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

Ichthyosis FOCUS

Summer 2011
A Quarterly Journal for Friends of FIRST
Volume 30, No. 1

Awareness on the PHILADELPHIA SKYLINE

Photo by Matthew Micchelli

The PECO Building in Philadelphia, Pennsylvania has long been a staple for messages in the community. The PECO Crown Lights, as they are known locally, displays community messages 24 hours a day, seven days a week. FIRST was fortunate enough to have our message *Ichthyosis Awareness - www.firstskinfoundation.org* scrolling for three days and nights early in the month of May. The entire Philadelphia area saw our message!

A Birthday Wish for TYLER

Wendy Breen, mother of 4-year-old **Tyler** who is affected with Netherton Syndrome, sent out a message on her blog. Tyler celebrated his birthday in May, which is also Ichthyosis Awareness Month. Wendy briefly described ichthyosis and asked friends and family members to make a donation to FIRST in honor of Tyler's 4th birthday. They responded and raised more than $160.00 for FIRST! Thank you to Wendy and her family and friends who made donations for Tyler.

INSIDE Ichthyosis Focus...

May was very busy with ICHTHYOSIS AWARENESS ACTIVITIES

FIRST staff and members visit the Today Show

The FIRST contingent

FIRST staff members and volunteers weathered the damp, rainy morning on Wednesday, May 18 and trekked into New York City to the Today Show studios on Rockefeller Plaza. Staff **Jean Pickford, Moe Wenik,** and **Chris Wassel** led the trip into the Big Apple. Members **Denise Benedetto** and her sons, **Marc,** who is affected with lamellar ichthyosis, and his younger brother **Eric,** arrived as early as 4:30 am to stake out a prime spot in front of the studio windows. With Denise was long-time friend **Virginia Scully** and her daughters, **Theresa** and **Laura.** Member **Allison Lyons** also participated with her daughter **Madelyn,** who is affected with EHK. Allison's sister, **Beth Connelly,** and mother, **Marian Egan,** also joined in on the fun.

FIRST's contingent donned their bright orange t-shirts from our 2010 National Family Conference in Orlando and brought large signs and the FIRST banner. Our group was so visible, they caught the attention of Today Show co-anchor **Ann Curry.** Ann was so taken with member Marc Benedetto that she made sure our message made it on air live. During the 8:00 hour, Ann featured Marc in her live broadcast outside the studio. And just like that, ichthyosis had national attention! Ann was so interested in our group, she spent time between segments chatting with Marc and learning more about ichthyosis. This was a fantastic outing and a remarkable success focusing the spotlight on ichthyosis!

Ann Curry with Marc Benedetto

Night at the Phillies game was a tremendous success!

FIRST's video on the scoreboard

Ichthyosis Awareness month kicked off with a fantastic event for our Philadelphia area members. FIRST hosted a night at the Phillies game. We sold more than 500 tickets, which allowed FIRST to show a 2-minute video on the HD scoreboard before the start of the game. In addition, 4 members of our

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May was very busy with Ichthyosis Awareness Activities

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The Wolkin family enjoys their tour.

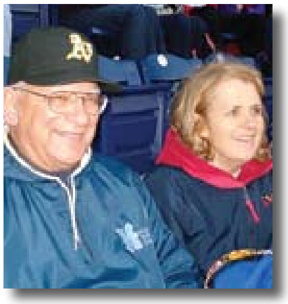
group were treated to a pre-game tour of the ballpark. **Evan Wolkin,** FIRST member affected with Ichthyosis Vulgaris, and his parents Karen and Allan, and a family friend enjoyed this opportunity.

The weather was cold and windy, but that didn't dampen the enthusiasm of everyone in attendance.

FIRST's 2-minute video was seen on the HD scoreboard and generated awareness to the sold-out crowd of 44,123, of which approximately 25,000 were in their seats when the video was shown just before the start of the game. After our video, FIRST member **Ryan Licursi** won the opportunity to throw out the first pitch to the Philly Phanatic, the team's mascot. FIRST's name also appeared on the scrolling sidebars throughout the entire game.

Ryan Licursi preparing to throw out the first pitch

In addition, FIRST's seats in the 400 level provided a fantastic view of the Philadelphia skyline. From this vantage point, our message on the PECO Building crown lights was visible during the entire game.



Lou and Pat Giuliana

Prior to the game, several participants were treated to a personal meeting with Phillies closer, **Brad Lidge.** Brad went to college with **Justin Scholl,** son of **FIRST President Dave Scholl.** Justin was kind enough to ask for Brad's participation, and Brad graciously agreed. He signed autographs, took photos and answered questions from our group. He even offered some pitching techniques!

In the parking lot before game time, the **Licursi family** hosted a pre-game tailgate with approximately 50 friends and family members joining the fun. There was great food, games, and a fun-filled atmosphere as everyone was looking forward to the game. Many thanks to the Licursi family for their outstanding efforts promoting our event to family and friends.

The Licursi family tailgate

Rich & Lisa Kass with Lisa's daughter, Casey Short

Also active in promoting the evening was the **Kass family.** More than 50 of their friends and family members supported our event. Thank you so much for your hard work on our behalf.

FIRST extends many thanks to all of our volunteers who spread the word and sold so many tickets to friends and family members. We could not have done this without your help! It takes the effort of our members to allow FIRST to fulfill our mission.

Correspondence Corner

Dear Jean,

Thank you so much for the very worthwhile information kit.

I am 78 years old and for all of my life I have been affected with ichthyosis. I have been fortunate in that I could conceal it when wearing clothing. I have worn long sleeve shirts and long pants most of my life. When I was told it was hereditary, I thought that I would never have any children so that I wouldn't affect anyone else. I did indeed have a daughter. She did not have this problem, but her first-born son, my grandson, did. I showed his mother how to treat it the best that I knew. For the first time I met another person, not related to me who had the disease, when I was in my late 30's or 40's. I have met one other during the last few months. He was in prison where I visit offenders.

For the most part the material you provided is greatly helpful to new patients. I don't find that knowing the genetics is at all helpful in living with the disease. In my opinion, knowing "why" is not helpful because it doesn't change anything. What was, was. What is, is. What will be, will be. The pamphlets "An Overview," "Release the Butterfly," and "Resource Booklet" provide good information about cautions and topical solutions.

I have personal experience with the helpless, hopeless humiliation that comes from bullying. Early intervention might have prevented some of this, but the intervention would have to include modification of the bullies' behavior and attitude as well as the acquiescence by the victims. Nothing hurts worse than when people stand up for the bully and blame the victim. I cannot tell you how many times I was told, "If you just wouldn't react they would stop." Live with that one when you are between 6 and 14. Even writing about it makes me feel like crying. But in the end, it shaped me into what I was meant to be, an advocate for the underdog.

James Huetson
Clarkston, Washington
Darier Disease

Hi Jean,

I just wanted to say that I thought all the new ichthyosis printed material was awesome! Thank you! Terrific job!

Also, I'm glad you changed ichthyosis awareness month to May. That was the month I was born. I'm turning 60 this year.

I currently volunteer at the local hospital (Fletcher Allen Health Care) and I know of one of the pediatricians there. His name is Dr. Lewis First. (Nice coincidence of names, yes?) He is well known in the state and nationally. His TV show is called "First with Kids."

I went to see him at the hospital and asked him if he could do a broadcast on ichthyosis. I will keep in touch with him to work on a future broadcast for ichthyosis.

Rich Graham
Burlington, Vermont
X-linked Ichthyosis

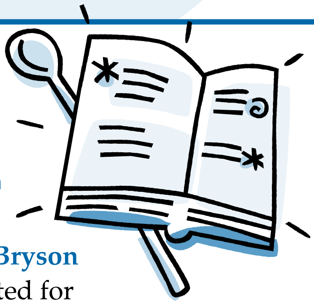
Dear Ms. Pickford,

I want to thank you for the information package on ichthyosis. I wish my mother could have been able to have this in the 1930's when I was a kid. I think it would have cleared up a lot of problems for both of us. The book on genetics was an eye-opener for me and I am 84 years old. Thank you very much.

Take care and keep up the good work.

John Kotz, Jr.
Panama City, Florida

A recipe to share...



FIRST member **Jennifer Bryson** has a recipe that she created for homemade lotion for her daughter, Ana. She has graciously agreed to share it with our members...

1 cheap blender that you don't mind gunking up
1 - 14 oz. (396g) tub of Aquaphor
3 – 7 oz. (210 ml) containers *(to put finished lotion into)*
1/3 c (40g) olive oil
1/3 c (40g) glycerin
1/3 c (40g) coconut oil
1/3 c (40g) safflower oil
1/3 c (40g) grapeseed oil
1/3 c (40g) purified water

Essential oils as desired for scenting (I like orange, but lavender is also nice.)

Sterilize all equipment and containers with boiling water before starting. Add ingredients to blender, then blend until the consistency of mayonnaise. Ta-da! You've just made lotion.

Executive Director's Report

Dear Members and Friends of FIRST,

Thank you to everyone who responded to our annual appeal mailing in March. Our goal is to raise $66,000 from this appeal. We still have a long way to go. In reviewing our records from last year, there are still over 400 families who have not renewed their commitment to FIRST. Your support really does make a difference! So, please take the time to send in a donation of any size or donate online at our website, www.firstskinfoundation.org.

I am also grateful to those who responded with the names of physicians and ichthyosis products. Our Marketing Committee will use this information to reach out to dermatologists and other physicians to educate them about FIRST and ichthyosis. We will also add them to our physician referral listing, so new members can find physicians experienced in treating these diseases. We'd love to hear from more members; so if you'd like to send your info, please email me at jpickford@firstskinfoundation.org.

It was an exciting spring at FIRST. Seven applicants received college scholarships in our first year of the new UFIRST Scholars Program. See page 5 for more details.

We are also busy getting ready for our annual Testimonial Dinner fundraiser. This year we are honoring Dr. Leonard Milstone on July 8 in Baltimore, MD. If you've been a member of FIRST for a few years, there's no doubt that you know how committed Dr. Milstone is to this organization. It is a privilege to honor him. If you would like to attend or show your support, please email me directly at jpickford@firstskinfoundation.org. You can look forward to seeing photos and highlights in our next issue of the newsletter.

We are also in full swing with our new national grassroots fundraiser – ***It Makes Cents to Help FIRST.*** I'm hoping that by the time you read this newsletter, we will have reached our goal of $10,000 with this new campaign. If you were unable to participate this year, please keep it in mind for next May. This fundraiser will always be tied-in with Ichthyosis Awareness Month (see page 1 for highlights from this year's IAM).

Moureen Wenik, our Program Director, attended the Society for Investigative Dermatology Meeting in Phoenix last month. She made many face-to-face connections with researchers who are interested in studying the ichthyoses. It's exciting to see so many investigators interested in research for these diseases, which is all the more reason for FIRST and our donors to continue to build our research fund.

FIRST has begun to reach out internationally. The United Kingdom Ichthyosis Support Group (ISG) asked me to talk about FIRST at their biennial family conference. I prepared a 15-minute video clip that will be shared with their attendees.

Over the summer, Moureen and I will be putting together the 2012 National Conference Program. If you have any ideas for a conference topic, please email us or call. We always look to our members for new ideas and ways to improve!

I hope everyone has a relaxing and enjoyable summer.

Most sincerely,

Jean

Jean Pickford, *Executive Director*

Congratulations 2011 UFIRST Scholars!

FIRST is proud to announce this year's seven scholarship recipients from the UFIRST Scholars Program. Congratulations to everyone. We wish you the best of luck as you continue your education.

Hannah Allen

Congenital Ichthyosiform Erythroderma (CIE)

College of the Ozarks

Goals and aspirations: *"I plan to graduate college in 2015 with a degree in Agriculture education. I want to teach high school agriculture."*

Mani Woodward

Congenital Ichthyosis

University of Oregon

Goals and aspirations: *"To pursue a career in medicine whether it be as a pediatrician or dermatologist. If medicine doesn't work out, I would love to become a teacher."*

Natalie Hulse

Ichthyosis Vulgaris

College of William and Mary

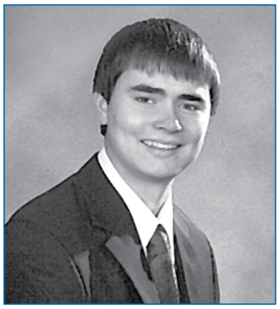
Goals and aspirations: *"Graduate from college and work in the field of international relations."*

Jenna Parfitt

Ichthyosis Vulgaris

Rhode Island College

Goals and aspirations: *"My goal is to become a pediatric nurse or a neo-natal intensive care nurse. I have wanted this ever since I can remember."*



Benjamin Johnson

Congenital Ichthyosis

Kansas State University

Goals and aspirations: *"My goal is to pursue a degree in Geographic Information Systems, and to get into a government sector job."*

Gina Messer

Lamellar Ichthyosis

Sierra College

Goals and aspirations: *"I want to become a psychologist specializing in the field of gerontology, and also would like to be a published author."*

Jose Alberto Ortiz Osalde, *Lamellar Ichthyosis*

Facultad de Medicina de la Universidad Autónoma de Yucatan

Goals and aspirations: *"To be the best dermatologist in ichthyosis and to be an investigator. I want to create a foundation like FIRST in Mexico some day."*

UFIRST Scholars was established in 2010 with a seed gift from Valerie & David Scholl. The Scholls are grandparents to an affected granddaughter and wanted to provide an opportunity for affected students to advance their post-secondary education in partnership with FIRST. Their aspiration is to provide the opportunity for students affected with a form of ichthyosis to achieve their highest educational potential. Donations are gratefully accepted to help grow the fund.

Applications are made available on February 1 of each year. Applications may be downloaded from FIRST's website, firstskinfoundation.org. Completed applications are due in March, with a specific deadline announced each year. Scholarship winners are announced in May.

A committee of volunteers evaluates each scholarship application. The applications are scored using the following six criteria: 1) demonstrated academic ability, 2) a written essay (topics vary each year), 3) extracurricular activities/community activities, 4) financial need, 5) recommendation letters, and 6) involvement with FIRST.

Spotlight On …

LOGAN RANDALL

by his mother, Glenda Charlene Randall
St. Joseph, Michigan

The Randall family

Logan Randall is 7 years old and has just finished first grade. He is the oldest of four children. His siblings are 4, 3, and 1 year old. He loves to read and listen to funny stories and jokes, and really enjoys comic books. He looks forward to going to water parks and swimming at our beautiful beach on Lake Michigan every summer. He plays soccer and T-ball. Halloween and Christmas are his favorite holidays, and PBJ's are his favorite food. His birthday is Christmas Eve, and he wouldn't change it (so far, anyway…). Logan has a gift for helping little kids and babies feel safe and secure, and he is very protective of his new baby sister (now one year old). Oh, and he has ichthyosis! He is affected with CIE and is the only one with ichthyosis in our family.

What is Logan's treatment routine? What types of lotions/creams do you use?

Typically, Logan has two treatments each day. Everything we use is over-the-counter. First, we apply Curel® Intensive Ultra-Healing lotion (red label) from head to toe, followed by Aquaphor® Healing Ointment. We do this every morning and night, as well as after a bath, shower, or time spent swimming. When his skin is really dry or peeling, we'll do an additional treatment after school (so, three times daily). When he begins peeling (about every 7-10 days or so), we apply an exfoliant, AmLactin® lotion, before bed to speed up the removal of the old skin. The goal is to keep his skin moisturized, seal that moisture in, and exfoliate the old skin. These are all things that our amazing largest organ, our skin, is able to do on its own when it is functioning normally. Ichthyosis has helped our family to appreciate, and even marvel at, the incredibly complex functions of the human body.

Approximately every 4 months, he needs to go to the Ear, Nose & Throat doctor to have his ears cleaned out. He often has more than 90 percent blockage in both ears, but the doctor explains that he can still hear surprisingly well. At each visit, the ENT pulls out a long, narrow plug from each ear made up of dead skin and wax. (Sounds like something out of one of those Gross Anatomy exhibits at kids' museums, huh?!) It's pretty fascinating to watch, though!

As a parent what concerns do you have for Logan regarding his skin condition? How about at school?

Among the most serious concerns for us as parents is Logan's lack of ability to sweat. We've had a few scary experiences with him in the heat, particularly in the care of others who were not aware that his red cheeks are like little thermometers, warning you that he is overheating. (Thus we learned the importance of making sure people are well-informed about his condition, even in the winter.) We always keep water with us, especially in the summer-time, and he has some fun little misting water toys to keep him cool. Logan wears 100% cotton clothing, and doesn't need as heavy a coat in the winter as most of us do.

The biggest concern when he first went to school was that the whole staff understands his need to be kept cool.

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Logan playing soccer last fall

His school does not have air-conditioned classrooms. We supply his teachers with spray bottles and whatever else they may need to keep him cool while he's in their care. All of the school staff understand the dangers of allowing him to get too hot; even staff members who don't have him in their classes are aware of his condition and help keep an eye on him. Within the first month or so of each school year, I am able to relax knowing the teachers are well-informed and that he is in good hands with them.

The teachers have also been fabulous when it comes to teaching other kids in his class about his skin disorder. At the beginning of the school year, his teachers have an introductory lesson about "differences" that helps his classmates understand the condition. They talk about differences in height, hair color, eye color, freckles or none, dark or light skin, etc. They then share how some people have dry skin and give a little explanation of ichthyosis (in simple terms) to the kids. They share what things Logan does differently than they do, like stay inside at recess if it's too hot out, get more drinks at the water fountain, etc. They invite Logan to share whatever he would like to with his class. It's quick and simple, the kids understand it very well, and they're completely supportive of Logan throughout the school year. I believe his classmates even forget about his skin condition, just as we do at home.

Another concern we have is about other students at the school (non-classmates) not being properly informed about the disorder. Kids who don't know Logan might be surprised when they see him peeling for the first time. It can be kind of shocking, and children don't always know the best way to handle their curiosity about it. Some people may call it "bullying," but in these early grades, I don't think there is any malicious intent. People mentioning his skin only becomes a problem for Logan when kids have not been taught how to handle their questions properly, and ask in a derogatory or negative tone, and he is made to feel like he's strange or weird.

How does Logan react when others stare at him? How do you handle that as parents? And how do you inform people about ichthyosis and FIRST?

So far, Logan is not self-conscious of, or even concerned about, any of the visible aspects of ichthyosis. He doesn't worry about how he looks or whether the dandruff flakes are easy to see if he wears a dark-colored shirt. And thank goodness, since he's only seven! So far, he doesn't notice people staring at him, or whispering and pointing at him after he passes by (this only happens when his skin is at the peak of its peeling phase). But I certainly do!

It does not anger or upset us as parents, but it can be quite disappointing when adults are gawking with their children, and not teaching their kids how to properly handle their questions when they see someone who looks different from them. (I guess I expect more from the adults than from kids!) When people act shocked when they see him peeling, I have been known to run back to them, tap them on the shoulder, and quickly educate them about his condition. I keep little info cards that I made in my car and purse to give out to people in public who seem even slightly curious. I might smile and say, "Handsome boy, huh? Takes after his Daddy," just to lighten the moment, then I hand them the informational card.* *(See Editors Note)* The more people understand the facts, the better. I don't want people left with false notions or assumptions simply because I failed to inform them. Education is vital.

At the beach last summer

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Spotlight On...Logan Randall

Continued from page 7

In our family, we like to assume that people have good intentions, that they are really just surprised when they see him peeling, and don't realize how their reaction looks, especially from our perspective. Most people are apologetic and embarrassed once the condition is explained to them. In fact, many are relieved just to know that we didn't forget to put sun block on him! (We just laugh about that one.)

We really do appreciate respectful questions! We don't want Logan to feel pity or shame for his skin condition, so we encourage him to answer the questions himself whenever possible. At times he may not feel like sharing details and simply says, "I just have dry skin;" usually, he's pretty good at explaining ichthyosis himself.

FIRST was recently chosen to be a recipient of a large fundraiser put on by our local MOMS Club, in which I am actively involved. That was a wonderful opportunity to create awareness in our community. Since it was a Mom's Club event, I knew many parents would be attending. I wanted to empower parents and give them tools to help their kids appropriately handle situations when they see anyone who looks or acts different from them.

I would encourage every member of FIRST to seek out opportunities to share whatever it is that you feel will be most helpful to you, your child/ren, or whoever is affected by a skin disorder. It can be a wonderful and empowering experience to kindly educate people, even when they are rude about it. By taking the high road, we leave an impression on those who might not have been properly taught by their parents, as well as those who witness the respectful interaction (especially our own kids!) .

**Editors Note: The FIRST office has a supply of awareness cards available for our members to hand out. Please contact the national office if you would like some.*

There are 26 Ambassadors in the USA!

Ambassadors build communication and friendships between families of affected individuals who live in close proximity to one another.

Are YOU the Next Ambassador?

Ambassadors visit NICU's, dermatologists, and other specialties that are located in their community.

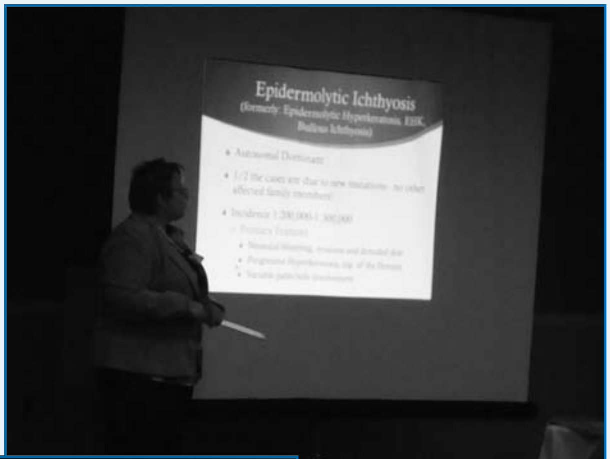
If you want to be the next Ambassador, or you want to learn more about this program
Contact Moureen Wenik: mwenik@firstskinfoundation.org or call 800.545.3286.

Let the Meetings Begin!

by Moureen Wenik, Program and Research Director

The 2011 Regional Meetings kicked off in Richmond, Virginia on April 30th, and the next three are expected to measure up to the success of it! It was great to see so many of our members travel from many parts of Virginia, Maryland, North Carolina, and even as far south as South Carolina, for this one day event. The meeting was a great day of learning, laughing, and lunching. A special thank you to **Dr. Gabriele Richard**, from GeneDx, and **Dr. Jorge Toro,** from National Institutes of Health; they did a great job educating the attendees in treatment options, and also offered an interactive genetic overview. These one day events bring a wonderful informal atmosphere, which allows for open question-and-answer sessions, and time to meet the medical professionals and chat during lunch. I am always intrigued by the common message I hear at the meeting from new attendees – "I thought I was the only one with this disease," and "I am humbled by the support and love I see from everyone in the room." These meetings give me the opportunity to meet more of our members and to know what important work needs to continue to be done for everyone! Thank you to everyone who attended or plans to attend the upcoming regional meetings this year.

Carol and Margaret Frost



Dr. Gabriele Richard explaining Epidermolytic Ichthyosis

Richmond Regional Attendees

The next three meetings will be hosted in Seattle, Atlanta, and Chicago.
An update on those meetings will be posted on facebook, on our website, and in the next newsletter.

News and Notes

FIRST's New Marketing Intiative

Volunteers assemble our marketing mailing

The Marketing Committee met at the FIRST offices for a weekend retreat in January to plan out and implement the next phase of the marketing initiative. The plan included dissemination of a packet of FIRST's updated materials to be used for members' personal use or information to be shared with important persons in their lives.

To save costs, FIRST's staff prepared the mailing in-house and enlisted the support from local high school volunteers. More than a dozen students donated their time and assembled over 600 packets during a week's time in early March. The Marketing Committee and FIRST's staff were extremely grateful for all the help and support. It was also a great way to educate some local young persons in the Lansdale, Pennsylvania area about ichthyosis and FIRST's mission.

If you would like to receive a packet of materials to share with your family, or others (teachers, doctors, daycare, etc.), please contact our office at 800.545.3286.

Tele-medicine site is available for clinicians

FIRST offers a teledermatology website to help derm-atologists and clinicians with the treatment and diagnosis of patients with ichthyosis and related skin types.

The site, which dermatologists can use for free thanks to a grant from The Lennox Foundation, is now available for dermatologists to upload questions, documents, and images for input and consultation from FIRST's expert panel. The site uses a store-and-forward teledermatology approach in a secure, HIPAA- compliant environment to facilitate communication between dermatologists dealing with this rare set of diseases.

Dermatologists seeking assistance in the diagnosis and treatment of patients with ichthyosis and related skin types can visit www.firstskinfoundation.org and click on *Medical Professionals* for more information or to have a case reviewed by FIRST's expert panel. A reply will be sent back in a timely and efficient manner.

News and Notes

Making connections in unlikely places

Janet Burns

During the planning for our annual Phantom Tea campaign, Development Co-ordinator Christine Wassel requested a donation of tea bags from area businesses. When Trader Joe's responded with a donation, Chris gratefully acknowledged the donation with a thank you note. Trader Joe's posted this note in their store. When Janet Burns did her regular grocery shopping, she happened to notice the letter posted on the wall. Janet and her brother Bill have Ichthyosis Vulgaris. The siblings had never met anyone else with ichthyosis. Janet noted the address on the letter and decided to stop in and pay us a visit. She walked into the FIRST office in March and was so happy to know about what we do, that she has been volunteering with us regularly since then. Bill lives in Virginia and has also become a member of FIRST. Janet says that she "feels at home" with the staff at the office and really enjoys spending time helping us with various clerical duties. The FIRST staff really appreciates Janet's help!

ADVERTISE WITH FIRST!

Ichthyosis Focus welcomes your advertisements! If you provide a product or service that you feel would benefit our members, place an ad in a future issue of the newsletter.

For information about placing an ad, contact Lisa Breuning, Ichthyosis Focus Editor, at 800.545.3286, or email lbreuning@firstskinfoundation.org.

JANE & HENRY BUKATY SKIN CARE FUND

FIRST realizes that the fight against ichthyosis is not only medical but also financial. As families of affected individuals maintain their daily routine of treatments, their efforts can be complicated by the ongoing costs of medical supplies and other comforting aids and procedures.

Thanks to the generosity of an anonymous donor, 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 application can be downloaded from FIRST's website. The application requests the specific product/treatment for which funds are needed, and a demonstration of the financial need for this product/treatment.

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.

Requests can be downloaded from FIRST's website and emailed to the national office at jpickford@firstskinfoundation.org, faxed to 215.997.9403, or mailed to the attention of:

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

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

Donations to the Jane & Henry Bukaty Skin Care Fund are always appreciated and enable FIRST to make this fund available to more of our members.

Writing from the heart

Landon Hoffman is in fourth grade at Hajek Elementary School in Burleson, Texas. When, his teacher, Ms. Wendee Neubauer, gave her students a writing assignment, Landon knew exactly the topic he wanted to choose. Landon's 3-year-old half-sister, **Madison Hoffman,** is affected with EHK. Below is Landon's story, in his own words, exactly as he wrote it.

Landon and Maddie last Halloween.

It all started out when I was in first grade. The office called for me to come up front. One of the teachers said congrats you have a baby sister. I was curious because she was not supposed to be born that early. My granfather was there. He said that she was very sick and it would take a while to see her. I didn't under stand.

It turned out that I couldn't see her for a couple of days. But after those days were up we went to the hospital. When I walked throe the door a nurse put a mask on me, ad I walked to my sister and looked I could feel my eyes watering up as if they were about to bearst out in tears. That's when I noticed her skin it was bad. If you touched it, it would peel off. This was not a sickness this was a disease. The doctors said that she would be in there for two or three months.

After three brutal months my sister came home! But one problem her skin has not been curde. It will be hard but its worth it to keep this baby alive. When all of our family found out that she was coming home they came to visit. I was so glad that they got to see her out of the hospital but also kinda sad seeing the faces on everyone cause of all shes ben throe. Its hard but knowing that angeles are always around her is very helpful.

After a while the doctors found out that she will haft to have surgery. What else could happen to this baby. It's bad that she has a desease but now you haft to put a cast on her. That's some mest up stuff. Whats realy sad is that it took them a long time to figure out how to put the cast on her because of her skin. The day she had surgery was not on a weekend it was on a school day and I was at school. I could'nt even focus because of it. When I got home I saw her cast from waste to feet, I could'nt believe it. It felt like my heart was split in half. It took a while but they took it off after two or three months.

One year later my parents researched for so many things for my sister. One day at my granparents house my parents had a conversation and said that they have found a cure*. They said that they will take a peace of her skin and do something with and replace it back on her body. They say it will heal and become regular skin.

Scientists are still reasearching for this cure. I am so glad that there are people that are to make a better world. I thank God for bringing my baby sister in my life and I thank him for bringing good news to this world and my family!

**Editor's note: This refers to research being conducted by Dr. Dennis Roop and Dr. Jiang Chen at the University of Colorado. For more information about this study, visit FIRST's website and click on the Research tab.*

Grassroots Fundraising

Our members across the nation have been very busy holding Grassroots Fundraisers for FIRST!

MOMS Club® holds bids for KIDS silent auction and dinner

by Glenda Charlene Randall, St. Joseph, MI

Logan, center, with the other 2 children who were also featured during the evening

The MOMS Club® of Stevensville/South St. Joseph, Michigan held a fundraiser in March and designated FIRST as a beneficiary of a portion of the proceeds! Two other foundations were also chosen to receive funds. Seven-year old Logan Randall, affected with CIE, has been actively involved in the MOMS® club with his family since he was two.

The fundraiser, which cost $40 per ticket for entry, consisted of an Italian dinner, held at an upscale local restaurant, *Santaniello's*, and a silent auction. Local businesses and MOMS® Club members were asked if they would donate items and services to be put up for bidding at the auction. Countless people came through with unbelievable generosity. Our family was deeply touched by the outpouring of support from our community, by the countless prizes that were offered, and by the many people who worked so hard to make the evening wonderful.

Looking over the items in the silent auction.

Especially touching was the generosity and goodness of everyday people, some of whom wanted to remain anonymous in their giving. A man showed up the night of the event and donated $80, saying he had seen the flyer advertising the evening in a local bakery and just wanted to support the cause. There are numerous examples of similar generosity.

Our family, with our four young children, went door to door to sell tickets in upscale neighborhoods (in the freezing cold February weather!). But we could not have imagined what a wonderful experience it would be for us. We met some of the kindest people on earth! They invited our family into their warm homes to hear us explain the fundraiser and FIRST, and to learn about ichthyosis. Our family had such a great experience educating people together as a family. Some people even wrote checks to the MOMS® Club knowing they could not attend the event.

The night of the auction, several couples we had met by knocking on their doors were kind enough to purchase multiple prizes. One couple bought a huge gift basket of toys then presented it to our family! It was so wonderful for our children, especially Logan, to feel that kind of support from people whom we did not even know before. Our kids continue to enjoy playing with the toys they "won" at bids for KIDS! The experience as a whole will be a memory we will cherish.

FIRST Staff member initates dress down day

The students at Mary, Mother of the Redeemer (MMR) school in North Wales, Pennsylvania participated in a dress down day that benefitted FIRST on April 29, 2011. **Chris Wassel,** Development Coordinator, and the newest member of the FIRST staff, coordinated the event. Three of Chris's daughters attend MMR and promoted the event. The students, who typically wear a uniform to school, were invited to "dress down" for the day and donate $1. The response was terrific and more than $500 was donated to FIRST! Thank you so much to Chris and the staff and students at MMR for their efforts.

Chris's daughters, Brady, second from left; Chase, 3rd from left; and Flynn, 2nd from right join with their friends in MMR's Dress Down Day

Grassroots Fundraising

The Foundation is very thankful to all of our wonderful members for their hard work. Grassroots fundraisers are a great way not only to raise money for FIRST, but also to raise awareness about ichthyosis in your community.

The Hoffman family thanks everyone who attended

Texas-Sized Barbeque

Jeremy and Emily Hoffman are the proud parents of 3-year-old Madison, who is affected with EHK. They have begun a tradition of hosting a barbeque event to raise funds for FIRST. The 2nd Annual Maddie's Miracle event was held at the Rafter 7 Ranch in Crowley, Texas on January 22, 2011. The barbeque was delicious. There were carriage rides in a beautiful, lighted, horse-drawn carriage, and all ages danced to the music played by The Cross Country Band. In addition to the beautifully decorated room and the entertainment, there was a silent auction featuring jewelry, handbags, sports memorabilia, handmade knives, and a handmade iron fire pit.

There was a terrific turnout and the evening was a tremendous success, raising more than $5,000 for FIRST!

Madison

Sisters Ugly Fashion Show

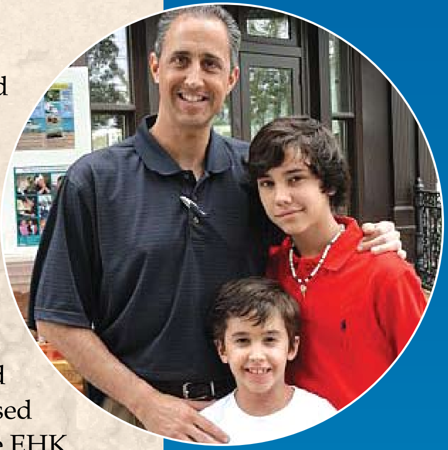
Participants browse the displays at Sisters Ugly Boutique

Diane Sinclair of Northfield, Minnesota has a 2-year-old granddaughter, ***Genevieve Schmaedeka,*** affected with EHK. Diane and her daughter, Jenny, are co-owners of *Sisters Ugly*, a fashion boutique. They held an event, Fashion Fix, at their boutique. They put on a fashion show with clothing from two boutiques in Northfield, their *Sisters Ugly* boutique, and The Rare Pair. There was also a local salon (Buzz Salon) that volunteered their time to do hair and makeup for the 14 models. There were over 65 women who attended the show, which included food and shopping. A portion of the proceeds from ticket sales and shopping sales was donated to FIRST. FIRST was chosen because, "it's a struggle to find good information about the condition and it needs to be researched and brought to people's attention." FIRST is very grateful to Diane and Jenny for their efforts on our behalf.

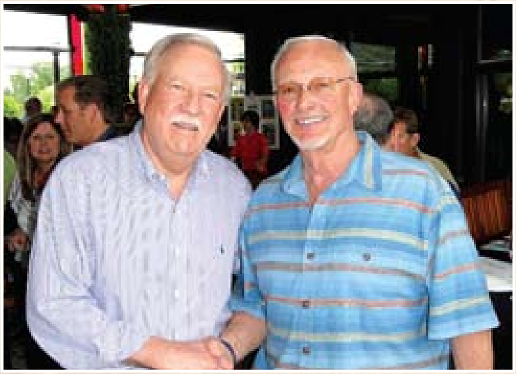
Modeling the fashions

5th Annual Find-a-Cure Event raises $30,000!

On Thursday, April 21, over 75 people gathered for good food, good spirits, and a good cause. Family, friends, and colleagues joined hosts Kelly & Mark Klafter and Lynn & Mike Briggs at the 5th annual Find a Cure fundraiser at the Olde Blind Dog in Milton, Georgia. Proceeds raised from the event supported the EHK Research Fund at FIRST. The Klafter's son and the Briggs' grandson, Adam, is affected with EHK, a rare skin disease that causes excessive scaling, blisters, infections, and painful movement.



Mark Klafter with sons Matthew and Adam

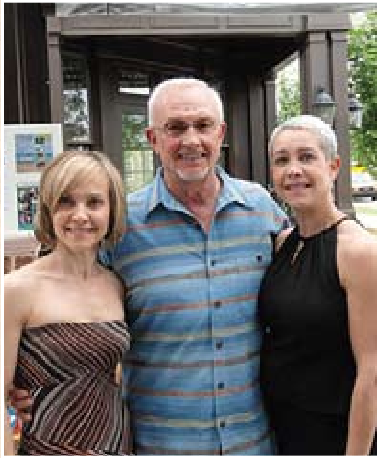


Researcher Dennis Roop with Mike Briggs

The fundraiser generated greater awareness and raised over $30,000 to support the EHK Research Fund.

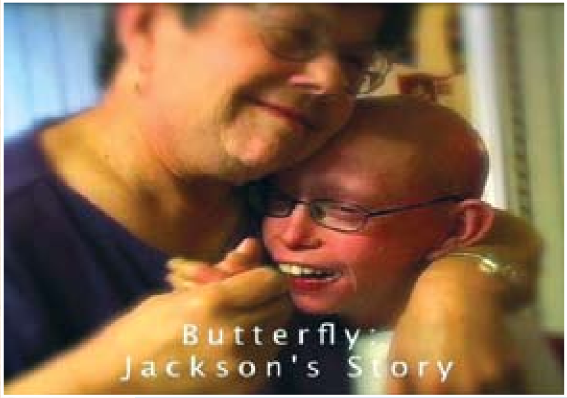
The evening featured a presentation from Dr. Dennis Roop, the country's leading scientist and expert on EHK research, a silent auction, and two upscale raffles for a one-week vacation in Big Sky Montana or a deep-sea fishing trip in Costa Rica. Each trip included roundtrip airfare for four donated by Delta Airlines.

The Klafters and Briggses are very grateful to their family and friends for their generous support and contributions to help find a cure. Special thanks to Ron Wallace and his team at the Olde Blind Dog for their hospitality and generosity.



Mike Briggs with daughters Kelly Klafter, left and Kim Price.

A Film Premier in North Carolina



Denver Hollingsworth, from Wallace, North Carolina, has a 14-year-old brother, Jackson, who is affected with Lamellar Ichthyosis and additional medical conditions. Denver and several friends made a movie titled *Dog Gone* last year and donated the proceeds of its premier to FIRST. Denver once again produced a new movie. His latest work is a documentary featuring his brother Jackson, titled *Butterfly: Jackson's Story.* Denver premiered his movie at East Duplin High School in June and once again donated the more than $600 in proceeds to FIRST! The film was a huge hit, and Jackson received a standing ovation from the approximately 150 people in attendance after the showing. The community certainly showed their support for Jackson and for FIRST by coming to the premiere. The film did a great job explaining ichthyosis and creating awareness in the community. Both Hollingsworth young men should feel very proud of their outstanding work.

In addition, another family affected by Lamellar Ichthyosis from Charlotte, North Carolina has expressed interest in showing Denver's film in their community in the near future. This could lead to additional showings as well!

Denver also appeared on a local radio show, Coastal Daybreak, the morning after the premier. With this and future appearances, Denver is doing a fantastic job generating awareness and "getting the word out." Thank you so much to Denver, Jackson, and the entire Hollingsworth family for your continued hard work on behalf of FIRST.

FIRST
Foundation for Ichthyosis & Related Skin Types™
Educate • Inspire • Connect
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2012 NATIONAL FAMILY CONFERENCE LOCATION ANNOUNCED!

The 2012 National Family Conference will be held in beautiful Denver, Colorado, at the Renaissance Denver Hotel.

This city is amazing and promises to be a great location for everyone.

Mark your calendars for June 22, 23, and 24.

More details to come!

June 2012

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