

NATIONAL FAMILY CONFERENCE PLANNED

Mark your Calendars!



FIRST's 2014 National Family Conference will be held at the beautiful Hilton Indianapolis in downtown Indianapolis, Indiana.

**Our 18th
Biennial Conference
will take place
JUNE 20 – 22, 2014.**

Details will be coming soon!

PATIENT SUPPORT FORUM DATES

June 8, 2013 - Dallas, TX
June 29, 2013 - Cincinnati, OH
Summer of 2013 - NY/NJ
Sept. 7, 2013 - San Jose, CA
Sept. 21, 2013 - Kansas City, MO

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FIRST Supports Gordon Research Conference

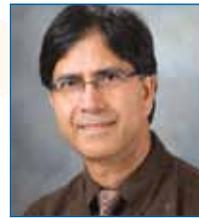
For the second year FIRST provided financial support for the Gordon Research Conference. This year's conference was held over the summer at Davidson College in Davidson, North Carolina.

Richard Eckert, PhD, Professor and Chair, John F.B. Weaver Distinguished Professor, Biochemistry and Molecular Biology at University of Maryland, and Kapil Mehta, PhD, Professor of Cancer Medicine (Biochemistry), University of Texas M.D. Anderson Cancer Center, submitted a summary about the skin disease-relevant work presented at the conference.

Understanding Autosomal Recessive Congenital Ichthyosis



Richard L. Eckert, PhD
Professor and Chair
John F.B. Weaver Distinguished
Professor, Biochemistry and
Molecular Biology



Kapil Mehta, PhD
Professor of Cancer Medicine
(Biochemistry),
University of Texas M.D.
Anderson Cancer Center

Autosomal recessive congenital ichthyosis (ARCI) is an inherited genetic disease that affects 1 of every 250,000 people. It includes lamellar ichthyosis (i.e. the plate-like scales) and CIE (i.e. congenital ichthyosiform erythroderma). The type I transglutaminase (TG1) gene is mutated in many of these disease patients. The TG1 protein is required for skin maturation, and mutation of this protein results in deficient epidermal cornification leading to an abnormal epidermal surface including the production of plate-like "fish" scales. TG1 mutations are found in a significant percentage of ARCI patients; however, how these mutations lead to disease pathology is not well understood.

In an effort to understand the role of TG1 mutations in disease, Dr. Richard Eckert and colleagues at the University of Maryland-School of Medicine in Baltimore are studying the intracellular events that control processing of normal and mutant TG1 in normal human skin cells. These

studies have led to potentially important new insights regarding the pathology of this disease.

These investigators found accumulation of mutant TG1 protein at abnormal locations inside cells. This finding, that the mutant TG1 proteins accumulate in the endoplasmic reticulum (ER), was "remarkable and not previously observed," comments Dr. Eckert. The ER is a protein processing

and quality control center that checks new proteins as they are synthesized in the cell. Unlike normal TG1, mutant TG1 proteins accumulate in the ER and are not successfully transported to the plasma membrane. This is in contrast to normal TG1 which passes through the endoplasmic reticulum and is deposited on the inner surface of the plasma membrane where it aids cell maturation.

Mutant TG1 appears to not be appropriately folded and, therefore, accumulates in the ER and never arrives at the plasma membrane. Since there is less TG1 at the plasma membrane, there is reduced TG1 activity. Dr. Eckert is currently testing the idea that treatment with chemicals that restore normal folding of mutant TG1 may alleviate some of the disease symptoms. Indeed, Eckert's laboratory studies show that treatment with chemicals that enhance protein folding reduces accumulation of mutant TG1 in the ER and increases TG1 activity.

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

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FIRST's New President, Mike Briggs Hosts Hollywood Movie Production



*Mike Briggs poses behind
Arnold's chair during filming*

When Mike Briggs, FIRST's new president, was approached by a scouting crew to use his home on Lake Lanier in Gainesville, Georgia for an upcoming movie, the answer was simple.

"I told them they were free to film at my home, as long as they agreed to donate all of the rental fees associated with the use of my property to FIRST," said Mike, whose term as President of FIRST began in January. "When the producers heard that, they decided to make the donation larger and have donated \$35,000 to the Foundation. We couldn't be more thrilled."

The Briggs' family home was filled with cameras, equipment, cast, and crew members of Arnold Schwarzenegger's newest movie during December. In fact, the entire street was transformed with trailers lining the roadway during production.

Filming wrapped up recently, and stars on the set, including Schwarzenegger, had a meet and greet with Briggs' grandson Adam Klafter, who is affected with epidermolytic ichthyosis. The movie, "Ten," is slated to come out next year.

"Although there is no known cure for this disease, donations such as this will assist us to fund research to help us not only get closer to a cure, but to better manage the disorder," said Jean Pickford, Executive Director of FIRST.



*Arnold Schwarzenegger meets with
Adam Klafter, left and his brother
Matthew*

Physicians E-Newsletter for Your Inbox

FIRST sends *Spotlight on Ichthyosis* e-newsletter to the physicians in our membership. Are you a physician and not receiving the Spotlight On in your inbox?

Email Moureen Wenik at mwenik@firstskinfoundation.org to get on the e-news list.



Correspondence Corner

Dear FIRST,

My son has X-linked ichthyosis. We recently had a check-up with our doctor. The doctor suggested that I let you know what we use for his head because we have had 100% success with it. Maybe it could help someone else!

My son had terrible scales on his head and always looked like he had dandruff.

He had used some medicines to no avail. His hair only looked greasy and like he had dandruff. He now uses Paul Mitchell's Tea Tree shampoo and conditioner. He has a head scrubber that he uses as well and now has NO shedding on his head. The scrubber is a little round thing with prongs. We get the shampoo at the salon where he gets his hair cut, but it is also available at amazon.com and drugstore.com. I believe I have seen it in a drug store as well. Hopefully you can share this with others in case it helps them.

Thanks so much!

Tracy Lehrer

McDonough, Georgia

Dear FIRST,

We have found that pure coconut oil works very well for my 12-year-old son who is affected with Netherton syndrome. It helps to hydrate his skin. With its natural antibiotic traits, he has avoided infection and many of his cuts have healed faster than we have ever seen before. We can get a month supply for less than \$20 at the grocery store! We still use another lotion, but the coconut oil has the greatest benefit for him that we have seen in a long time!

Dana Curren

Dagmar, Montana

Dear FIRST,

I am 48 years old and have ichthyosis vulgaris. I wanted to let you know that I have been using natural progesterone cream to control severe chronic pain (brand name ProGest, available OTC) and noticed that my ichthyosis symptoms are not as bad as usual. Progesterone is an anti-inflammatory hormone in both women and men. My thumbs haven't cracked and bled in winter like they normally would, and my scaly parts are not as severe.

I am not a doctor, I only know that my severe chronic pain disappeared after using it, and my skin has improved. The cause of my severe pain was never diagnosed. No one can explain why I hurt so badly, or why progesterone stopped my pain.

Christine Brush

Albuquerque, New Mexico



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Editor's Note: Neither FIRST, its Board of Directors, Medical & Scientific Advisory Board, nor any officials recommend treatments. Before trying any new treatments, please consult your physician.

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Executive Director's Report

Dear Friends and Members of FIRST,

There are two times every year that make me think of rejuvenation, realigning, and restarting things in my life – a new year and the springtime. To me, a new year signifies a chance to start something new or confirm a renewed commitment in parts of my life. It serves as a marker for a beginning point in time, which gives me a feeling of hope and inspiration.

This New Year's feeling sets the tone for all of us at FIRST. We begin a new year with renewed hope and optimism for our members and the organization. Because of our efforts in reaching healthcare professionals, the internet, and social media communities, more and more people are connecting to FIRST and each other. We have grown so much over the past 10 years. We consistently receive feedback from individuals and families about how FIRST has made such a difference in their lives. This inspires us to continue to work harder to keep making that difference.

With the New Year, comes new leadership for FIRST. Three new members have joined our Board of Directors. **Denise Benedetto** comes to FIRST with fifteen years of experience as a mother to an affected son and as a teacher in the Long Island area. **Dr. Gabriele Richard** is the Chief Medical Officer at GeneDx in Maryland. Dr. Richard has been an active volunteer with FIRST for many years and currently serves on our Medical & Scientific Advisory Board. She is an expert in the genetics of ichthyosis. **Larry Silverman** is a founding member of MyCFO4Life, a comprehensive financial planning firm in Texas. Larry will take the reins as FIRST's CFO, working with the Finance Committee to continue our financial responsibility to our donors.

In my last report, I talked about our new, refreshed focus on communications, which prompts my next question to you: When was the last time you logged on to our website, www.firstskinfoundation.org? It is the number one way we communicate to our members and the public. We post new articles every four days on our home page. Whether it's a new research finding, a way to improve yourself, or a chance to meet another affected person, we are constantly updating our site. It will be a great benefit to you, so be sure to make a point to visit at least twice a week to learn the latest and greatest.

Another way to get frequent updates from FIRST and our members is to join our Facebook and Twitter communities. On Facebook, we are listed as the Foundation for Ichthyosis & Related Skin Types, Inc. Our Twitter handle is @FIRST_Skin. Many members are connecting with each other and FIRST using these social media channels so don't be left out!

Some other exciting things to look forward to this year include five Patient Support Forums throughout the country, a large growing number of grassroots events, and our FIRST to Know Conference Calls. Our Board of Directors will meet face-to-face for our biennial retreat in Philadelphia in the fall, and FIRST will be represented by either Moureen or me at several professional conventions, including the American Academy of Dermatology and Dermatology Nurses Association.

As always, FIRST exists to help you, our members, families, and friends. So don't hesitate to pick up the phone or email our staff at any time. We love to hear from you!

Best wishes,



Jean R. Pickford
Executive Director



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Foundation for Ichthyosis &
Related Skin Types, Inc.

FIRST IS THE RECIPIENT OF TWO CORPORATE GRANTS



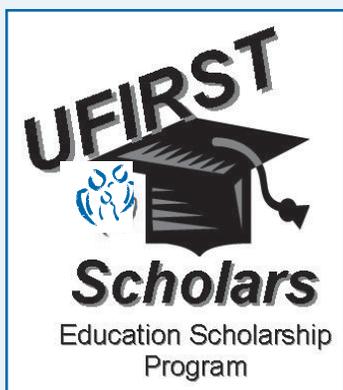
Karen Foster, a friend of the *Hamill* family, contacted FIRST back in October. Karen's company, FLIR, a Thermal Imaging company, allows employees to designate money to charitable organizations that are important to them. Karen's son is a classmate of *Lauren Hamill*, and she was moved to help, so she chose FIRST! We worked with FLIR to set up an electronic donation, and FLIR donated \$500 to FIRST in November. Thank you goes to Karen for thinking of Lauren and of FIRST. Thank you to FLIR for making the donation. We truly appreciate your generosity.



Stephanie Sawyer-Ames reached out to FIRST because she was aware that her company, TJX, had a charitable giving program and she wanted to nominate FIRST. The office worked hand-in-hand with Stephanie and submitted an application that was later approved for a \$2,500 grant for FIRST! We were thrilled with the donation from TJX and the awareness that was created at Stephanie's company. Many companies have charitable giving programs that are available to employees.

If your company, or the company of a loved one or a friend, has a charitable giving department and you are not sure how to get started, please contact Chris at FIRST for more information, 215.997.9400, or cwassel@firstskinfoundation.org.

Please contact your human resources department for more information about opportunities on charitable giving programs.



UFIRST Scholars Program

History

The UFIRST SCHOLARS Program, established in 2010 by a seed gift from Valerie & David Scholl, is now accepting applications for 2013. The Scholls are grandparents to an affected granddaughter who wanted to provide an opportunity for affected students to advance their post-secondary education in partnership with FIRST. Their inspiration is to provide the opportunity for students affected with a form of ichthyosis or related skin type to achieve their highest educational potential. Other donors are encouraged to contribute to the fund to help grow its capacity.

How to Apply

- The 2013 application will be available on **Tuesday, February 1st**.
- Completed applications **will be due no later than March 29**. Faxes and online applications will be accepted.
- Scholarship winners will be notified in May.
- Eligible candidates are individuals affected with some form of ichthyosis or a related skin type, seeking post-secondary education at an accredited university, college, junior college, or trade school.
- Qualified applicants may apply throughout the duration of their education career; however, a new application is required every year and proven success in previous year(s) will be required to be considered for future funding.
- Funds can be for school tuition and/or fees. All monies for tuition and/or fees are paid directly to the institution.
- Participation in FIRST activities, communication with the national office, and advocating in your local community strengthens your application.

Scholarship Selection Criteria

A committee of volunteers will evaluate each scholarship application based on the following criteria:

1. Demonstrated Academic Ability
2. A Written Essay (topics vary each year)
3. Extracurricular Activities and Community Activities
4. Financial Need
5. Recommendation Letters
6. FIRST Activities

Spotlight On ... Samiha Chowdhury

No Longer Alone

I am *Samiha Chowdhury*, a 27 year old female from Dhaka, Bangladesh, Southeast Asia. I am working as a Patient Advocate & Region 10 Ambassador in Dhaka/Lagos for the Foundation for Ichthyosis & Related Skin Types, Inc. (FIRST). I am a general practitioner and currently training in Dermatology & Venereology.

I was born with a rare skin disease, ichthyosis vulgaris. Dealing with this every day is difficult and tiresome as my skin does not function normally. Neither my parents nor grandparents and extended relatives are affected.



Samiha as a baby

When I was born in 1985, doctors could not diagnose my problem and treated it purely as dry skin. My parents used Vaseline and olive oil to soften my skin. In 2003, while in medical school, a doctor diagnosed me with ichthyosis. Most of the best products used for treatment are not available in my country, so I try managing my skin with lotions and creams from the local super market which are made for dry skin. I also take scrub baths for about an hour.

Since childhood, I used to believe that my dry skin would fade away. But when I realized that there is no cure my heart shattered. I felt alone. I was scared, had low self-esteem, and experienced depression and frustration. I worried about relationships and tried to hide my condition from friends and relatives. In 2009, as there is no organization for those affected with ichthyosis in my country, I began searching online for ichthyosis-affected families. I met FIRST members and beautiful families. Since then I am exchanging thoughts and experiences with them. Inspired by those who raise awareness about this rare condition, I started online advocacy for the ichthyosis community. Now, I am the one who loves to educate, inspire, and connect those touched by ichthyosis.

I recently married a very kind and handsome guy. I am so grateful to my husband, who is very supportive and accepts me as I am. Now it feels good, knowing that I am not alone on this earth. Living with ichthyosis has taught me patience, resilience, and strength.

I hope that my transformation, my experiences, and my success will teach, inspire, and uplift all those who are affected with ichthyosis and chronic illnesses.

Samiha Chowdhury

Dhaka, Bangladesh



Samiha on graduation day

FUNDRAISING CAN BE VERY REWARDING

"It was such a rewarding experience" ...

"I was so touched by everyone's generosity" ...

"I never thought I could make a difference."

These are just a few of the comments made by FIRST members after they've hosted a grassroots fundraiser. As always, the most difficult step in hosting a fundraiser is deciding to have one in the first place. The FIRST office will work with you every step of the way, from providing you with awareness materials to helping to publicize your event, to even suggesting ideas for the event itself.

All members, in their own way, can positively affect the lives of those with ichthyosis by hosting a fundraiser. The event not only raises money for FIRST, but it also raises ichthyosis awareness in the community where you live. Awareness helps all of us by alerting others to this rare set of diseases. Maybe one of the people in the room will help to fund the next advancement in ichthyosis research, or will make a significant donation...you never know. On top of all that, it is such a rewarding experience for the host. We have heard it over and over again. In fact, many members



sign up to do it again before the current event is even over!

During our National Family Conference, we spoke with a member from California who hosted a fabulous silent auction and dinner. She said that she cried after the event thinking, "How can \$10,000 possibly help?" As Dave Scholl, FIRST's former President said, "\$10,000 is 10% of our total grassroots budget. It's a very big deal!"

For bigger fundraisers that involve a lot of credit or debit



transactions, consider using our card swipers. FIRST has four card swipers that can be sent to you in time for your event. If you have a smart phone (iPhone or Droid) or an iPod or iPad, all you need to do is download the app and start processing your transactions on your very own device.

These swipers were first used at the Dane's Friends for FIRST Concert held in September. Suzanne Phelps commented that they made the check out process much faster and smoother and emailed receipts immediately.

If you'd like to host a grassroots fundraiser for FIRST, please contact Chris at cwassel@firstskinfoundation.org or call her at 215.997.9400. Hosting a grassroots fundraiser is fun and so rewarding.



FIRST is very thankful to our 2013 Medical & Scientific Advisory Board members for their outstanding contributions.



Leonard Milstone, MD, Chair
Yale University School of Medicine



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GeneDx, Inc.



Susan Bayliss, MD
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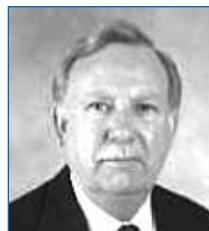
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Dennis Roop, PhD
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University of California, San Francisco



Albert Yan, MD
Children's Hospital of Philadelphia



Moise Levy
Dell Children's Medical Center

REGIONAL SUPPORT NETWORK

Time to Meet Other FIRST Members

Mark your calendar for the 2013 Patient Support Forums. These one-day meetings are filled with medical information, networking, sharing about product ideas, and skin care routines. The meetings will include a light breakfast, lunch, and childcare for families with children. Registration information and cost will be posted on FIRST's facebook page and website. We hope to see you at one of the following events:

June 8, 2013 - Dallas, Texas

June 29, 2013 - Cincinnati, Ohio

Summer of 2013 - New York/New Jersey

September 7, 2013 - San Jose, California

September 21, 2013 - Kansas City, Missouri

International Connections and FIRST

Ichthyosis has no international boundaries, which means FIRST has friends all over the world. There are a number of international support groups and RSN Ambassadors in many countries outside of the United States. FIRST has personally met a number of our international support group leaders, and frequently works with groups such as the ISG to exchange resources and connect families through support volunteers. One of our volunteers, *Esther Njeri*, Ambassador in Kenya, received approval from the Kenyan government to help others in her region through the Ichthyosis Africa Foundation. Since 2007, Esther has been diligently working to bring families together in her

region, working tirelessly to educate, inspire, and connect others with ichthyosis. She has been featured on local TV and in the local newspaper. Congratulations to Esther on her accomplishment of forming the support group.

FIRST is also proud of the work another active volunteer, *Samaha Chowdhury*, has accomplished in the Asia Region. Samiha contacted FIRST in 2010, with the goal of educating the medical community and bringing affected individuals together, while strengthening the network in the Asia continent. Along with a very supportive group of individuals both in India and the United States, Samiha has a large following of individuals who meet for conference calls and keep in touch often.

FIRST is thankful to have Esther, Samiha, Ichthyosis Support Group (ISG) in the UK, and all of the other international support groups and individuals working globally to reach out to their communities and be the advocate for others.

A full list with links to the international groups is on FIRST's website, under Research Support, then Resources and Related Information.

Are You Online?

The Regional Support Network has a monthly e-newsletter to help keep FIRST's 100 plus support volunteers informed about the events at FIRST. If you are a RSN member, and have not received your e-newsletter, email Moureen Wenik at mwenik@firstskinfoundation.org with your current email address. If you are interested in becoming a Support Volunteer, email Moureen and she will include you as a volunteer.

Gordon Research Conference *Continued from page 1*

Dr. Eckert states that "identification of this novel mechanism is an important step that will enhance our understanding and may lead to new therapies for this disease." An initial discussion of this work was presented in July 2010 at the prestigious "Transglutaminases in Human Disease Processes" Gordon Research Conference at Davidson College in Davidson, North Carolina and continued at the July 2012 meeting. A manuscript describing some of these findings was published in the Journal of Biological Chemistry (Jiang-H, Jans-R, Xu-W, Rorke-EA, Lin-CY, Chen-YW, Fang-S, Zhong-Y and Eckert-RL JBC 285:31634, 2010) and a second manuscript is in preparation.

Rare Disease Day

FIRST will again participate in global Rare Disease Day on *February 28th, 2013*. As a Rare Disease Day Partner, we will join hundreds of other patient organizations, government agencies, medical societies, and companies in focusing attention on rare diseases on that day.

The theme is that rare diseases are a public health issue, affecting millions of people around the world. The hope is that Rare Disease Day will increase awareness of rare diseases, the special challenges encountered by those affected, and the need for research to develop safe, effective treatments or cures.

As a Rare Disease Day Partner, FIRST has agreed to help publicize and promote Rare Disease Day.

Partners and their members are encouraged to work with their media contacts, post videos and messages online, share human interest patient stories, and nominate researchers to a Rare Disease Hall of Fame.

FIRST member, Laurie Ann Fiore has initiated her own “Wear That You Care” campaign. She began by asking students and staff at her children’s elementary school to wear jeans or blue in support of Rare Disease Day. In addition, she is making awareness ribbons for participants to wear. In this digital age, word of Laurie’s efforts spread and she has people participating from 12 states across the country! She is also asking people to support FIRST with a donation. If you would like to support Laurie’s efforts, you may email her at lfiore2@verizon.net to order a ribbon to wear on February 28 or make a donation.

For more information on these and other activities, visit the Rare Disease Day website at www.rarediseaseday.org.



New 2013 Health Planners Are Available From the NIH



National Institutes of Health
The Nation's Medical Research Agency

With the start of a new year, the National Institute of Health (NIH) invites you to dedicate yourself, your family, and your community to a year of health in 2013!

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), part of the National Institutes of Health (NIH), has launched a multicultural outreach initiative to raise awareness about the availability of NIH and other federal resources to help people with diseases and conditions of the bones, joints, muscles and skin. The initiative also aims to emphasize research as the foundation for progress, and to support and involve organizations in multicultural outreach.

The NIAMS has created a series of health planners—titled A Year of Health—that provide health tips and information

about staying healthy and managing conditions of the bones, joints, muscles and skin. The four planners, created with community input, are tailored for the following audiences:

- African Americans
- American Indians/Alaska Natives/Native Hawaiians
- Asian Americans/Pacific Islanders
- Hispanics/Latinos (bilingual planner)

These planners are free. If you would like to receive one, please contact the FIRST office at 215.997.9400 or email FIRST’s Program Director, Moureen Wenik at mwenik@firstskinfoundation.org.



Do We Have Your Email?

The Foundation often sends email updates about upcoming programs, events, and activities. Don’t miss out on the news we have to share!

Email Donna Wiggins at dwiggins@firstskinfoundation.org with your current email address so you can be informed!

Please note that donation acknowledgements will be sent to you via email.

Have You Been on a *FIRST to Know* Call?

The past *FIRST to Know* conference calls have been well received by our members. It is wonderful to have individuals talking to one another, sharing tips, and sharing stories and challenges. There have been requests from our membership to add disease-specific calls to the calendar. This is a great way to “meet” other families with the same ichthyosis type. Dates and topics have been designated for the next series of *FIRST to Know* conference calls. To join one of the conference calls listed below, simply RSVP to Moureen by emailing her at mwenik@firstskinfoundation.org, or call the national office at 1.800.545.3286. A call-in number will be sent to you via email. All calls are held in Eastern Time and are phone calls only, so you only need a phone, not a computer.

Thursday, February 21 – Lamellar: Connecting Families Together

Tuesday, March 5 – Netherton Syndrome: Connecting Families Together

Tuesday, March 26 – EI: Connecting Families Together

Tuesday, April 9 – X-linked: Connecting Families Together

Thursday, April 25 – Teens Rock: An Open Dialogue for Teens, with Teens

FIRST Night at the Ballpark 2013



The successful FIRST Night at the Ballpark events are in full swing!

The Kansas City Royals are joining with FIRST for “*Ichthyosis Day at the K.*” Join FIRST members Russ and Cora Cossel and a host of friends at Kaufman Stadium in Kansas City, Missouri on **Sunday, May 5, 2013** for a 1:10 afternoon game.

Please save the date, **Monday, July 8, 2013**, 7:05 pm for our 3rd Annual *FIRST Night at the Phillies!*

Events are also planned for games in Chicago, Pittsburgh, and New York, so stay tuned to our facebook page and website for announcements!

These events are a great way for our local members to gather together, to socialize, to have fun, and to connect. If you would like to help us set up a game in your city, please contact Chris Wassel at the FIRST office via email at cwassel@firstskinfoundation.org. **PLAY BALL!**

WHAT IS YOUR ITCH TIP?

In Their Own Words...

A question was asked on facebook recently. What is your itch tip? Here are some of the reponses:

RC: Always wear cotton, keep moist, and rub instead of scratching your skin.

JR: Smack it, don't scratch it! You get a sensation, but you're not ripping flakes of skin off in the process.

MT: Frogg Toggs cooling towel

MC: Avoid getting stressed, and rest.

MS: I always have moisturizer with me.

MM: Keep busy, distracted, and hands occupied

MF: Pure and unrefined Evening Primrose Oil supplement. It has made a huge improvement!

TB: We use “boo boo” packs, which are ice packs with terry cloth covers on them so the ice pack won't directly touch the skin. When they get hot, all bets are off. Cool them down and it helps. Also, we gently “slap” the itch instead of scratching.

HS: Pour cold water over the itch.

RB: Moisturize, use appropriate prescribed cream and sometimes antihistamine. Pat it, don't scratch it. And always wear 100% cotton clothes.

JE: Aloe. My daughter loves putting it on herself.

VD: Bath and moisturizer with Avène cream.

SR: Ice

IM Keeping my nails filed.

TL: Vegan soap, Eucerin cream (I keep it in the fridge so it's nice and cold), antihistamines, taking internally and applying fish oil omega 3 supplements directly to the skin. And stay busy, get your mind off of the itching if you can.

BS: A cold, damp washcloth.

AM: A bath with apple cider vinegar.

RE: Moisturize-Moisturize. Ice for unbearable itching and burning. Find and address your triggers. Always ask your doctor before starting any treatment program.

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Photo Contest Leads to Awareness

by Bailey Pretak

This summer some of my advanced pointe students and I did a ballet photo shoot. Our photographer was Hannah Lampman, a former dancer at our studio who is now a sophomore in college studying art therapy. We were inspired by the NY Times Bestseller, *Dancers Among Us* and discovered that the photographer of that book, Jordan Matter, was holding a photo contest. We submitted several photos and were happy to find that one of our photos was selected as a finalist. Jordan Matter then held an online voting campaign and our photo was the winner!



I never considered that this would be an opportunity for awareness of ichthyosis. I guess it's because I forget I have it most times, haha. During the voting, a comment was posted on the site about my legs. The photographer, a long-time friend, responded to the comment; then, I used this as an opportunity to promote FIRST by posting the website on the comment thread.

A few days later, I found another comment, and it brought tears to my eyes...

"I love the picture of the girls holding the newspapers best. It was the legs of the beautiful girl on the right that brought me to my decision. Talent is not only portrayed by what is visible, it comes from the heart. I can't see what they look like, but I know they have a passion for the arts...great mystique!"

It was my very own legs, my very own imperfect skin that drew her attention to our picture and caused her to vote for us. I also shared with her about ichthyosis. The prize for the contest was a headshot photo shoot by Jordan Matter. Hannah, as the photographer, was the person to receive the prize, but she told Jordan to give it to me since it was my idea. Traveling to New York City for headshots by a NY Times Bestselling author/professional photographer was so exciting for me!



Bailey shares information about ichthyosis and FIRST with Jordan

I brought my friend Natalie along with me on the trip because she knows how to navigate New York City and I don't. We arrived in the city a little early, so we decided to go to a nearby coffee shop. I walked up to place my order and the barista asked, "Are you Bailey? You're the one who won Jordan's contest?" Imagine my surprise when someone in NYC not only recognized me but knew my name! I was so dumbfounded that Natalie answered for me! It turns out that the barista was the person who had left the slightly negative comment about my skin. After Hannah (our photographer) told her about it and I left the website for FIRST, the barista started doing a lot of research on it. She ended up writing a final paper in college on ichthyosis! How crazy cool is that?! She was so excited to meet me! It never ceases to amaze me how God works. I never even gave it a thought that my skin disorder would be present in the pictures and I never expected this outcome!



Bailey and Natalie with Jordan Matter (center)

After that excitement, we met Jordan. He is such a great guy! I made him a photo book of our ballet photo shoots we did over the summer that were inspired by his work. He loved it so much! And I told him the crazy story from the coffee shop...even he was impressed at how things turned out...influencing people we don't even know. Then he took some headshots of me. He was so great to work with. He really made me feel at ease. He even chose his most favorite place to shoot the pictures. Then he wanted to do a dance picture with me. Just a little bit further down the street was a stand with a bunch of floral bouquets. I stood in a bit of a dance pose with my awesome blue heels smelling a rose and he shot a few pictures. Who knows, maybe I'll end up in a "Dancers Among Us" sequel.

We then went back to Jordan's studio and he autographed my book. There, I shared with him about my skin disorder and gave him a brochure from FIRST. He was very attentive. He didn't ask many questions but said that he was definitely going to read up on it. He placed the photo book that I made for him on his coffee table right next to his own book. I then talked to his make-up artist about the events at the coffee shop earlier in the day.

It is just amazing how many opportunities for awareness there were from this experience.

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.

Half-Marathon for Harlequin

In October, *DeDe Fasciano's* good friend *Leif Ellison* ran the Hartford Half-Marathon in honor of De De's son *Evan*. It was a very cold morning



in Connecticut, but it was a very quick finish and excellent time for a 13-miler; 1:29:44. Congratulations Leif, and thank you from everyone at FIRST! Thank you for raising funds at the race and at your office and for spreading ichthyosis awareness in the Connecticut area.



DeDe and Leif with Evan (center)

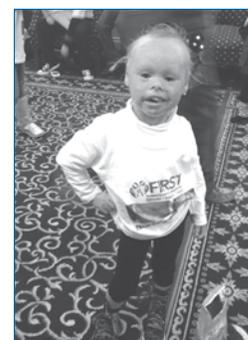
A Banner Day for a Delaware Family



Jane with her daddy, Richard

Margaret Sherlock and a very large contingent of her family and friends set out on foot to run in the Baltimore Half-Marathon on October 13, 2012. It was a beautiful, sunny day and they all completed the race. What became even more impressive was the awareness and the amount of money that they were able to raise for FIRST. Margaret started with a conservative goal of \$500 and ended up raising an incredible amount of over \$15,000 when all of the donations were totaled! It was an incredible experience for the entire family, and we are all so proud of them for their efforts.

In early November, Margie, her daughter Jane, Margie's sister Kate, and Kate's daughter Angeline drove up from Bear, Delaware to deliver the money to FIRST. It was a great day!



Jane posing at the race

A Great Way to Celebrate!



FIRST member *Karen Tanner* is the grandmother of adorable one-year-old *Calvin Kocher*, who is affected with an unspecified type of ichthyosis. This past December, Karen and Barry Brandt got married. When Karen and Barry sent out their wedding invitations, they included a request for donations to FIRST in lieu of gifts. Their friends and family members responded with such generosity and raised more than \$2,100 in their honor to FIRST! Congratulations on your wedding and for thinking of FIRST during this exciting time!

Barry and Karen pictured with Karen's grandsons, Ethan Tanner (with Barry), Ryan Lanigan (with Karen), and Calvin



A visit with the FIRST staff; from left, Jean Pickford, Kate, Angeline, Donna Wiggins, Jane, and Margaret

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Jeans Day at Wells Fargo



On November 9, 2012, in the Pepper Pike Wells Fargo office, **Lisa Klima** hosted her repeat grassroots event, **Emma's Jeans Day**. For a donation to FIRST, employees were able to wear jeans to work. A local establishment, Bruegger's, donated delicious bagels for breakfast. And, Branch Manager Bob Marquardt purchased pizza and pop for lunch! It was a fun day that raised awareness for ichthyosis while also raising \$660 for FIRST. Thanks go out to Lisa Klima for another great grassroots event!



Lisa Klima, center, poses with Wells Fargo staff members

Caravan Of Beads Event Raises Money for Epidermolytic Ichthyosis

Kim and Mark Mayone held their 7th annual Caravan of Beads fundraiser in Portland, Maine. Everyone got in on the action and wanted to raise money for epidermolytic ichthyosis (EI) with the thought of helping beautiful children like **Evan Mayone**.



Kyle manns the table

Evan's big brother **Kyle** skipped basketball practice to man the raffle and poster donation table. Grandpa and Grandma, **Patti Sundik**, as always, helped out and also couldn't resist purchasing some of the beautiful beads. A friend of Patti's, Sunday, donated a pillow to the cause as well!



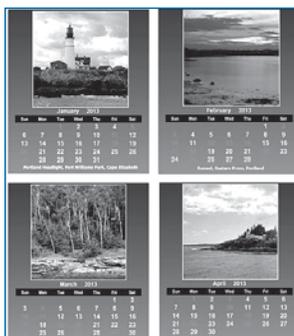
Evan helps out at the event

Great fun was had by all while also raising research money for EI.

Online Sales to Benefit FIRST

Patti Sundik, dear Mimi of **Evan Mayone**, once again generously donated \$300 to go towards epidermolytic ichthyosis (EI) research. Patti was able to donate \$260 by gathering 10% of the profits generated by the sales through her online etsy shop <http://www.etsy.com/people/LovesParis>. In addition, she saved \$40 by not sending Christmas Cards this year and sent that to our office. It is Patti's never-ending hope and prayer that a cure for ichthyosis will be found. We want to thank Patti for always thinking of FIRST.

Patti offers these beautiful calendars featuring scenes from the Maine coastline for sale on her site, with proceeds benefitting ichthyosis research



What's New in New York!

Once again, longtime FIRST supporter, **Eddie Wohlgang**, held another great grassroots fundraiser. This time, it was the "What's New Fair" held in November in Jamestown, New York. Eddie's dear friend **Terry Klein**, who is also an untiring supporter of FIRST, was instrumental in getting access to the event. Terry is the chair of admissions for the American Association of University Women (AAUW), the hosts of the event. Terry extended the invitation to Eddie's Beadies to show jewelry at the event. Eddie sold her beautiful jewelry and beads and raised \$500 for FIRST. Thanks again for all that you do for FIRST Eddie and Terry!



Eddie and Terry showing off Eddie's jewelry

FIRST travels through the National Football League

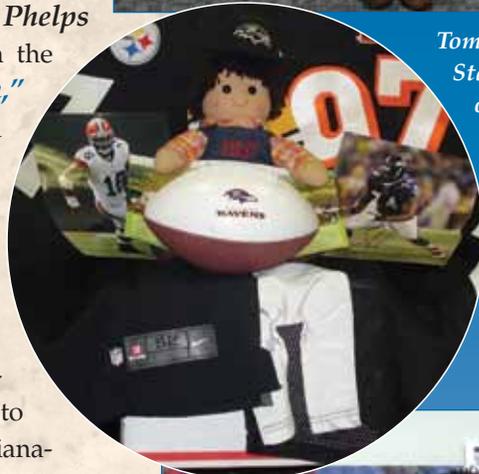
In an effort to broaden ichthyosis awareness, *Suzanne & Eric Phelps* have enlisted the help of FIRST to reach out to every team in the National Football League. *Tommy, "the NFL's biggest little fan,"* is traveling via the US Post Office to every NFL team with the goal of gaining each team's support and a team jersey or related item. After all 32 donations are received, they will be auctioned off at the *Dane's Friends for FIRST 2013 concert*.

Tommy began his trip from the FIRST office in early November. During this cross-country excursion, each team has been asked to send in some pictures of Tommy's visit. The pictures are pouring in!

Tommy has been to the Philadelphia Eagles, Indianapolis Colts, Seattle Seahawks, San Francisco 49ers, and many more! The office has even received the first box of team donations from all of the AFC West Teams! Hopefully, at the end of this campaign, we'll have pictures of Tommy and his new friends from all 32 NFL teams. Tommy is helping to generate nationwide awareness about ichthyosis and also creating excitement for the *2nd Annual Dane's Friends for FIRST Concert* to be held on *September 7, 2013*. Go Tommy!



Tommy tours Lucas Oil Stadium, the home of the Indianapolis Colts



The teams from the AFC North Division responded to our all



With Antonio Garay of the San Diego Chargers



Tommy poses with autographed photos from the teams of the AFC West Division.



With Seattle Seahawks John Moffitt and Russel Okung (above)

Tommy gets a lift from Philadelphia Eagles defensive end Vinny Curry (right)



Tommy has a great view from the shoulders of Seahawks strong safety Kam Chancellor (right)



Pro-Bowler Geno Atkins from the Cincinnati Bengals (right)



Jacoby Ford shows Tommy around the Oakland Raiders facility (above)



CAMPS 2013



CAMP DISCOVERY

The American Academy of Dermatology (AAD) is celebrating the 20th Anniversary of Camp Discovery with six weeks of camp in five states, providing an amazing camp experience to approximately 350 children each year.

There is no fee to attend. Full scholarships, including transportation, are provided by the AAD through generous donations from its members, outside organizations, and individuals. All campers must be referred by their dermatologist.

For more information about attending or volunteering, please visit www.campdiscovery.org or contact Janine Mueller at 847.240.1737 or jmueller@aad.org. The 2013 dates are listed below.

Little Pine, Crosslake, MN – ages 10-14, June 23-28

Camp Reflection, Carnation, WA – ages 8-16, June 24-28

Big Trout, Crosslake, MN – ages 14-16, July 7-12

Camp Horizon, Millville, PA – ages 8-13, August 10-17

Camp Dermadillo, Burton, TX – ages 9-15, August 11-16

Camp Liberty, Hebron, CT – ages 8-16, August 11-17



CAMP WONDER

Camp Arroyo, Livermore, CA - June 23-28

For information, contact Francine Tenconi via email at ftenconi@csdf.org or call 925.947.3825