



# My Life As An Ichthyosis Mom

*by Tracie Pretak*

Over the years FIRST has collected and shared hundreds of “life stories,” as storytelling offers a meaningful way for members to open up and communicate their most significant, emotional, and inspirational moments. And, equally as important, stories can heal our hearts and open our minds. Today, we’d like to share a mother’s story that began with a life-changing choice in 1986...

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## Kindness, connecting, and unexpected blessings



**Jean R. Pickford,  
Executive Director**

*This issue will warm your heart and soul. Over the years, FIRST has observed, time and time again, that making connections with other families and individuals with ichthyosis may just be the most beneficial medicine of all. Sharing personal stories and tips for skin care, opening up about fears, dreams and hopes for the future, or simply lending an empathetic ear, can truly broaden one's perspective and provide a deep level of emotional support. In this issue you'll learn about all the ways FIRST connects with members – one-on-one. We're uniting medical experts and families from around the world, and in addition to our ongoing patient support forums and family conferences, we've even developed new opportunities for connection including our latest initiative – the YAWI group (Young Adults With Ichthyosis). Young adults can connect on Facebook, conference calls, and special events – designed exclusively for their age group (18-30). Plus, we've started a FIRST Teens Facebook group (13-17), so young folks can speak their mind and connect with others who may be facing the very same issues. We hope you enjoy connecting with FIRST, each other...and finding out about the many new ways to get involved.*

*Happy fall!*

**Jean R. Pickford**



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# Members held FUNdraisers All Summer Long...

## **Dane's Friends for FIRST concert**

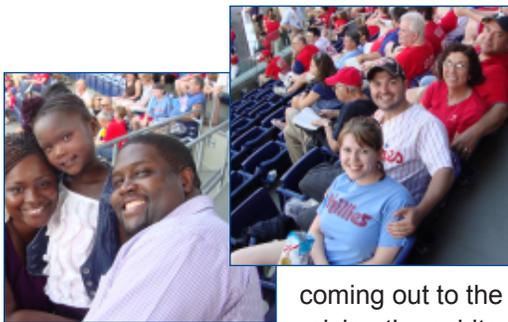
On September 7, nearly one thousand people gathered at the Flint Center in Cupertino, California to celebrate the life of Dane Christian Phelps. Dane's spirit of hope filled the theater, and each performance and presentation served as special tribute to a beautiful young boy with a profound message: never lose hope for a cure. It is with much love and gratitude that FIRST extends a warm thank you to all of the performers, attendees, doctors, and volunteers for the unforgettable Dane's Friends for FIRST Concert. We continue to be inspired, each day, by the eternal hope and joy of young Dane and the strength of the entire Phelps Family, and are privileged to consider them a part of ours.



**Denise Lewis** - mom of Brennan Lewis affected with EI, from Shelby, Ohio, rolled up her sleeves and planned a good old-fashioned garage sale, raising \$320!



**Diana Gilbert** - raised \$930 at her fun and casual Jeans Day at work! Great job Diana! (Netherton)



## **Phillies game**

After a little "rain scare" at Citizens Bank Park—cutting the pre-game warm up a little short—the Phillies-Nationals game took a turn for the best! Not only a win for the Phillies (yes, FIRST is in Philly territory), but members enjoyed a night of sunshine, cool breezes, and, the Philly Schmitter (famed sandwich named after Hall-of-Fame 3rd baseman, Mike Schmidt). Thanks to the Philadelphia Phillies Organization for the scrolling shout out on the marquee. And, of course, a BIG thank you to the Beyer, Cina, Strassburg, Wolkin, and Hollis families for coming out to the game, supporting the cause, teaching us some superior new dance moves, and raising the spirits of the entire FIRST family. Your support makes all the difference!

## **Annaliese Beckham -**

mother to Josslin, who is affected with epidermolytic ichthyosis, spread awareness to her local American Legion by introducing her daughter and giving a speech to the members regarding her skin condition. Thanks for all your hard work, Annaliese!



## **It Makes Cents campaign**

Member Dede Fasciano, mom to Evan Fasciano affected with Harlequin ichthyosis, spearheaded an "It Make Cents to Help FIRST" campaign and raised \$589! Way to go DeDe!



## **Cleveland Indians game**

Fun was had by all at FIRST Day at the Cleveland Indians (and congrats on the win Cleveland)! A big THANKS to the Klima family for organizing the lively group of 46 attendees. It's the enthusiasm and commitment of our members that makes all the difference! "It was a great time and well worth the effort," said Margot Klima, grandmother of Emma Klima, affected with epidermolytic ichthyosis. "It's always rewarding to me personally to do whatever I can to help your wonderful organization."

# Conferences And Patient Support Forums

## 18th Biennial Conference: Connecting at the Crossroads Indianapolis, Indiana June 20-22, 2014



IMAGINE a roomful of open arms; people from all backgrounds, all ages...from all over the world, who know exactly what life is like living with ichthyosis. That's what you'll find at the family conference, plus much, much more!

The National Family Conference is an amazing, worthwhile, and moving event for the entire family. Attendees will arrive at all different times, most arriving on Thursday. It's typical to see clusters of people gathered in the lobby, hallways, and sitting areas chatting with old and new friends. Registration takes place early Friday morning and is complemented by a group breakfast. Kid's Camp and educational workshops run throughout the rest of the day on Friday, with a break for lunch. Friday's workshops will end by 4:30 pm, and attendees are on their own for Friday night activities.

We begin early again on Saturday morning with a group breakfast followed by Kid's Camp and workshops throughout the day until 5:15 pm, with a break for lunch. Everyone has a chance to freshen-up before the dinner/dance party which begins at 6:30 pm. The dance party features a live DJ who will play the latest hits and party games. (Some people think this is the best part of the conference!) You'll be sure to see some smooth dance moves by young Michael Jackson and JLo wannabes! The evening also features an exciting talent show, raffle, and auction items.

The last day, Sunday, begins with the group breakfast, Kid's Camp, and workshops until 12:15 pm. This is followed by a closing session and farewell lunch. Friends and families exchange addresses, hugs, and best wishes until the next conference! But they are not leaving empty handed. They have gained something invaluable...friendships that will last a lifetime.

### ***What's on the agenda for the conference in Indianapolis?***

- Disease-specific workshop focused on your type of ichthyosis or related skin type, moderated by a knowledgeable physician
- Lotions, creams, and "what works" information sharing
- Newly-diagnosed families workshop
- Understanding the complicated world of genetics
- Research updates and how it will impact you
- Group networking workshops focused specifically for moms, dads, teens, affected men and women, grandparents, young adults, and spouses
- Specific care workshops – Foot, scalp, hair, diet, nutrition, natural care, exercise, eyes, ears, and pregnancy
- Skin management workshops – infections, long term use of antibiotics, retinoids, and overheating
- Communications workshops – confidence building, addressing rude people, dealing with doctors, school and bullying concerns, and teenage/young adult issues

### ***Hear firsthand what others have said about the National Family Conference:***

- I most enjoyed networking with others and realizing how important it is that our population interacts collectively with the researchers so that connections toward research can be made.
- Every year this experience changes my views on life and makes me a more positive and comfortable person.
  - Fantastic! Thank you so much. This conference was truly incredible and inspiring. I learned so much.

Registration will begin in November, 2013. You'll find updates and information at [www.firstskinfoundation.org](http://www.firstskinfoundation.org), in upcoming months.

**APPLY FOR  
FINANCIAL AID TO ATTEND  
CONFERENCE  
ON PG. 15**

## Patient Support Forums -

### Dallas, June 8, 2013

Anticipation filled the room at the Renaissance Hotel in Dallas as our esteemed panel of speakers, including Dr. Moise Levy, Dr. Meena Julapalli, Dr. Fred Ghali, and Dr. Keith Choate (via webex), took center stage and offered a riveting summary of the latest genetic research and skin care therapies. Overall, the consensus amongst doctors and attendees was that skin care is very individual – you need to do some trial and error to see what works for you and your particular skin condition. However, many of the general tips did not require a hefty investment, or any particularly complicated regimen. For more on the Dallas Patient Support Forum, go to [www.firstskinfoundation.org](http://www.firstskinfoundation.org).

### Mahwah, August 3, 2013

On August 3, 2013, FIRST held a Patient Support Forum at the Doubletree in Mahwah, NJ. The gathering was well attended with a total of nearly 30 members and medical professionals filling the room. Dr. Leslie Castelo-Soccio of Children's Hospital of Philadelphia, and Dr. Keith Choate and Dr. Brittany Craiglow from Yale University were the medical experts in attendance. And, it was a first for FIRST, as our communications director ventured into the real-time technique of live blogging from the forum. If you were unable to attend, you will find our live blog at [www.blog.firstskinfoundation.org](http://www.blog.firstskinfoundation.org).

### San Jose, September 7, 2013

Members and medical experts joined FIRST at the San Jose Patient Support Forum at the Marriott Hotel in San Jose, California. Twenty-five attendees enjoyed mingling and meeting new friends, listening to informative speeches on the origin of genetic mutations and the latest advances in stem cell research, and one-on-one conversation with some of the top medical experts in the field of ichthyosis treatment and research: Dr. Keith Choate from Yale, Dr. Philip Fleckman from the University of Washington, and new to the FIRST family, Dr. Joyce Teng from Stanford University and Dr. Erin Mathes from University of California, San Francisco. The day wrapped up with an invitation extended to all attendees to the exciting Dane's Friends for FIRST concert, happening only fifteen minutes from the hotel that very same night!

## THE SKINNY: *Hot Tips from the Patient Support Forums*

- Virgin coconut oil is a natural moisturizer and disinfectant and highly recommended by some of the attendees (cost effective too!).
- The group collectively agreed that some moisture creams sting less than others. Over-the-counter petroleum jelly is still a popular alternative following a bath, and some members have not had the need to even try other products. It doesn't sting and it is inexpensive.
- Bleach – Some participants agreed that adding simple bleach to the bath water is effective for some types of ichthyosis, as a skin softener and for bacteria and odor control. Although the precise measurement of the mixture varies from person to person, it is recommended to use approximately 1 to 2 teaspoons per gallon of water.
- Dawn dish detergent is a great additive to the laundry, with regular detergent, add a squeeze in the washer.
- Shea butter, mixed with lotion, is a popular and inexpensive choice for moisturization.

## Join A FIRST to Know Call?

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 call is interesting to you and phone in. You can be an active participant, or call in and listen to what others are saying. All calls are held at 7:00 PM Eastern Time. The schedule with dates, topics, and call number is located at [www.firstskinfoundation.org](http://www.firstskinfoundation.org) under the Conferences, Forums, and Meetings section.

**Do you have an idea for a *FIRST to Know* topic? Contact Moureen Wenik, Program Director by email at [mwenik@firstskinfoundation.org](mailto:mwenik@firstskinfoundation.org) or by telephone at 1.800.545.3286.**



# Why Attend a FIRST Conference or Regional Meeting?

***Blogger and board member Rachel See offers six compelling reasons to attend a FIRST conference or patient support forum:***



**1. An opportunity to learn more about ichthyosis from medical experts.**

**2. An opportunity to meet other people affected with ichthyosis, and to learn from their experiences.**

Learning about the underlying science and medical issues is very important, but these conferences let the attendees learn from each other about their common experiences. After the lecture-style presentations, the conferences break out into smaller, less formal discussion groups where people can share their experiences. At recent FIRST conferences, my family shared our experiences with basic skin care tips, from Aquaphor and other lotions to Cling Wrap to our use of nail files and a Dremel. At the very first conference we attended, we learned a lot from other attendees about accommodations at school and cooling vests. It's one thing to read about things online, but sometimes in person show-and-tell can be a lot more fun!

**3. An opportunity to ask questions about ichthyosis and get answers.** The really nice thing about the smaller regional conferences is that all of the sessions are small enough that there's enough time for questions and dialog. Some people might be afraid to stand up and ask questions in a session with 100+ people, like the ones at the Family Conference; the smaller regional conferences provide a more intimate setting.

**4. An opportunity to make new friends. Dealing with ichthyosis can be very isolating, especially for parents dealing with newborn children.** Many

parents feel overwhelmed — not just coming home from the NICU, but dealing with everything that comes along with skin care, infections, injuries, school issues, social issues, and everything else. The “ichthyosis family” runs wide and far; we may come from vastly different backgrounds, but we do share this one thing — our skin — in common. And that's often enough to form the spark of lasting connections.

FIRST conferences provide a vehicle for meeting other people with these common connections. And it's an important way for the community to show our newest members, “You are not alone in this experience.”

**5. An opportunity for parents of affected children to talk to affected adults.** Related to the “you are not alone” message, I think it's a great opportunity for parents of affected children to meet and talk with affected adults.

The affected adults certainly aren't perfect, but our own life experiences can help parents of young children understand that their skin doesn't define who they are. And that their children can have the same opportunities as others to grow up, to love and be loved, and be successful in life.

**6. An opportunity to meet the FIRST staff. FIRST is more than just an anonymous funding source for ichthyosis research, or an anonymous author of “fact sheets.”**

FIRST conferences provide a great opportunity to get to know the FIRST staff a little better, and to encourage them in the work they're doing.

[as previously published at [confettiskin.com](http://confettiskin.com)]



# Medically Speaking

## Why Some Ichthyoses Get Infected

**Peter M. Elias, M.D. - Dermatology Service, VA Medical Center & Department of Dermatology, UCSF, San Francisco, CA**

**Mary L. Williams, M.D. - Departments of Dermatology and Pediatrics, UCSF, San Francisco, CA**

Recurrent skin infections caused by pathogenic bacteria, like *Staphylococcus aureus*, or by fungi, are a common problem for many people with ichthyosis. Some types of ichthyosis, such as epidermolytic ichthyosis (also called EHK) and Netherton syndrome, are especially prone to this complication. In addition, infants with more severe forms of ichthyosis can develop life-threatening, even fatal, disease from the spread of the skin infection into the blood stream (“septicemia”). Precisely why the skin in ichthyosis is so vulnerable to infection is not known.

To begin to answer this question, we started from the fact that all of the ichthyoses have an abnormal permeability barrier function. This barrier, which holds our body water inside as we move about in a dry, terrestrial environment, is the most important function of the skin. In fact, the severity of the different types of ichthyosis parallels the severity of their barrier defects. Of course, this same barrier is also charged with keeping out many bad things from the environment, such as allergens, excessive ultraviolet light, toxins, and free radicals, as well as disease-causing microbes. We reasoned that when the permeability barrier fails, these other barrier functions may also fail, including the barrier against infectious organisms. Prior studies from our laboratory have shown that the permeability barrier and antimicrobial barrier, which keeps out microbial pathogens, are closely related. For example, when one type of barrier is compromised, the other barrier also frequently demonstrates significant abnormalities. In this study, we look at three genetically-unrelated types of ichthyosis: Harlequin ichthyosis (HI), Netherton syndrome (NS), and epidermolytic ichthyosis (EI, or EHK), because all three are characterized by severe permeability barrier abnormalities accompanied by recurrent skin infections.

We and other laboratories also had previously shown that these ichthyoses (HI, NS, and EI) have abnormal lamellar bodies. Lamellar bodies are tiny structures formed inside the cells of the epidermis. They are filled with lipids (fats) that will ultimately coat the outside of the cells of the stratum corneum, and, in so doing, waterproof the skin. Lamellar bodies can be thought of as tiny delivery vans. These bodies not only deliver the lipids that are needed for the permeability barrier, but they also carry enzymes needed for normal shedding of the stratum corneum, as well as two

antimicrobial peptides that are critical for the defense against microbial pathogens (Fig. 1). Therefore, we hypothesized that the increased risk of infections in HI, NS, and EI could reflect abnormalities of the lamellar body delivery system.

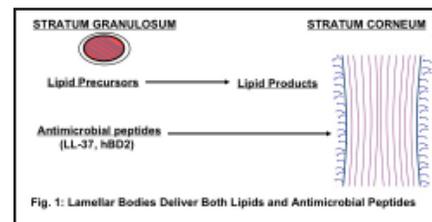


Fig. 1: Lamellar Bodies Deliver Both Lipids and Antimicrobial Peptides

For these studies, we used stored skin samples from our laboratory, the Ichthyosis Registry (Dr. Phil Fleckman), and from some of our collaborators at Yale University (Dr. Keith Choate), and Yonsei University, Seoul, Korea (Dr. Eun-Ho Choi). In addition to HI, NS, and EI, we also examined normal human skin, and three other types of ichthyosis (X-linked ichthyosis [XLI], neutral lipid storage disease [NLSDI], and Gaucher disease [GD]), in which lamellar body formation and secretion are normal.

We were interested in seeing whether the infections in HI, NS, and EI could be due to a deficiency of these critical antimicrobial peptides – because of problems in loading the protein into the lamellar bodies, or getting them delivered to the stratum corneum (i.e., a secretory defect), or because they were being rapidly destroyed or inactivated. We examined the fate of another protein delivered by lamellar bodies, acid lipase. We chose this enzyme to study because we could follow its fate using a method called ultrastructural cytochemistry, which provides a way of seeing the molecule with the electron microscope. Using other techniques, we also assessed the production and fate of one of the antimicrobial peptides, the cathelicidin protein, LL-37, which fights many types of pathogenic microbes, including staphylococci, streptococci, and even some viruses, as they try to invade through the skin.

This is what we found: In normal human skin, and in the three other types of ichthyosis without known defects in the lamellar body secretory system (XLI, NLSDI, and GD), enzyme protein (acid lipase) is loaded into lamellar bodies, secreted completely from lamellar bodies into the stratum corneum, and persists high into the stratum corneum. Likewise, abundant antimicrobial LL-37 is produced,

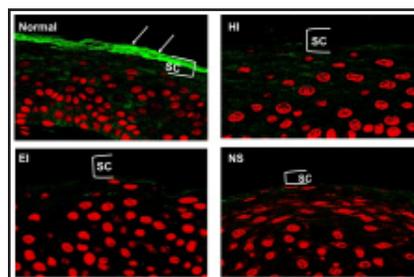


Fig. 2

secreted, and persists in the stratum corneum in normal stratum corneum (Fig. 2), and in the stratum corneum of these other ichthyoses.

**continued on the next page**

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HI is caused by deficiency of a transporter molecule that loads lipid into lamellar bodies. In HI, we saw very little protein being loaded into or secreted from lamellar bodies, and, similarly, very little of the antimicrobial LL-37 was delivered to the stratum corneum. Therefore, the increased infections in HI are likely due to a reduced delivery of LL-37, and perhaps other antimicrobial peptides to the stratum corneum, where they need to be positioned to fight off pathogens that try to invade (Fig. 2).

In EI, the problem is somewhat different. This disease is characterized by abnormalities in either keratin 1 or keratin 10, two proteins that form the cytoskeleton of epidermal cells. Mutations in either of these proteins disrupt the cytoskeleton, basically interfering with the transport of lamellar bodies out of the stratum granulosum (they cannot reach the edge of the cells from which they need to be secreted). As a result, very little protein (or lipids) is secreted, and even though abundant LL-37 is produced, very little is delivered to the stratum corneum, where it needs to be in order to intercept microbial pathogens as they try to invade (Fig. 2).

NS is caused by deficiency of an inhibitor of enzymes that chew up proteins ("proteases"). This results in overactive proteases. In NS, we saw that abundant protein (acid lipase) is loaded into lamellar bodies and lots of protein also gets

secreted, but as soon as the protein reaches the lower stratum corneum, it is destroyed by the high levels of proteolytic enzyme activity. Of course, we also observed almost no LL-37 in the stratum corneum in these patient samples (Fig. 2). Thus, the increased infections in NS can be ascribed, at least in part, to the rapid destruction of antimicrobial peptides, as soon as they are secreted into the stratum corneum.

These studies may explain, at least in part, why patients with such diverse forms of ichthyosis as HI, NS, and EI experience problems with skin infections. Knowledge of this pathogenic sequence now provides us with an opportunity to look for appropriate therapy – could we supply the stratum corneum of these patients with LL-37 or comparable antimicrobial materials, or could we increase either the production or secretion of LL-37 in HI and EI, or delay the destruction of this peptide in NS?

*This work was presented at the International Investigative Dermatology Meeting in Edinburgh, Scotland, May 6-8, 2013. Co-investigators included Aegean Chan, Elena Godoy, Almudena Nuno, Debra Crumrine, Melanie Hupe, Philip Fleckman, Keith Choate, Robert Gruber, and Eun-Ho Choi.*



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# Kindness

## Is Kindness Good For You?

As you may already know, FIRST engages in social media in a plethora of different ways, all in an effort to educate, inspire, and connect all those affected with ichthyosis. Some days we are greeted with new and unexpected skin care tips, other times, it brings us to the very doorstep of the compassionate souls out there in the world advocating, tirelessly: for our members.

A few weeks ago, we even decided to post an online facebook poll, asking followers to tell us, in a single word, what volunteering actually feels like. Then, we kicked back (only for a minute!) and watched as comment after comment filed in. So, today we are happy to announce that social media has served us in yet another new and exciting way. It has helped support a theory: Doing good...feels good!

We have since found out that our theory is simply a scratch on the surface of a much bigger, broader, biology-based, "do good" theory! In fact, did you know that there is a biochemical reason for helper's high?

We've even found someone who has dedicated his work and his life to researching this very theory. We are happy to welcome guest blogger, Dr. David R. Hamilton, PhD, a friend of FIRST, scientist, speaker on and the author of "Why Kindness is Good for You" and "The Contagious Power of Thinking," and the creator of the popular blog "Using Science to Inspire."

### The 5 Side Effects of Kindness by David R. Hamilton, PhD

When we think of side effects, the first thing that springs to mind are the side effects of drugs. But who'd have thought that kindness could have side effects too? Well, it does! And positive ones at that.

**1) Kindness Makes us Happier** When we do something kind for someone else, we feel good. On a spiritual level, many people feel that this is because it is the right thing to do, and so we're tapping into something deep and profound inside of us that says, "This is who I am." On a biochemical level, it is believed that the good feeling we get is due to elevated levels of the brain's natural versions of morphine and heroin, which we know as endogenous opioids. They cause elevated levels of dopamine in the brain and so we get a natural high, often referred to as "Helper's High."

**2) Kindness Gives us Healthier Hearts** Acts of kindness are often accompanied by emotional warmth. Emotional warmth produces the hormone oxytocin in the brain and throughout the body. Of recent interest is its significant role in the cardiovascular system. Oxytocin causes the release of a chemical called nitric oxide in blood vessels, which dilates (expands) the blood vessels. This reduces blood pressure and, therefore, oxytocin is known as a "cardioprotective" hormone because it protects the heart (by lowering blood pressure).

The key is that kindness acts can produce oxytocin and, therefore, kindness can be said to be cardioprotective.

**3) Kindness Slows Aging** Aging on a biochemical level is a combination of many things, but two culprits that speed the process are free radicals and inflammation, both of which result from making unhealthy lifestyle choices. But remarkable research now shows that oxytocin (that we produce through emotional warmth) reduces levels of free radicals and inflammation in the cardiovascular system, and so slows aging at source. Incidentally, these two culprits also play a major role in heart disease, so this is another reason why kindness is good for the heart. There have also been suggestions in the scientific journals of the strong link between compassion and the activity of the vagus nerve. The vagus nerve, as well as regulating heart rate, also controls inflammation levels in the body. One study that used the Tibetan Buddhist's "Loving Kindness Compassion" meditation found that kindness and compassion did, in fact, reduce inflammation in the body, mostly likely due to its effects on the vagus nerve.

**4) Kindness Makes for Better Relationships** This is one of the most obvious points. We all know that we like people who show us kindness. This is because kindness reduces the emotional distance between two people, and so we feel more "bonded." It's something that is so strong in us that it's actually a genetic thing. We are wired for kindness.

Our evolutionary ancestors had to learn to cooperate with one another. The stronger the emotional bonds within groups, the greater were the chances of survival and so "kindness genes" were etched into the human genome. So today, when we are kind to each other we feel a connection and new relationships are forged, or existing ones strengthened.

**5) Kindness is Contagious** When we're kind we inspire others to be kind and studies show that it actually creates a ripple effect that spreads outwards to our friends' friends' friends – to 3 degrees of separation. Just as a pebble creates waves when it is dropped in a pond, so acts of kindness ripple outwards touching others' lives and inspiring kindness everywhere the wave goes. A recent scientific study reported that an anonymous 28-year-old person walked into a clinic and donated a kidney. It set off a "pay it forward" type ripple effect in which the spouses or other family members of recipients of a kidney donated one of theirs to someone else in need. The "domino effect," as it was called in the New England Journal of Medicine report, spanned the length and breadth of the United States of America, where 10 people received a new kidney as a consequence of that anonymous donor.

*This information and all scientific references can be found in more detail in my books, "Why Kindness is Good for You" (Hay House, 2010) and 'The Contagious Power of Thinking' (Hay House, 2011).*

# Correspondence Corner



**Dear FIRST,**

Thank you so much for your time and for this wonderful opportunity. We are very thankful to you all for all of the hard work and effort you put into FIRST and for providing so much support for us and other families. You all are truly amazing!

**-Founder Summer Sky Organics**

**Dear FIRST,**

(In reference to Mahwah, NJ Patient Support Forum) "...I just wanted to say I enjoyed the meeting so much! It was great to hear other ideas and refreshing to meet everyone!

Thank you for organizing such a great event! In case it wasn't obvious by the numerous exclamation points, I am beyond excited to attend the national conference next summer!

Thanks

**-Abby Evans**

## Testimonial Dinner, Honoring Dr. Amy Paller

*"It was wonderful to be surrounded by my family, friends, and colleagues during this heartwarming tribute. Although I was very humbled to receive this honor, my ultimate goal was to raise awareness and support for FIRST and the patients they serve. Thank you to everyone who supported and attended this magical evening. It will be a memory I'll treasure for a lifetime."*

**- Amy S. Paller, MS, MD**

One hundred guests joined FIRST, as we proudly honored Amy S. Paller, MS, MD, at a Testimonial Dinner at the University Club of Milwaukee. As one of the most dedicated physicians on our Board of Directors and Medical & Scientific Advisory Board, Dr. Paller was so deserving of this honor. She has held many leadership positions within our organization over the past fifteen years, and has devoted a major part of her career to studying and treating patients affected with all forms of ichthyosis. It was a privilege to honor her amongst her family, friends, and colleagues.

The event, raising nearly \$50,000, was a spirited evening of guests mingling, touching speeches, and a special tribute video comprised of personal messages from students who had studied under Dr. Paller and consider her not only a remarkable person, but a lifelong mentor. Speakers for the evening included Vice President of FIRST and a long-time friend and colleague, Dr. Moise Levy, along with Mary Williams, MD, Leonard Milstone, MD, Adelaide A. Hebert, MD, Joan Guitart, MD, Jon A. Dyer, MD, patients Laura Hogan & Shelley Trojanowski, and husband Etahn Cohen, Esq.



# My Life as an Ichthyosis Mom

... continued

Things definitely did not start out easy. I was a freshman in college with huge plans and dreams for my future...but it was all crushed in a hurry when I made a life-changing choice and I faced an unplanned teen pregnancy. I became a single mom on June 15, 1986. I will never forget that day.

I remember going to the doctor on Friday for a check-up. It was still 3 weeks until my due date, and he said he expected me to go full term. It was weird but I had this strong sense that the baby was going to come early. On Saturday, our family attended my cousin's wedding and then a graduation party. My brother Mark kept trying to get me to dance. I finally gave in when the Blues Brothers were playing, but at the end of the song, he dipped me and lost his balance. We fell to the ground and his knee hit my lower back. I was up all night with muscle spasms...and when the labor started, every labor pain was accompanied by more muscle spasms.



On Sunday morning we headed to the hospital. I had this really strong belief that something was going to be wrong with the baby. I couldn't explain it. I just knew. I also decided not to breast feed. I didn't know why, just that I shouldn't. And I knew that even though something was going to go wrong, somehow, the baby would be okay. I truly believe that this was God preparing me for what was to come.

The delivery went quickly, but I knew the moment I looked at my mom's face that something was wrong...VERY wrong. Little Bailey Rae was born encased in a collodion membrane. The best way to describe it is to say she looked like a little "sausage". There was fluid between the membrane and her skin. I didn't even get to hold her! They brought her over in an incubator so I could reach in and touch her. Then, within 20 minutes of her birth, she was life-flighted to the nearest NICU. My doctor looked in his medical books and came in to tell me he believed she had ichthyosis. A dermatologist at the NICU called me the next day and confirmed it was lamellar ichthyosis.

I wasn't released from the hospital until Tuesday, so she was 2 days old when I finally got to hold her! She stayed in the NICU for two weeks, until most of the membrane had peeled off. An unplanned teen pregnancy radically changes your life. Being a single parent is incredibly difficult, and having a baby born with ichthyosis is truly overwhelming. As fate would have it, I had all three! I honestly don't know how I would have done it without the love and support of my family. My parents offered to watch her so I could finish college. Kip and Katrina helped, too. I wish I could say it was also easy, but there were parents who called the school principal and asked to have their kids moved to a different class; people who wouldn't touch things she had touched; kids who teased her and called her "Scaly Bailey." Those things just broke my heart.

As the years went on, I became more and more angry at people's reactions and Bailey became more shy. She would hide behind me because she knew she was different. It wasn't until I watched Bailey's reaction the first time she saw a black person that I realized it was just a natural reaction for people to stare at something they've never seen before (however, this still doesn't explain their rudeness). So we decided that every time someone stared, we would smile and wave. It has helped so much. You see my negative reaction to the stares and rudeness was only making her more insecure. It was a turning point for both of us.

However, she is blessed with so many amazing people to help her. She was loved and accepted by teachers, principals, dance teachers, and many friends along the way. She got a "daddy" who loved her like his own and adopted her, and she had a "sister by heart" in Cailtyn Pretak, who practically lived here at times. She had a pen pal, Laura Ashton, who was the first person she ever met with ichthyosis and who truly understood what she was going through. There was a moment of her journey I will never forget—when she was crowned homecoming queen (voted on by her classmates!), a moment we never dreamed was possible for a girl with ichthyosis.

Bailey has grown from a shy, insecure little girl into a strong, beautiful woman who now teaches little "princesses" the meaning of true beauty.

Yes, it has been extremely difficult at times, but I can honestly say that what began as my greatest challenge in life has turned out to be my biggest blessing ever. God has given me the sweetest, most compassionate, and most inspirational person I have ever known as my very own daughter. Wow! Today I am feeling SO blessed to be an "Ichthyosis Mom."



**Bailey  
Pretak**



# Are you a Young Adult With Ichthyosis?

*You've come to the right place.*

Hello FIRST readers! I would like to introduce myself. My name is Greg LiCalzi. I am a 31-year-old guy with lamellar ichthyosis, and I am proud to lead a new group at FIRST focused on young adults with ichthyosis. I live in New York City with my wife and 4-month-old daughter Colette. I have struggled with ichthyosis my entire life and feel privileged that FIRST has given me this opportunity to help start this amazing group. I think we can really help each other out.

***“Young Adults With Ichthyosis,” what a mouthful! From now on, let's just call ourselves YAWI.***

## **Who is a YAWI?**

A YAWI is someone with ichthyosis between the ages of 18 and 30. This is an important age, when you are making many critical decisions in your life. During these years, many folks are dealing with the highs and lows of leaving high school, moving on to college, finding their first job, dating, marriage and ultimately starting a family! So much going on – not to mention a little skin condition called ichthyosis! It is not easy and sometimes you need support from others who really know what you're going through. That's where YAWI comes in.

## **What is the YAWI Group?**

This group will serve as a support network for all YAWI. We hope to be with you during the good times, the bad times, and all those in between. Collectively, we have mountains of advice, experience and information.

But ichthyosis, as you know, is rare. Not too many people have it and without some sort of database, finding a fellow YAWI is like finding a needle in a haystack. I live in New York City, home to over 8 million people. Of those 8 million people, 40 people have lamellar ichthyosis. Forty people! One out of 200,000! I consider myself social, BUT it will take me a long time to meet 200,000 people.

Our hope is to keep a database including the following:

- Name
- Age
- Location
- Type of Ichthyosis
- Contact Information



Greg LiCalzi and Family

This database will serve as a central source of communication between YAWI. It will be a private list monitored by me and YAWI Group leadership. No one will have access to this list. With this database, we can set up connections. For example:

- YAWI breakouts at the family conference and regional meetings.
- Depending on locations of those that join, arrange get-togethers in convenient geographic areas.
- Plan conference calls on specific topics (i.e., starting college, job interviews, dating, etc.).
- Develop content for YAWI blog, newsletter column, and other YAWI communications.
- Create a closed Facebook group to talk and exchange ideas, share concerns.

I lived the first 29 years of my life without meeting someone else affected with ichthyosis. I think it is important to make connections with others who know EXACTLY what you are going through.

## **What does the future hold?**

My hope is that you share your information with us and become involved. This is a tough disease. I have been LIVING with it for 31 years. We all LIVE with it. If you don't have it, you will never understand the emotional and physical drain that it can be. This YAWI group will allow us to talk to people first hand who are also living with ichthyosis. I hope the YAWI group can allow us to help others and be helped by others.

This is awesome and I want to be involved!

The YAWI group is forming right now. Get in on the ground floor and help jumpstart our future. For more information and to sign up for YAWI, contact [mwenik@firskinfoundation.org](mailto:mwenik@firskinfoundation.org).

Please reach out!

Thanks so much,  
**Greg LiCalzi**

# FIRST Member Develops Organic Topical Skin Treatment

*You never know where life may lead. FIRST members Jamie and Brandon Bond never imagined that one day they would launch an organic skin product company... and then their beautiful son Carter came into their lives. We are happy to share their story of love, inspiration, and nature – a combination that led to the launch of Summer Sky Organics.*

Our son Carter was born on March 2, 2012 (happiest day of our lives!) with a rare genetic skin disorder called lamellar ichthyosis. Thankfully, I was already a licensed Esthetician with experience and a passion in caring for skin. My husband and I knew from the beginning that we wanted to use more natural products for Carter, when possible. After being disappointed with the “organic” options on the market, I began blending organic butters, oils, and herbs in our kitchen at home. While on a mission to find what would work best for Carter, we became inspired to help others, too, by offering truly authentic certified organic products. We then set out to create Summer Sky Organics!

One of our main goals in starting Summer Sky Organics is to support and raise awareness for the ichthyosis community and FIRST (Foundation for Ichthyosis and Related Skin Types). A portion of every purchase will go to support FIRST, and we’ve even included the FIRST logo on our product label!

As for the product we developed for Carter, it’s called “Soothing Balm.” It’s a blend of Organic Cocoa Butter (deeply moisturizes and conditions the skin), Organic Beeswax (provides a protective barrier on the skin), a blend of Organic Oils (hydrate, soothe, and soften), Organic Chickweed & Organic Gluten-Free Oats (Calms and relieves itching associated with dryness).

We currently use this balm on Carter’s entire body, but when he is older this will not be very practical as it is quite expensive to make. We will be marketing it as more of a multi-purpose balm for dry skin (dry hands, cuticles, intensive face moisturizer, lip balm, and dry/cracked feet). We will also have a multi-purpose baby balm called “Baby All Over Balm” that is a wonderful alternative to petroleum jelly. Although it’s a baby balm, it is truly great for any age!

We would like to offer a discount code for all FIRST members. Please email Jamie Bond at [jamiieb@summerskyorganics.com](mailto:jamiieb@summerskyorganics.com) for the code. Be sure to mention in the email that you read their story in the FIRST newsletter! Website is: <http://www.summerskyorganics.com/>

Have a great day,

**Jamie**

*[P.S. We are not marketing our Soothing Balm as a treatment for ichthyosis, as our Soothing Balm is not categorized as a pharmaceutical. Any claims of a product helping a disorder or disease require the product must be a certified “drug.” Although we developed the product for Carter and it has been extremely beneficial for him, we will be marketing it only for people with dry skin. We are however, allowed to say that we created it for his use.*



# Tips for Skin Care During Winter Months



For people affected with ichthyosis, the cold days of winter bring more than just a rosy glow to the cheeks. They also bring an increased uncomfortable dryness to the skin, face, hands, and other extremities. Cold winter air, with its associated low humidity, can worsen the dry skin of persons with all forms of ichthyosis, which often results in increased discomfort. Plus, the winter can even dry out your skin at a much quicker rate, and once you turn the heat on indoors, it can dry out even more quickly.

Although the condition can be painful and uncomfortable, there are some steps that patients can take to alleviate symptoms.

- **Moisturize as much as possible:** Although it won't cure the dryness, it can alleviate symptoms and help prevent additional scaling, cracking, and build-up of skin. FIRST suggests using lanolin creams and products containing urea, lactic acid, and other alpha hydroxy acids.
- **Know when to moisturize:** Apply lotions and creams to wet skin to trap in the moisture (typically within 3 to 5 minutes of showering and/or bathing).
- **Avoid hot baths:** Although a hot bath feels great after being in the cold, keep in mind that the heat of a hot shower or bath actually breaks down the lipid barriers in the skin, which can lead to a loss of moisture. A lukewarm bath with oatmeal or baking soda can help relieve itchiness, as well.
- **Try to resist scratching:** Scratching can cause a thickening of the skin that can eventually lead to infection.

As always, no matter what the season, be sure to keep a "skin care" journal and establish what routine works best for you.

## Jane & Henry Bukaty Skin Care Fund

*Financial Assistance for Ichthyosis Treatment*

Thanks to the generosity of donors Jane & 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. Here's your opportunity to apply for some financial assistance for ichthyosis treatment. Since the fund is limited, the following criteria must be met by the applicant in order to be eligible for a grant.

The applicant must be registered in our database and is required to submit an application indicating his/her need for funding. The applicant will specify the product/treatment/cooling device for which funds are needed and demonstrate his/her financial need for this product/treatment/cooling device.

Awards will not exceed \$200.00 and will be awarded two times per year as determined by the Review Committee. Applicants will be eligible to receive one award every two years.

Applications can be downloaded from our website at [www.firstskinfoundation.org](http://www.firstskinfoundation.org) and emailed to the national office or mailed to the address below.



**Jane & Henry Bukaty Skin Care Fund** Foundation for Ichthyosis & Related Skin Types, Inc.®  
2616 N. Broad Street, Colmar, PA 18915

The next cycle of funds awarded will take place in February 2014.

The deadline for submitting an application is January 31, 2014.

You will be contacted by the office if you have been awarded aid from this fund.



Foundation for Ichthyosis & Related Skin Types, Inc.®

## Family Conference - Indianapolis, IN

### Financial Aid Application

# Application Deadline: February 1, 2014



Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Province: \_\_\_\_\_ Country: \_\_\_\_\_

Home Phone: \_\_\_\_\_ Work Phone: \_\_\_\_\_

Cell Phone: \_\_\_\_\_ Email: \_\_\_\_\_

How many people will be attending the conference?

Name: \_\_\_\_\_ Age: \_\_\_\_\_ Type of Ichthyosis: \_\_\_\_\_

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

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

Annual Family Income:	<input type="checkbox"/> Under \$20,000	<input type="checkbox"/> \$51,000 - \$60,000
(please include a copy of your most recent W-2)	<input type="checkbox"/> \$21,000 - \$35,000	<input type="checkbox"/> \$61,000 - \$75,000
	<input type="checkbox"/> \$36,000 - \$50,000	<input type="checkbox"/> Over \$75,000

Why do you want to attend the FIRST Family Conference (Use additional paper if necessary)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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

### Please return this form to the FIRST office by February 1, 2014

*Applications received after February 1 will not be considered*

*FIRST and it's officials reserve the right to disqualify any application that is incomplete.*

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

Phone: 215.997.9400 • 800.545.3286 • Fax: 215.997.9403 • Email: info@firstskinfoundation.org

Web Address: www.firstskinfoundation.org



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

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# *18th Biennial National Family Conference*

*Indianapolis, Indiana*

**June 20, 21, & 22, 2014  
Hilton Indianapolis**

