRST plays a pivotal role in the Registry. As a co-sponsor, FIRST is providing support and resources to ensure the Registry is managed, sustained, and utilized to its fullest capability. FIRST resources will support the principal investigator of the Registry, Dr. Keith Choate, and many of the functions in his laboratory at Yale University. FIRST will also allocate resources to encourage our members to enroll in the Registry and receive a genetic diagnosis. FIRST will also support outreach to research investigators and health organizations who specialize in ichthyosis and related skin types, helping them to utilize the Registry's many benefits.

**Why enroll in this registry?** A registry is the cornerstone to research. Investigators working within a certain track of medical research will have access to the patient data they need to experiment, discover, and achieve medical breakthroughs. Without patient registries, the process of scientific discovery in medical treatments can be slowed,

halted, or even dismissed. Studies of these disorders may take years to finish. If a cause is found, however, investigators maybe be able to develop better tests and treatments in the future.

Participating in a registry is one of the most direct ways to participate in the future treatment and possible cures for your skin disorder.

**What if I already enrolled in the Yale Disorders of Keratinization Research Project, can they use my information for the Registry?** Yes, however your file may need to be updated or more information may be needed. When contacting Yale for more information, be sure to inform them when you were tested and/or diagnosed.

**Who can access the Registry?** Investigators from universities or pharmaceutical companies interested in ichthyosis can send an application to the registry. If the proposed study has appropriate protection for human subjects and is approved by the Registry advisory committee, investigators will be permitted to contact enrollees to inform them of the study opportunity. Participation in future studies is optional and you can choose which, if any, studies to join. Your information will not be transferred to these investigators without consent. The Registry will function solely to inform you of studies relevant to your skin condition.

**If I have a diagnosis from another laboratory or institution, can I provide it to Yale for the Registry?** Yes. When contacting Yale for more information, be sure to inform them of where, when, and by whom you were diagnosed.

**What does it cost to get diagnosed and be part of the Registry?** There is no cost for participating in the Registry. If you do not already have a laboratory diagnosis, Dr. Choate's lab will perform the DNA testing under his research funding at no cost to you or your insurance.

**Do I need to travel to Yale University to participate?** No. The Yale lab will work with you or your physician to obtain all relevant medical records and consents. Any costs of shipping will be covered.

**How do I get diagnosed and join the Registry?** To participate, please email the Registry's patient coordinator, Maryann Ackerman, at [maryann.ackerman@yale.edu](mailto:maryann.ackerman@yale.edu) or call the Yale lab at 203.785.5364. A member of the team will promptly respond.

# FIRST ADVOCATES

"Each time I attend the National Conference I am forever changed. The compassion that is shared, the sense of home, and the dedication of our physicians fills my heart."  
- Chris Wassel, Director of Operations, FIRST  
cwassel@firstskinfoundation.org



what ichthyosis is, and use photos if you have them to illustrate your point. As you get to know them, you will be given the opportunity to talk about it extensively, if you choose to." - **Chrissy See on raising awareness in your community**

## Three key takeaways for raising awareness and lobbying for ichthyosis from the 2016 FIRST National Conference

Although it was the last leg of the conference, and one of the final breakout sessions, it was hard to wind down, or even be the least bit distracted by impending airport dashes, while the powerhouse trio of Denise Eiser, Chrissy See, and Sam Zavitz took the lead of "Be Your Best Advocate in the Community." Each participant was not only thoughtful and provocative in their presentation, but shared personal stories and anecdotes from their own unique perspective on living with ichthyosis - affected adult, extended family member, mother of affected child. However, in the end it was clear that their resounding message to the audience was one of empowerment - never be afraid to use your voice.

More specifically, the women presented real-life examples of how to advocate and raise awareness, not only in your local community, but to inspire change in rare disease legislation at the government level. Three key takeaway messages were:

1. "Social media is a powerful way of owning your inner dialogue, finding your voice, and using it to achieve great things. It is a tool that can help create a world that is softer, more supportive, and more aware of the perspective of 'other.' My brother who is also affected, hiked the Pacific Crest Trail two years ago - he did it to teach others. That was how he wanted to use his voice and tell his story. Don't be afraid to tell your story, in any way you choose."  
- **Denise Eiser on social media and advocacy**

2. "As you know, most people have never heard of ichthyosis and it can be a very complicated and emotional topic to explain. Find a way to explain ichthyosis, and your relationship to it, one step at a time. If you are meeting someone for the first time, or a group of people for the first time, give them a simple explanation of

3. "First of all, I'd like to say that you can do this! Going to Capitol Hill was one of the most intimidating things for me. I have absolutely no experience in lobbying or speaking with government officials, but I applied for the grant to attend as a representative for the state of Georgia on Rare Disease Day and I got it! I learned that there's nothing to worry about! First of all, you are lobbying with a group of patients and doctors that are all focusing on advocating for the same issues and the event organizers totally prepared all of us to speak to the Representatives. But I was also pleasantly surprised to find out they actually wanted to hear about my story, from me. Plus, I had no idea someone in Congress actually cared about me before I did this. It was so motivating! I have gone to Capitol Hill Rare Disease Day for two years now and advocated for my daughter and for ichthyosis. If I can do it, you can do it!"  
- **Sam Zavitz on lobbying for rare disease legislation**

Sharing your story, and advocating for your rare condition, can have a great impact on your life, your community, and your world. Remember there are many resources and tools available at FIRST to assist you in the power of telling your story. Awareness cards, brochures, videos, and online resources produced by FIRST can help to explain the genetics and the challenges of living with ichthyosis. For more information on rare disease advocacy initiatives, contact Chris Wassel at [cwassel@firstskinfoundation.org](mailto:cwassel@firstskinfoundation.org). Interested in sharing your story with FIRST? Contact Maureen Neville at [mneville@firstskinfoundation.org](mailto:mneville@firstskinfoundation.org).



# Thank You For The Support!

FIRST families raise funds, awareness and hope.



"Hi, wonderful members of FIRST! It was truly extraordinary to meet so many of you in person in San Diego and hopefully I'll meet even more of you at events and meetings this year. I wanted to also send a shout out to our RAISE partners and grassroots fundraisers! You guys rock! Your commitment to the FIRST community is changing lives every single day."  
-Maddy Bergman, Director of Development, FIRST  
mbergman@firstskinfoundation.org

## SPOTLIGHT ON THE SACCENTE FAMILY!



Brooke and Michael Saccente from Mohegan Lake, New York, have been co-hosting the FIRST Night with the Mets since 2012 (reaching 550 tickets sold this year!). Their daughter, Kylie, was born with ichthyosis in 2008, and Brooke and Michael became FIRST members shortly after she was born. Brooke and Michael are such strong advocates for the ichthyosis community and FIRST, serving as grassroots coordinators.

**Why did you decide to start fundraising for FIRST?** Ichthyosis is such a rare condition. We knew this was the only way to build a platform for FIRST and raise awareness. Otherwise, people would never learn about ichthyosis. Our daughter is 8 years old and outside of FIRST, we have never met someone who also has ichthyosis or knows what it is. Thanks to our fundraiser, more people are becoming aware.

**What is one tip you can offer to someone who is considering hosting an event?** We decided to host an event around something our whole family enjoys – the Mets. It's America's favorite pastime, so we knew that our friends and family would also enjoy coming to the game. Ichthyosis is so rare and our community is small. I just want people to know that any type of fundraiser, regardless of the size or amount raised makes a difference to FIRST.



## The Grass Keeps Growing! Thank You to Our Fabulous Family of Grassroots Fundraisers!

Cruise in the Park	Meghan & Brian Straight	\$300
Wharton Happy Hour	Aaron Fisher	\$540
7th Annual Lido West Beach Run & Walk	Greg LiCalzi & Ace in the Hole Foundation	\$10,000
The Woodlands Marathon	Andrew Sanders	\$860
FIRST Annual Wine Tasting for FIRST	Bill & Shirley Bergman	\$1,310
2016 Cina Family Wine Tasting Event	Sean & Jolie Cina	\$5,770
IAM Fundraiser	Courtney Westlake	\$1,530
Doughnut Day at District Doughnut & Step 2 Raffle	Melissa Beard, Courtney Westlake & Step 2	\$569
Dress Down Day at Queen of the World School	Ella Hager (student)	\$135
FIRST Day Out at the Pirates	Lauren & Matt Kocher	\$8,821
FIRST Night Out at the Mets	Benedetto & Saccente families	\$13,021
Goshen Center School Activities	Dede Fasciano	\$470
Jeans for Genes Rare Disease Day Event	Kelly Robinson	\$623
Rare Disease Day Campaign	Kimberly Cole	\$325
Lewis Family Tshirt Sales	Paul & Denise Lewis	\$1,658
Paine Intermediate Casual Wednesday	Karen Ekonen	\$600
Release the Butterfly CD Release Party & CD Sales	Bailey & Tracie Pretak	\$2,776
Sarah Hodgkinson's Birthday Party	Sarah Hodgkinson	\$417
Bottle Collection	Jim Borden	\$70



# Congratulations to 2016 UFIRST Scholars!

Please join us in congratulating this year's UFIRST scholarship recipients! Each student was asked to share their goals and aspirations. Read what these outstanding students had to say...



**Haddasah Abraham**

*Lamellar Ichthyosis*

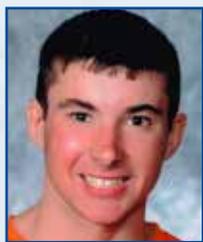
**Trinity Western University** "I am pursuing a career in the life sciences, particularly in the medical field whether that is through research, lab work, or medical school. I have also developed an interest in oncology and I hope to work in that field helping people struggling with cancers or other diseases."



**Atique Ahmed**

*Lamellar Ichthyosis*

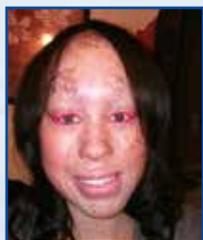
**Pakistan Government Gordon College** "To help mankind for the treatment of incurable diseases."



**Ryan Balog**

*Congenital Ichthyosiform Erythroderma (CIE)*

**LaRoche College** "I want to graduate from LaRoche College with a degree in math education and become a middle level math teacher and influence student's lives."



**Victoria Carranza**

*Lamellar Ichthyosis*

**Loma Linda University** "My dream is to graduate with a master's degree as a child life specialist. My degree will allow me to work at a children's hospital where I hope to inspire belief."



**Cheyenne Coleman-Lyons**

*Ichthyosis Vulgaris*

**California State University Stanislaus** "I would like to travel around the world to learn about different cultures, learn to speak Spanish fluently, obtain my real estate license so that I can flip properties and lastly, continue my quest in learning how to play the piano and read sheet music."



**Maria Gad**

*Lamellar Ichthyosis*

**Ohio State University**  
*Goals and aspirations:* "To make a difference in the world of those around me."



**David Horton**

*Lamellar Ichthyosis*

**British Columbia Institute of Technology** "To become a professional land surveyor for the province of British Columbia and raise a family."



**Christian Kalwa**

*X-Linked Ichthyosis*

**North Carolina State University** "My goal is to receive my doctor of veterinarian medicine license and to become a veterinary board certified surgeon."



**Alicia Kouba**

*Congenital Ichthyosiform Erythroderma (CI)*

**Bowling Green University** "After graduating, I'm going to grad school. Eventually I plan to work for a professional sports team to work with athletes on their health to improve their performance."



**Brandon Laird-Fletcher**

*Congenital Ichthyosis*

**Glendale Community College** "To receive a bachelor's in criminology, justice and psychology. Then I would like to become a homicide detective or a behavioral analyst. I want to get one of these degrees so that I can help citizens in the US and protect society."



**Gina Messer**

*Lamellar Ichthyosis*

**Humboldt State University** "To become an insightful, empathetic therapist who guides her clients toward lives that are healthier for them. In general, I want to live a fulfilling life full of love and adventure."



**Austin Milam**

*Lamellar Ichthyosis*

**University of Colorado Springs** "I would like to someday own my own greenhouse, and enjoy life and be happy."

## UFIRST Scholars continued...



**Kayla Murray**

*Congenital Ichthyosiform Erythroderma (CIE)*  
**Stanly Community College** "I plan to obtain my Associate of Arts degree from Stanly Community College, and then transfer to a four-year university. I plan to obtain a master's degree in psychology."



**Muhammad Nasir**

*Lamellar Ichthyosis*  
**University of Massachusetts Boston**  
"My goal is to pursue a degree in aerospace and biomedical engineering to one day work for NASA and become an astronaut."



**Casey Nordgaard**

*Lamellar Ichthyosis*  
**Minnesota State University Moorhead**  
"My goal is to attend MSU, Moorhead, and earn a degree in business administration and marketing."



**Kyle Pappas-Adamson**

*Epidermolytic Ichthyosis (EI)*  
**Metropolitan State University**  
"My goal is to become an athletic trainer for a professional sports team and help the athletes improve themselves in their athletic abilities."



**Alexis Rodrigues**

*Netherton Syndrome*  
**Midlands Technical College**  
"My long-term goal is to pursue an undergraduate degree in biology. I aspire to become a dermatologist."



**Hannah Suda**

*Lamellar Ichthyosis*  
**Bemidji State University** "My goals are to graduate in May of 2018 with my Bachelor of Science in Nursing along with a minor in psychology."



**Michael Wetterlund**

*Netherton Syndrome*  
**Metropolitan Community College**  
"I want to be a master electrician!"

# FIRST Ichthyosis Picnic

**Please join Dr. Amy Paller and her team from Northwestern University for a support picnic.**

**All individuals and families with ichthyosis are welcome to join!**

**Saturday, September 10, 2016**

**Mallinkrodt Community Center  
1041 Ridge Road, Wilmette, IL**

**1:30PM to 4:30PM**

**RSVP by September 6, 2016**

**Contact: [thy.huynh@northwestern.edu](mailto:thy.huynh@northwestern.edu)  
312.227.6486**

**Visit  
<https://firstannualouting.wordpress.com>  
for additional information**





# FIRST

Foundation for Ichthyosis & Related Skin Types®

Educate • Inspire • Connect

2616 N. Broad Street • Colmar, PA 18915

## 12 Ways To Connect In 2017!

Meeting another person with ichthyosis can be both emotional and life changing. I am hoping to change lives in 2017, with 12 Patient Support Forums being planned across the United States! I hope to meet many of you at one of these meetings, and to reconnect with those of you I already know! Are you ready to change a life as well?

- Moureen Wenik, Senior Director  
Programs & Research, FIRST  
mw Wenik@firstskinfoundation.org



Have you been to a FIRST Patient Support Forum? Well, chances are this coming year there'll be one near you. In fact, there are 12 chances that there will be one near you. As of this printing, the schedule for the forums are below. There are still a few dates to be determined, but we'll keep you posted along the way.

Why should you go? Well first of all, you'll get free product samples. Lots of them! Plus, you'll meet other families and individuals that have the same or similar issues with their skin, and, likely, form close ties and friendships that last for many years to come. (We know this because we've seen it happen at FIRST gatherings for over 35 years!). And, after all, they not only relate to your life with a rare skin condition, but they live in your region too.

A perfect combination.

Plus, our ichthyosis medical specialists are the best in the world. We stand behind that claim every day of the year, 100% of the time. And this is your very rare opportunity to meet with these experts face-to-face, and ask them all the questions that keep you up at night. Although your hometown docs may be fantastic, most have not gone full-court press on rare skin disorders of keratinization. FIRST medical experts have been in the game for years, even decades. Oh, and last but not least, you'll get to meet FIRST staff up close and personal. And no, our pictures don't lie -- we are as happy to meet you as we look! Let's keep connecting. Okay?

Boston, Massachusetts	August 19, 2017	Milwaukee, Wisconsin	June 24, 2017
Philadelphia, Pennsylvania	May 6, 2017	Omaha, Nebraska	May 20, 2017
Raleigh, North Carolina	March 25, 2017	Billings, Montana	TBD
Louisville, Kentucky	TBD	Denver, Colorado	September 16, 2017
Jackson, Mississippi	TBD	Las Vegas, Nevada	September 23, 2017
San Antonio, Texas	April 1, 2017	Portland, Oregon	June 10, 2017