



# FIRST is My Other Family

## An interview with Eric Schweighoffer

*At the end of this year we will be wishing farewell to a great friend and dedicated member of the FIRST Board of Directors, Eric Schweighoffer, as his term will officially end December 31.*

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The Foundation for Ichthyosis  
& Related Skin Types, Inc.®  
2616 N. Broad Street  
Colmar, PA 18915

Phone: 215.997.9400

Toll-free: 800.545.3286

Fax: 215.997.9403

Email: [info@firstskinfoundation.org](mailto:info@firstskinfoundation.org)

Web: [www.firstskinfoundation.org](http://www.firstskinfoundation.org)

**Chief Executive Officer**

Jean Pickford

**Editor**

Maureen Neville

**Medical Editor**

Amy Paller, MD

**Editorial Assistant**

Kimberly Cole

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## Chief Executive Officer Report



*I am so proud and honored to be leading this caring, compassionate, and enthusiastic community. Witnessing the growth of FIRST and the unwavering commitment of our medical professionals, patients, families, and advocates of the ichthyosis and related skin type community, has been one of the truly remarkable privileges of working for FIRST.*

*In this issue, you'll meet members of the community from the doctors who are tirelessly committed to scientific innovation, and the pursuit of better treatments and cures, to the cast of the Release the Butterfly Tour, to a member, who at the very last minute, changed plans to join FIRST's advocacy efforts in Washington, DC. You'll learn more about a truly remarkable mom who has published an inspiring book about finding beauty in all of life, and last but not least, an 8-year-old girl who has already become the most powerful advocate for herself imaginable - this issue of *Ichthyosis Focus* will cause you, as it has me, to take pause. Our community is strong because of the strength of our members. And there is no greater proof than the stories that come straight from our members themselves.*

*Together, we will continue to grow, continue to hope, and continue to support one another as we enter the final chapter of 2016.*

*I look forward to connecting with you in the upcoming year and beyond, on this incredible journey toward finding better treatments, cures, and hope for all those affected by ichthyosis and related skin types.*

*Do you enjoy reading this newsletter? What does this communication mean to you? Let us know so we can be assured this newsletter has value to you - <http://www.firstskinfoundation.org/survey>*

**Jean R. Pickford**

**Chief Executive Officer**

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# Correspondence Corner

## Dear FIRST Foundation,

"The day Isabel was born, I found your website on my phone while in absolute despair. I was so grateful to read stories of people living full lives with ichthyosis. It made me feel a lot more relaxed. When we left the NICU, our doctors literally just printed pages from your website for us because it is absolutely the best information available. Thank you to you and your colleagues for providing such outstanding support for this rare condition. It means a lot to me.

**Janet Holt**

I love this group (Facebook - FIRST Ichthyosis Parents) and I'm super new to the whole community. We are newly diagnosed and both my son and I have mild cases of vulgaris. The support and advice in this group is the best around. Thanks everyone for sharing your stories and advice, it is so comforting.

**Meghan Carr**

Wow! Thank you so very much! Words cannot express how thankful I am to have FIRST and the UFIRST scholarship to help me follow my dreams!

**Jessica Lewis**

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## *Thank you to all those who participated in the Aldeyra Phase II trial for topical treatment of Sjögren-Larsson Syndrome (SLS) with NS2*



Aldeyra Therapeutics, Inc. (Aldeyra) reported positive results of a randomized, double-blind, placebo-controlled, multi-center clinical trial of a topical dermatologic drug (NS2) for the treatment of the ichthyosis in Sjögren-Larsson Syndrome (SLS). SLS is a rare genetic error of metabolism caused by mutations in fatty acid aldehyde dehydrogenase, leading to elevated toxic fatty aldehyde levels that are thought to contribute to ichthyosis, neurological disorders, and retinal disease. NS2 is specifically designed to reduce levels of toxic aldehydes, and is the first therapy to be directed at the underlying cause of SLS.

"The results of this randomized and controlled clinical trial represent a significant advance in the effort to develop a treatment for SLS," said Dr. William Rizzo, the principal investigator of the trial and a leading expert in SLS. "The data from this trial suggest that NS2, when applied to the skin, has the potential to help patients suffering from SLS by lowering toxic aldehyde levels and preventing the dermal dysfunction that causes ichthyosis. I am excited about these results, and I am particularly excited for SLS patients and their caregivers."

"We are thrilled to report positive data from this rigorous and controlled clinical trial studying the use of topical dermatologic NS2 to treat the severe skin disease associated with SLS," said Dr. Todd C. Brady, president and CEO of Aldeyra. "There is currently no FDA-approved therapy for SLS, and we believe these results represent a major milestone for patients afflicted with this disease."

FIRST is excited that Aldeyra Therapeutics is focusing on developing a therapy for SLS. It is expected that follow up clinical studies on SLS will be started in the near future to extend these initial results. Any updates to this research will be posted at <http://www.firstskinfoundation.org/news-events>.

# FIRST Member Anne Kaier in The New York Times



Please join us in congratulating FIRST member Anne Kaier, affected with lamellar ichthyosis, whose essay “Finding Refuge With the Skin I’m In,” was published on August 24 online in The New York Times as part of a series of essays featuring art and opinion that explore the lives of people living with disabilities.

Anne is a very gifted writer and has many stories and life experiences to offer the ichthyosis community. Her essays have appeared in The New York Times, 1966 journal, the Gettysburg Review, Alaska Quarterly Review, and the Kenyon Review. “Maple Lane” was mentioned on the list of Notables in the 2014 edition of “Best American Essays.” Her memoir, “Home with Henry,” is available from PS Books and her book of poems is entitled “InFire.” Her poetry also appears in “Beauty is a Verb: The New Poetry of Disability,” which is on the American Library Association Notable Books list for 2012. She is a Pushcart Prize nominee with degrees from the University of Oxford and Harvard University. Kaier teaches at Arcadia University in Pennsylvania. For more information, visit [www.annekaier.com](http://www.annekaier.com).

*Here is an excerpt from The New York Times essay.*

## *Finding Refuge With the Skin I’m In*

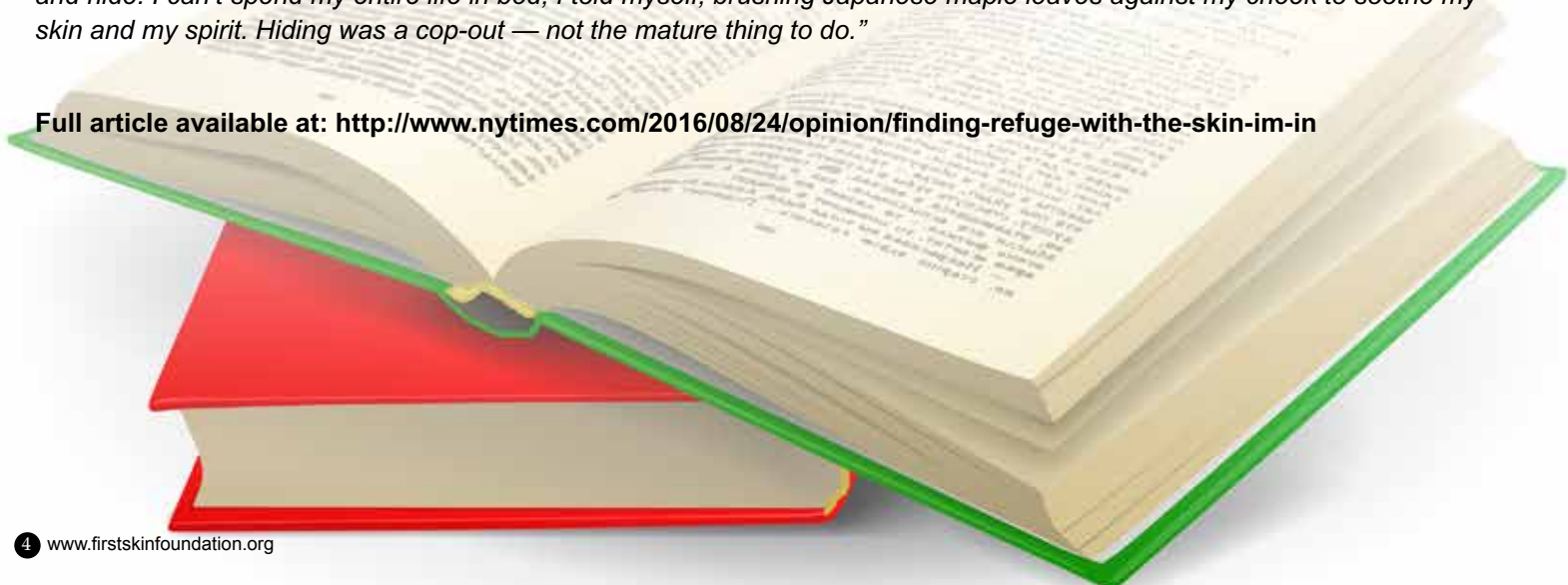
*“The checkout lady’s panic surged as she held the coins six inches above my hand and dropped them into my palm. They clanged until I made a fist. She ran her fingernails through her hair.*

*“What’s wrong with you?” she asked, her voice rising to a higher pitch. I slid the money into a jeans pocket and stroked my thigh to calm down.*

*“Just dry skin,” I murmured. That wasn’t true. I have lamellar ichthyosis, a genetic disorder which manifests itself in scales not just on my face, arms, hands — which she could see — but over my whole body. My skin is perpetually red and itchy. I can’t sweat well, so I’m careful not to get overheated, and I can’t walk far in strong sun. I naturally seek the shade. My skin isn’t painful, but much of the time, the entire surface of my body feels tight. My eyelids are pulled down by this tightness, too, so I often shield my face with a hat. Standing in the checkout line, I jammed the lovely straw boater I’d gotten in England down to blunt my face. “Damn it,” I thought, “get me out of here.” I knew I could smile and tell her my condition was not contagious, but instead I hurried home through narrow city streets, slammed my heavy front door, and headed straight into the tiny walled garden in the back.*

*The garden is my refuge. It’s the reason I bought this house. Even a small leafy space is unusual among Philadelphia row homes and I craved a private place with fresh air and shaded light. I water my three trees in hot spells and nurture cool white moonflowers. The unseeing trees and plants comfort me. Pacing the bricks, I fought the instinct to go into the house and hide. I can’t spend my entire life in bed, I told myself, brushing Japanese maple leaves against my cheek to soothe my skin and my spirit. Hiding was a cop-out — not the mature thing to do.”*

Full article available at: <http://www.nytimes.com/2016/08/24/opinion/finding-refuge-with-the-skin-im-in>



# Our Surprise About Brenna's New Teacher

By *FIRST* member, Courtney Westlake

Previously published at [www.courtneywestlake.com](http://www.courtneywestlake.com)

The energy was lively among the young students who sat waiting for their classroom doors to open on the first day of school, and after giving Connor a kiss, I held Brenna's hand as we walked slowly down the hall toward her preschool classroom. I began to feel heads turn, conversations quiet, eyes on us, and I maintained a perky smile as I exclaimed, "We're almost to your class, Brenna! This is going to be so fun!"

As we passed, I heard a little boy loudly remark, "Why's she so hot?" and another boy sitting next to him, who was in Brenna's class last year, answered that she wasn't hot. "Well, why's she so red?" came the next loud question, to which I could barely hear – among the chatter that had started again in the hallway – the second reply that was firmly given: "She has sensitive skin. She's NICE."

We rounded the corner to Brenna's class, where we were met with almost entirely new faces, with only a couple of familiar kids from previous semesters – and along with that, very noticeable reaction to Brenna's entrance. My heart tightened deep in my chest, and the threat of tears burned in my eyes. It was unexpected, and I felt defensive; I was barely able to concentrate as I went over care instructions with Brenna's new aide.

## ***I cried on that car ride home.***

The tears continued after I shut the garage door, as I wrestled with how to make things like this easier or better, how to prepare, how to react myself, how to not project my own feelings onto Brenna when I struggle as her mother.

That first week of school this year was emotional for me, and I prayed fervently during those days for wisdom, understanding and grace.

Other new developments this school year were staff changes. Brenna was assigned a new personal aide, and the school hired a new nurse – and what comes with that kind of changing of the guards is the restart of education and awareness about her condition, her IEP and health plan, her routines, her personality.

So when Brenna's head classroom teacher announced that she was taking a new job at a different school, as well, it felt like this school year was a new road containing unexpected twists that left us swerving, frustrated, trying to catch up, perhaps even a little alone.

It was a Friday when there was a little tap on my window as I buckled in, ready to drive off after picking up Brenna from school.

"I just wanted to introduce myself," said the tall, friendly woman standing next to my van. "I'm going to be the new preschool teacher starting on Monday."

And I will never forget what came out of her mouth next...

## ***"I have ichthyosis too."***

This rare skin disorder that no one's ever heard of? Brenna's new teacher actually has it... a mild form called ichthyosis vulgaris.

## ***I cried on that car ride home.***

The tears continued after I shut the garage door, as I marveled at how God makes all things beautiful, how he redeems hard situations, how he works through others to reach us and works through us to reach others.

This relationship between Brenna and her new teacher has blossomed quickly, and witnessing their fast connection has made my heart soar day after day. I've peeked into a school assembly to see them dancing together, and I've even received emailed selfies that Brenna asked her teacher to take with her. Mrs. G has gone out of her way to ensure that Brenna is fostering one-on-one relationships with her classmates, and Brenna now loves to share that "my new teacher has special skin like me!"

One day recently, I smiled as the two of them walked out of school together, hand in hand.

"I showed her today how much my hands were like hers," Mrs. G said with a smile. Both of them stopped walking, and Brenna placed both of her hands on top of her teacher's, palm on palm, examining them.

"Our hands say a whole lot about us." Mrs. G bent down to Brenna's level. "And our hands sure have big stories to tell, don't they!"

***When Courtney Westlake's family was given the shocking news that their daughter, Brenna, was born in 2011 with the severe, life-threatening skin disorder, harlequin ichthyosis, they began to discover a new and different kind of beautiful in their lives—one that values extraordinary differences and appreciates the wonderful sameness found in our humanity. In *A Different Beautiful*, Courtney explores what her family has discovered in raising a child with physical differences and what she has learned about true beauty. Available online at Amazon, Barnes and Noble and book stores in the US, UK, and Canada.***



# Science, Innovation and Research in Ichthyosis & Related Skin Types

## Research Reveals Reason for Perplexing Redness Associated with Ichthyosis and Other Skin Disorders

Children and adults travel from as far as Australia, Africa and Mongolia to see her, because she is one of the few dermatologists in the world who specializes in the rare and perplexing genetic disorder that causes their skin to be disfigured by redness and dark scales across their entire bodies, known as ichthyosis. And now, Dr. Amy Paller, who has spent 30 years researching ichthyosis, has found the cause of red skin and has a promising biologic drug to begin testing soon in clinical trials.

In a new study published in the *Journal of Allergy and Clinical Immunology*, Dr. Paller, the Northwestern Medicine chair of dermatology, Northwestern Medicine, together with Dr. Emma Guttman-Yassky of Mount Sinai Medical School, discovered that an arm of the immune system – the Th17 pathway – in these patients is way too active, and the higher its activity, the worse the disease severity. Dr. Paller is about to launch a clinical trial to test a new biologic (a cutting-edge drug), with the goal of targeting and calming down this pathway.

In ichthyosis, the skin barrier is abnormal, so the skin is inflamed, dry and scaly. “These patients can be tremen-

dously disfigured by this skin disorder,” said Paller, also an attending physician at the Ann & Robert H. Lurie Children’s Hospital of Chicago. “It can be painful, itchy and easily gets infected. They may have trouble using their hands and walking.”

Patients also have trouble sweating, so it’s hard for kids and adults to participate in sports. The drug Dr. Paller will test, secukinumab, has already been highly effective in psoriasis, a more common skin disorder with an increase in this Th17 pathway, leading to inflammation and scaling. And with Dr. Paller’s new discovery, she thinks the drug could be even more helpful in ichthyosis because the overactive immune pathway was actually more strongly correlated with ichthyosis than with psoriasis.

The research was supported by the Foglia Family Foundation Endowment and the National Psoriasis Foundation.

REF: September 19, 2016 | by Marla Paul, Northwestern University.

Published Article: <http://www.jacionline.org/article/S0091-6749%2816%2930806-5/pdf>

## From the Desk of Dr. Amy Paller...



“This research shows the power of taking research for common skin problems, such as eczema and psoriasis, and expanding it to rare skin problems, like ichthyosis. Because of my long-term commitment to the ichthyosis community, I was able to engage Dr. Guttman-Yassky, a scientist collaborator on eczema research in children, to team up with me and look at what may be driving the redness of ichthyosis. These studies identified that all evaluated ichthyosis subtypes (lamellar ichthyosis (LI), congenital ichthyosiform erythroderma (CIE), epidermolytic ichthyosis (EI) and Netherton syndrome) were tightly linked to increases in the same arm of the immune system that is activated in psoriasis, a common skin issue characterized by skin redness and scaling.

FIRST members have been instrumental in our research, starting with the national conference in Indianapolis (including for this recent paper) and through volunteering at the San Diego conference, which will support future research. We are so grateful to our patient partners. We are particularly eager to move forward with a trial to test whether a new, commercially available psoriasis medication, which specifically targets the arm of the immune system that is overactive in ichthyosis, will reduce redness and scaling. While the initial trial is only open to adults 18 years and older, we will push for an extension to children if results are favorable. We encourage any FIRST members who are interested in participating in our year-long trial (to be held in Chicago and New York City) to contact us by email at [thy.huynh@northwestern.edu](mailto:thy.huynh@northwestern.edu) or [apaller@northwestern.edu](mailto:apaller@northwestern.edu) or by phone at 312.227.6486 for more information.”

# Chicago Ichthyosis Picnic a BIG Hit!

The 2nd Annual Ichthyosis Picnic in Chicago on September 10, was by all accounts a great success! Hosted by Dr. Amy Paller and her team from Northwestern University/Lurie Children's Hospital, it was attended by more than 75 individuals and their families, in addition to medical personnel and volunteer staff. The picnic was planned by a committee of adults with ichthyosis, who raised funds and planned the activities. Magic Matt amazed the crowd with magic tricks and ornate balloon animals. Three concurrent hour-long discussion groups were geared for teenagers, adults, and parents – and yielded great tips that were shared with the entire group. Most of all, many new friends were made who are looking forward to staying connected and seeing each other again.



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"The MicrodermaMitt is AMAZING!! I cannot tell you enough how happy I am that I found this mitt for my daughter. After our first bath using it, I was speechless! Her skin was soft, smooth, shiny and so healthy looking. Her skin has been wonderful since we started using the Mitt. It looks so much smoother and virtually flake free. The skin also comes off so easy without much effort."

# Stay Connected with FIRST to Know Calls!

*"The Sjögren-Larsson Syndrome (SLS) call last night was an unbelievable experience. Although I was available as the "expert" doc and took some questions, most of the hour was actually taken up by the families discussing common medical issues in their SLS children and sharing their practical knowledge. To my knowledge, this call was the first time that so many SLS families have had the opportunity to get together, share and learn from each other. We all had a wonderful time." - Dr. William Rizzo, Member of FIRST Board of Directors and FIRST Medical and Scientific Advisory Board (MSAB)*

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 topics are interesting to you and phone in. You can be an active participant, or call in and listen to what others are saying. Please register for the call prior to the scheduled time. Contact Moureen Wenik at [mwenik@firstskinfoundation.org](mailto:mwenik@firstskinfoundation.org) or 1.800.545.3286, to register. All calls are held at 8:00 PM Eastern Time.

## Upcoming FIRST to Know Calls

**Sunday, November 27** – How to Work with Your Insurance Company

**Sunday, December 18** - Palmoplantar keratodermas (PPK): Sharing Information

# 12 One -Day Patient Support Forums Planned for 2017!

Come out for a day of networking with other families affected by ichthyosis, and related skin types. Meet other families in your area and learn how to build a stronger network in the ichthyosis community. These one-day meetings are filled with medical discussion, research updates, networking, product sharing, and skin care routines. The meetings will include a light breakfast, lunch, and childcare for families with children. Online registration will be available soon on our website, [www.firstskinfoundation.org](http://www.firstskinfoundation.org).

## PSF SCHEDULE FOR 2017:

**March 25** - Raleigh, North Carolina

**April 1** - San Antonio, Texas

**May 6** - Philadelphia, Pennsylvania

**May 20** - Omaha, Nebraska

**June 10** - Portland, Oregon

**June 24** - Milwaukee, Wisconsin

**July 22** - Billings, Montana

**August 19** - Boston Massachusetts

**September 16** - Denver, Colorado

**September 23** - Las Vegas, Nevada

**TBD** - Louisville, Kentucky

**TBD** - Jackson, Mississippi





# Strategies for Success in the ER

Emergency room visits are a fact of life for many people with rare disorders. For many types of ichthyosis, overheating, heat stroke, or a sudden skin infection, among other illnesses, can play a large factor in the frequency of emergency room visits. And when the patient is a child, these experiences can be especially stressful for the entire family. Here is a checklist to help you prepare for the ER, long before you need to make the trip. Some are simple, some require a bit more effort – but all may make your experience as smooth as possible:

- 1.** Prior to your child getting sick or injured, ask your pediatrician and pediatric specialists where you should take your child for emergent care. Remember to inform your child's daycare or school of your ER/hospital choice should an emergency arise.
- 2.** Create and frequently update a list of your child's diagnoses, surgeries, medications, allergies, vaccinations and special diets. Be sure to include the name and date of the surgery and the concentration/dosing/frequency of all prescribed (and non-prescribed) medications and formulas.
- 3.** Prepare an ER to-go bag. Fill it with comfort items, warm clothes, phone charger, snacks, medical records, ichthyosis educational booklets, and a copy of the updated health care list mentioned above, so you can grab and go when needed.
- 4.** Prepare an emergency pocket card for first responders who arrive at the scene. (Or, hand them an ichthyosis awareness card from FIRST). Be sure to include the name and contact information of your ichthyosis healthcare practitioner as well as the FIRST website and contact information: [www.firstskinfoundation.org](http://www.firstskinfoundation.org) and 215.997.9400.
- 5.** Have a print-out from the FIRST website explaining your or your child's condition so you can hand it directly to the ER doctor. As ichthyosis and related skin types are rare, they may have little or no experience treating the condition.
- 6.** Use your voice and encourage children to use their own. Explain everything that has occurred, as well as how it may have been handled in the past, and ask your child to explain their symptoms in their own words. Sometimes a clue for treatment pops up when a child offers their own description (ear hurts, tummy hurts, etc.).
- 7.** Be sure to have your speech prepared. For example, "My child has ichthyosis and cannot sweat due to her condition. She is prone to overheating and that is what has happened here." Or, "My child has developed a sudden infection due to her skin condition. She likely has a fever and will likely need antibiotics immediately."
- 8.** Be sure to give a Medical Consent note to your child's guardians. If there is an emergency, they will be able to authorize care for the child. Also remember to inform them of your preferred ER choice.
- 9.** Find out if your local hospitals, and hospitals near your child's school, have a Child Life Specialist on staff. Keep their name and number handy. In an emergency, they can meet with you in the ER and can offer support and guidance during a highly stressful situation.
- 10.** Try to stay as calm as possible. Breathe and realize everyone is doing their best. Your child's life is what matters and everyone is on the same team. Again, being prepared beforehand can help avoid a panic situation.
- 11.** Remaining informed and up-to-date on your child's disease and medical history is an absolute necessity, for it affords you the opportunity to actively collaborate in your child's emergency care management and treatment. Always remember, as the expert on your child and a vital member of the medical team, never be afraid to voice your thoughts and concerns during any medical encounter!



# FIRST is My Other Family

## An interview with Eric Schweighoffer

This year we will be wishing farewell to a great friend and dedicated member of the FIRST Board of Directors, Eric Schweighoffer, as his term will officially end December 31. Eric has been a part of the FIRST family since 1994 and has served on the board since 2008. His contributions are as plentiful as they are significant. First and foremost, his broad reaching multi-media expertise has guided the organization along the challenging terrain of modern technology, media and advertising, and he has been pivotal in the tremendous growth of FIRST. As chair of our marketing committee, Eric was responsible for spearheading an entire rebrand of FIRST's logo, messaging and marketing materials, boosting our reach across all channels of communication. As well, our community has been honored to know his kind heart and his friendly, compassionate nature. And although his term is coming to an end, we know that Eric will never be far from the FIRST community.

*Please join us in congratulating Eric for a term well-served, and please read more in the interview below about Eric's experience with FIRST, and his hope for the future of ichthyosis.*

### **Why did you initially join the FIRST Board of Directors?**

I joined the FIRST Board of Directors because I wanted to give back to an organization that had inspired me in so many personal and professional ways. Prior to joining the board, I had been a member of FIRST for many years learning about my specific skin condition while developing many personal relationships with the staff, families, and other board members. It presented a unique opportunity to apply my career advertising skills in helping to create awareness of ichthyosis, FIRST, and the outstanding support it provides. The thought of collaborating with other board members from many walks of life was also very appealing. I felt the timing was right for me to make a contribution because it coincided with the start of the website, online videos, and social media marketing as a powerful communications tool.

### **What did you learn about the organization from this unique "inside" perspective?**

I learned the organization, staff, and board members are very unique. They are incredibly talented, dedicated and

passionate to bring support and change to anyone dealing with a rare skin disorder. The amount of time and effort they invest is extraordinary and amazing. I've seen up close the many ways this group delivers on its mission to educate, inspire, and connect anyone with a rare skin disorder. Through board meetings and retreats, I've gotten a closer view into the development and execution of FIRST's strategic plans encompassing issues ranging from marketing to medical research. Most importantly, this group consists of people who are thoughtful, compassionate, and very tolerant of each other. They are like another family.

### **How has FIRST changed or grown since you've been involved with the organization?**

FIRST has changed dramatically since the first family conference I attended in the late 1990s to the present. All for the better. It's grown and evolved in many ways. Not only does it have more members, but the support, services, and medical research conducted has increased significantly. FIRST now reaches people with ichthyosis, their families, and medical researchers all around the world. The national and regional conferences continue to break attendance records every year. The management of the organization through the Board of Directors and its staff is as professionally diverse and as talented as ever.

### **What is your hope for the future of FIRST?**

I hope FIRST continues on the path it's developed to become the worldwide resource for ichthyosis and related skin types. I hope anyone who has this condition finds FIRST at their most critical time of need and advocates for FIRST after being helped. Most importantly, I hope FIRST receives the national and international financial support it deserves to carry out its mission to find treatments and eventual cures.

### **Will you stay involved with FIRST?**

I will continue to attend FIRST conferences and fundraisers as well as participate on any committees the organization feels I can contribute to.





# Put Your Best Foot Forward

Ichthyosis and related skin types can be particularly challenging for the feet! Cracks, blistering, and extreme build-up are among the most common symptoms. And the best practices for foot care is consistently a “hot topic” on FIRST Facebook groups, as well as a frequently voiced concern at patient support forums and conferences. But what are the best lotions, tools, and tips? How often should they be used? And does the treatment vary with the season of the year? To address some of these concerns, we’ve compiled a list of products and skin routine suggestions for adult footcare, from patients themselves. Please keep in mind that not every process or product works for every skin condition. Skin care is a matter of trial and error until you find what works best for you.

- I try to use a pumice stone more often in the summer than I do in winter to keep the build up down.
- I use Dream Cream all over. I use Lemony Flutter on areas that crack or are sore, and Helping Hands on my hands throughout the day. I also tried a sample of Ultrabalm which is good for cracking.
- For my cracked feet I use Bag Balm then cover with a Band-Aid. It usually heals overnight.
- As for bandaging my feet, I would use moisture-wicking socks as the bandages. They would be much easier to put on and so much more comfortable than bandages.
- Spas are made for ichthyosis people, too! Salt water pool, salt water hot tub, and steam sauna = amazing skin this weekend. Don't be shy, folks! It's worth it!
- I went to the podiatrist for help and that's where I learned about the Dremel which has made a huge difference.
- I put Vaseline on the cracks in my hands and feet and wrap them in Saran Wrap every night. I've been doing that for over 20 years and it makes a huge difference for me.
- During the day, rub your cracks with Chapstick. Chapstick will moisturize and seal your cracks without getting everything greasy. I always carry Chapstick in my purse for quick moisture and relief for the small cracks on my hands/feet/wherever during the day.
- I use a Scholl Diamond foot file and it's probably the best thing I've used to get my feet looking somewhat normal.

*Neither the Foundation, Its Board of Directors, nor Its Medical & Scientific Advisory Board endorse any of the products in this article. FIRST encourages patients to speak with their doctor prior to engaging in new skin care routines and products.*

# Member Spotlight

*Sharing stories will offer comfort, but it can also be the most effective and direct road to self-confidence and empowerment. In our Member Spotlight section each quarter, you'll meet one of our truly remarkable families or individuals and learn about their personal experience living with ichthyosis or a related skin type.*

## *Maddie's Big Dream!*

Hello, FIRST family! My name is Emily Preston from Texas, and I have epidermolytic ichthyosis (EI). I am a single mother of two precious young ladies who keep me constantly on my toes. Maddie is 8 years old and is also affected, and Kinlee is 4 years old and is unaffected. I have been involved with FIRST for many years. The first conference I attended was in Seattle in 2002, when I was 27 years old. It was a life-changing experience for me, and one that I will never forget. However, I didn't truly get immersed with the FIRST community until after my Maddie was born.

I have an extremely mild case of EI so I didn't really have a reason to get heavily involved until I was told that Maddie may not survive at birth due to her ichthyosis.

From the day she was born, I have been relentless in my pursuit of trying to make her everyday life as comfortable as possible. Not only was she born with ichthyosis, but hip dysplasia as well. It was not diagnosed at birth because they simply were trying to keep her hydrated and infection-free at the time. When Maddie was 2 months old, my mother was changing her diaper, and noticed her hips were uneven. At 4 months, we were referred to Scottish Rite Hospital in Dallas, since her particular circumstance was so rare due to her skin condition. At age 1, she had surgery to repair her hip. She was in a full body cast for three months, without baths, or skin care for her ichthyosis. This was yet another battle for my angel to overcome at her very young age.

Fast forward to 2016, a challenging time, when I was beginning to feel tired and helpless to care for Maddie's condition. I wanted to do so much more for her, but I was

also coping with my reality of being a single mom, and that there was only so much I could do. I reached out to a couple of my friends who I knew could help Maddie, but it has never been easy for me to ask for help. I have been coping with this on my own for four years. I am an extremely private person so it took everything I had to admit to myself and others that I needed help.

I told my friend that Maddie's dream is to be on The Ellen Show, and raise awareness for research for a cure for ichthyosis. Well, hearing about Maddie and her Big Dream was enough to inspire my friend. She quickly found someone who could help in the cause and out of his own pocket, he created a YouTube Channel, Facebook page, and a blog.

I write for the blog, and share my stories of raising Maddie and Kinlee as a single parent. Maddie's job is to do weekly videos in order to spread her message about an 8-year-old child who lives with ichthyosis every day, and all that entails. As she says in one of her videos, she wants to "change the world!" Because we have angels in our lives to help us get the word out, Maddie and I both will continue this crusade until her dream comes true! At the end of the day, it's all about ichthyosis awareness, being kind, and making a difference in our community.

Please help us fight the fight of ichthyosis awareness by liking and sharing her Facebook page and blog. Her Facebook page is Maddie's Big Dream, and her blog address is [maddiesbigdream.com](http://maddiesbigdream.com). Together, we can make a difference. Education and awareness is what breaks down barriers of ignorance and opens doors to create a cure and solution for this challenging and rare disorder.

**- FIRST Member, Emily Preston**



# What is the Regional Support Network (RSN)?

Looking for support from another family or individual affected with ichthyosis or related skin type? We can help. In addition to our FIRST to Know calls, support meetings, and conferences, FIRST's Regional Support Network (RSN) has a team of volunteers, and we can put you in touch with those in your region, or with the same ichthyosis type, who may be in the same or similar situation. Sharing stories, tips, or just a shoulder to lean on, can make all the difference as you learn to cope with the very rare and unique experience of living with ichthyosis.

## Join Our RSN Team!

Or, perhaps you've benefitted from the RSN and would like to give back? Our amazing team of volunteers across the US and Canada, and some international countries, have been connecting families and individuals with ichthyosis for nearly 25 years. You can volunteer as much or as little time as you choose. It's up to you! If you would like to help other affected families and individuals find the support they need, please contact Moureen Wenik, [mwenik@firstskinfoundation.org](mailto:mwenik@firstskinfoundation.org). Here's what our passionate RSN volunteer Joann Waldrop had to say about joining our team of volunteers!

## MEET RSN Volunteer, Joann Waldrop

### **What inspired you to volunteer for the FIRST Regional Support Network?**

When my son was born, I felt so alone with his diagnosis. I didn't know anyone who had a child with any medical condition much less ichthyosis. When FIRST presented the opportunity to volunteer as a point of contact for others who just had a child diagnosed with ichthyosis, I felt like it was a great way for me to get involved. I wanted parents of newly diagnosed children to have someone they could connect with as they navigate this diagnosis.

### **What do you feel is the most important benefit provided by the RSN?**

As a mother, for me it is the connections you can make with others who are walking a similar path as your own. While no two stories are identical, the knowledge we gain from each other is invaluable, whether you are the parent or the affected individual.

### **How do you specifically connect the families and individuals?**

I am willing to share my experience with others when asked. I have emailed with mothers after their child's initial diagnosis and shared my story and experiences. In each case, their children received a different Ichthyosis diagnosis than my son, so they also connected with others whose children have the same type of ichthyosis.

### **Is there an experience or story that stands out to you, regarding a connection that was made through the RSN that you'd like to share?**

When our son was in his early teen years, he wanted to meet other affected teenagers in the area. As a family, we attended the local Patient Support Forum. Unfortunately, there were no other teenagers in attendance; so, our son attended a session for affected young adults. He was glad

that he attended the session. He said it was great to learn from the experiences of others concerning roommates, marriage, employment, insurance issues, etc. The most valuable piece of information he received is that life with ichthyosis does get better after the teen years.

### **Would you recommend volunteering for the RSN?**

I would recommend volunteering for the Regional Support Network! It is great to be part of a community that understands life with ichthyosis in a world where ichthyosis is rare and often misunderstood. I love knowing that I am available for a parent whose child has just received this diagnosis. I can let them know there is hope for a great life beyond the diagnosis.

***Please join us in extending a heartfelt thank you to Joann for all of her hard work and compassion for the FIRST community.***



# Grassroots in the News, Fall 2016

## ***Benedettos Honored in New York***

Over 60 guests gathered in Wantagh, New York, to celebrate the Benedetto family for their countless contributions to FIRST and the ichthyosis community.

Denise and Marc were named FIRST Champions as both have been true advocates for the ichthyosis community, since their son, also named Marc, was born with lamellar ichthyosis in 1997. In the past 19 years, the Benedettos have attended and participated in several FIRST National Conferences and regional Patient Support Forums and hosted many fundraisers for FIRST to support its valuable programs and services. They continue to help newly diagnosed families during challenging times with a sense of understanding, compassion and a much-needed laugh.



Adding to the festivities, several FIRST members and families attended the event including the Carroll family, the Pretaks, the Steinitzes, the Cinas, Sal Consiglio and Eric Schweighoffer. The event raised over \$6,400 for FIRST programs. Congrats Denise, Marc, Marc and Eric for this well-deserved honor.

## ***Release the Butterfly Tour Continues...***

It's been a jam-packed few months for the *Release the Butterfly Tour*. Tour organizers, Tracie and Bailey Pretak, along with Hunter and Mark Steinitz continued to inspire audiences with four performances from August through October!

The tour performed at the FIRST Champions event on August 27 in Wantagh, New York. Then on September 17, the Pretaks organized two performances in one day in their hometown at Johnsonburg High School and then at the Elk County Catholic School. In October, the tour traveled to Lancaster to do their second annual concert with the Stern family.

Each of the concerts features multiple musicians and dancers performing inspirational songs with a message of hope and strength. The performance also features a segment called, "Behind the Butterflies," which is a Q&A with panelists Bailey Pretak and Hunter Steinitz sharing their personal stories of growing up "different." For the first time, the segment featured a parental perspective with Mark Steinitz and Tracie Pretak sharing some thoughts.

The tour travelled to Providence, Rhode Island in late October to perform at the FIRST Champions event organized by Kelly and Kyle Robinson. All of us at FIRST want to thank Tracie and Bailey Pretak for all their hard work in organizing these tour stops and to the talented performers, like Hunter Steinitz, for continuing to share messages of hope and inspiration.

## **RAISE Wrap-Up**

Our 2016 RAISE campaign ended on September 30. We had 52 fantastic individuals and families sign up to be RAISE partners! Each of them shared their story and asked their friends and families to support FIRST and the ichthyosis community. Over 270 of their friends and family answered by donating \$33,549 to FIRST. We cannot thank our RAISE partners and donors enough for joining us in our mission. Your generosity is appreciated by all of us!

*Thank you to all grassroots event coordinators and participants for your generosity, support, and enthusiasm!*



<b>Event</b>	<b>Location</b>	<b>Amount Raised</b>	<b>Organizer</b>
<b>Elite OC Young Professionals Society Event</b>	Costa Mesa, California	\$278.00	Chrissy See
<b>FIRST Night Out at the LA Dodgers</b>	Los Angeles, California	\$1,829.00	Roland & Lani Coates
<b>FIRST Night Out at the NY Mets</b>	New York, New York	\$24,255.00	Brooke Saccente & Denise Benedetto
<b>FIRST Night Out at the Chicago White Sox</b>	Chicago, Illinois	\$6,545.00	Frank Osowski
<b>GeneDx FIRST to Win Raffle</b>	Gaithersburgh, Maryland	\$1,370.00	Gabi Richard & Sherri Bale
<b>Release the Butterfly CD Sales &amp; Tour</b>	Johnsonburg, Pennsylvania	\$2,559.00	Tracie & Bailey Pretak
<b>Cade &amp; Chandler Phelps 16th Birthday</b>	San Jose, California	\$630.00	The Phelps family
<b>Softball Tournament</b>	Flandreau, South Dakota	\$1,200.00	The lott family



**Would you like to plan a grassroots fundraising event? Please contact FIRST Development Director Madeline Bergman at [mbergman@firstskinfoundation.org](mailto:mbergman@firstskinfoundation.org).**



## *UFIRST Scholars Program Accepting Applications Beginning February 1st*

*The UFIRST Scholars program is an opportunity for affected students to advance their post-secondary education in partnership with FIRST. The 2017 UFIRST Scholars applications will be accepted beginning February 1. Deadline to apply is March 31. Please go to [firstskinfoundation.org/ufirst-scholars-program](http://firstskinfoundation.org/ufirst-scholars-program) for more information.*



## *Jane & Henry Bukaty Skin Care Fund Application Deadline is January 31st*

*Thanks to the generosity of Jane and Henry Bukaty, FIRST has established the Jane & Henry Bukaty Skin Care Fund to help alleviate some of the financial burden that may be facing our members. This is your opportunity to apply for some financial assistance for ichthyosis treatment. Application deadline is January 31. For more information go to [firstskinfoundation.org/jane-henry-bukaty-skin-care-fund](http://firstskinfoundation.org/jane-henry-bukaty-skin-care-fund).*