



FIRST's offices have moved!

Our new address is:
 2616 N. Broad Street
 Colmar, PA 18915

Phone:
 (215) 997-9400

Fax:
 (215) 997-9403

Toll free (remains the same):
 (800) 545-3286

E-mail:
info@firstskinfoundation.org

Website:
www.firstskinfoundation.org

Frontiers in Ichthyosis Research Meeting

Two days prior to the family conference, FIRST hosted its first-ever scientific meeting of international experts in ichthyosis research at the Regal Sun Resort. The *Frontiers in Ichthyosis Research* meeting agenda combined reports of recent progress in a few cutting-edge areas of ichthyosis research and frank discussion about how to efficiently and effectively move research forward. To have this



most respected and knowledgeable group of investigators, interested clinicians, and representatives of FIRST together in one room for two days was simply awesome. The group identified new technologies and opportunities for research collaboration, and discussed new ways in which the investigators, patients, and patient support groups can achieve ongoing synergistic interactions for better patient care.

In addition to meeting with their peers the investigators also had opportunities to meet with affected patients, and learn from affected individuals about daily living with ichthyosis. Many of these scientists work in laboratories, so they have few chances to interact with affected patients. To quote one investigator, "It was profound."

The *Frontiers* meeting was funded by a grant from the National Institute of Arthritis, Musculoskeletal & Skin Diseases (NIAMS) and the Office of Rare Diseases Research (ORDR). A summary report will be published in industry journals and will be available on our website in the coming months.

Scaly skin and bath pH: Rediscovering Baking Soda

To the Editor: The republication in the newsletter of the Foundation for Ichthyosis and Related Skin Types (FIRST) of a translation, from German,¹ of a paper by Küster,² has prompted testimonials about the usefulness of bicarbonate baths for exfoliating scales from patients with ichthyosis. Küster² treated more than 300 patients who had ichthyosis and routinely recommended adding baking soda to the bath water. Having been professionally interested in ichthyosis for a number of years, I was stunned that this simple therapeutic suggestion was completely foreign to me. Quick consultations with colleagues both here and abroad revealed that none had heard of this remedy, and no modern texts make mention of baking soda for scale removal. An intellectually

INSIDE Ichthyosis Focus...

| | |
|-----------------------|-------|
| Regional Meetings | pg 2 |
| Free Aquaphor | pg 4 |
| Conference Highlights | pg 13 |

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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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Correspondence Corner

Dear FIRST,

I enjoyed reading the newest newsletter. Thank you so much for all the work you and your staff do in publishing that! It is truly appreciated!

I wanted to add one more thing to your fine tribute to Frances McHugh...

It was her letter to Ann Landers, published on March 30, 1992, that made me aware of FIRST and that there were actually other people who had ichthyosis. I was 42 years old at the time, and up until then, I thought I was the only one on the planet with ichthyosis. I will be eternally grateful that she published that letter.

Since then, I have met so many wonderful people who have ichthyosis as well as their wonderful relatives/friends who don't have it. And when I attended my first FIRST Family Conference, I found out about a cream that has dramatically cleared up my skin! (Aqua Glycolic Hand & Body Lotion.)

Anyway, I'm sorry I didn't get the chance to meet Frances in person. But her spirit lives on in all the people she touched.

Thanks again for all you and your staff do and keep up the great work!

In community,

Rich

2011 Regional Meetings Scheduled

One-day meetings to connect with members in your region.

SAVE THE DATE FOR YOUR REGION



REGION 2

April 30, 2011 ~ Virginia

Delaware, Maryland, West Virginia, Virginia, North Carolina, South Carolina

REGION 3

Date to be determined - Atlanta, GA

Tennessee, Georgia, Alabama, Mississippi, Florida, Louisiana, Arkansas



REGION 4

September 10, 2011 - Chicago, IL

Missouri, Illinois, Indiana, Ohio, Michigan, Kentucky



REGION 7

October 8, 2011 - Seattle, WA

Washington, Montana, Oregon, Idaho, Wyoming, Alaska



Ichthyosis Research Pioneers Honored at 2010 Testimonial Dinner

FIRST hosted a Testimonial Dinner on March 5, the eve of the AAD meeting in Miami, Florida. This year's honorees were Dr. Phillip Frost and Dr. Gerald Weinstein.

Drs. Frost and Weinstein were early pioneers in the field of ichthyosis. Because of their initial research focus on epidermal biology, they were important advocates for patients with skin diseases. Their efforts laid the building blocks for other investigators to make advances in the study of ichthyosis, which paved the way to find better treatments and eventual cures. Drs. Frost and Weinstein's efforts helped to improve the quality of life of our members, and FIRST is proud to honor and recognize their invaluable service to the ichthyosis community.

Held in the beautiful Starlight Room at the Miami Beach Resort, sixty-five people were in attendance to pay tribute to Drs. Frost and Weinstein. The evening featured poignant tributes by friends, colleagues, and patients of the researchers. The event was a tremendous success, raising \$90,000 for FIRST, its programs, and services.



Marjorie Locke, Phillip Frost, & Jean O'Brien



Gerry & Ellie Weinstein, Jean Pickford, Patricia and Phillip Frost

EDITOR'S CORRECTION

In the Annual Report of our Spring issue, the following errors were made:

Omitted from the report:

\$100-\$249

Sarah Geilen-Rosenberg

\$250-\$499

Mr. William Horton

Mr. & Mrs. Paul Licursi

\$500-\$999

Mr. & Mrs. Easton Smith

The following names appeared with typographical errors. Below is the correct listing.

Mr. & Mrs. Alex Howard

PJ Markwald Family Foundation

The Foundation sincerely appreciates all of our members and donors.

We apologize for these errors.



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ADVERTISEMENT

A new appointment for FIRST's Executive Director

Jean Pickford, FIRST Executive Director, was recently appointed to a position on the NIAMS (National Institute of Arthritis and Musculoskeletal Skin Diseases) Advisory Council. This council is comprised of scientific and lay members who have expertise in the mission areas of the Institute and provides advice to the Institute on broad policy issues as well as making recommendations on research proposals. The council meets quarterly and Jean's term will run until 2014.

The Foundation extends sincere congratulations to Jean on this very prestigious appointment.



NIAMS director Dr. Stephen Katz (front, r) and deputy director Dr. Robert Carter (back row, l) welcome new members to the institute's council. They include (back row, from l) Jean Pickford, Dr. Julio Vergara and Dr. Regis O'Keefe. Joining Katz in the front row is Bradley Stephenson. (Not pictured: Dr. Harry Dietz)

FIRST Scholarship Fund

FIRST Scholarship Fund Created

FIRST President, Dave Scholl, and his wife Valerie have very generously donated start-up funds for an educational scholarship program for affected individuals. Details will be posted in future issues and on our website, www.firstskinfoundation.org, in the coming months. Applications will be accepted beginning in January 2011.

The Foundation extends its sincerest thanks to the Scholl's for this very generous donation. The goal for this fund is that others will add to the contribution so that more individuals may benefit.

Does your family use large quantities of Aquaphor?

If so, you can ask your doctor to send a letter on his/her letterhead with your contact information, diagnosis, treatment regimen, and how much Aquaphor you use. You will be sent a case of Aquaphor – **FREE!** The letter from your doctor needs to be faxed to 203.563.5630. You can send in a new request every 3 months.

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HEALING OINTMENT

obligatory—but alas increasingly less frequent—trip into the stacks of the local library revealed that texts from 100 years ago routinely did recommend baking soda baths.^{3,4} Quietly and without explanation, those recommendations vanished from textbooks 70 to 80 years ago. So what are we to think? Is baking soda in the bath good, bad, or useless? A review of the existing data provides some clues.

Water facilitates scale removal, and we all hear reports from patients suggesting that the source of the water matters. Many patients who have ichthyosis report that their skin looks and feels better after a week at the seashore. Patients rarely voice such praise for lake water. Most dermatologists assume it is the salt. Could it be the pH? Two handfuls of baking soda (Küster's recipe) raises the pH from 5.5 to 7.9 in a tub half-filled with tap water drawn from Hamden, CT. According to the US Geological Survey (http://ga.water.usgs.gov/edu/ph_diagram.html), most "fresh" water has a pH of around 5.0. In striking contrast, ocean water usually has a pH above 8.1.

Do dermatologists have a bias against alkaline pH? Eighty years ago, Schade and Marchionini⁵ reported that the stratum corneum of epidermis is slightly acidic. Since then, this "acid mantle" has intrigued skin biologists as to its origin, its purpose, and its role in disease.⁶ We have therapeutic and cosmetic uses for weak organic acids. By contrast, we warn that strong alkalis, such as ammonia and lye, are caustic to skin. Most soaps contain lye and have pH above 9.5. Dove soap, the best-selling soap worldwide, was introduced in 1957 and widely marketed—and then recommended by dermatologists—as the first pH-neutral bar soap.

We may have to rethink our opposition to alkaline pH in specific situations. Normal desquamation requires enzymatic dissolution of desmosomes, and several of the serine proteases involved in desmosome degradation have alkaline pH optima.⁷ Topical application of superbases raises the pH and increases the amount of stratum corneum, which can be mechanically removed by tape stripping.⁸

Are there risks to alkalization? I can find no data indicating that exposure to the mildly alkaline nature of dissolved sodium bicarbonate is either irritating or harmful. Moreover, long immersion in sea water at pH 8.1 is generally not irritating, some natural spring water spas have alkaline pH, and distributors of some home "spas" recommend alkalizing the water.

Normal stratum corneum has evolved to have a particular thickness so that it can perform its protective functions and still renew itself on a regular basis. Many disorders in which the stratum corneum is thickened represent a quantitative response (increased thickness) to a qualitative defect (abnormal function). We must be careful that our attempts to normalize the thickness do not exacerbate the functional defect(s). In patients with excessive scaling, periodic (1-3 times per week) exposure to lengthy (approximately 30-60 minutes) immersion in water at pH 8 followed by application of bland emollient is likely to be safe and, for some, may be justified in order to facilitate removal of scale and improve comfort and cosmesis.

Leonard M. Milstone, MD

Department of Dermatology, Yale University School of Medicine, New Haven, Connecticut

Funding sources: None. Conflicts of interest: None declared.

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doi:10.1016/j.jaad.2009.04.011

In Memoriam

Georg'Ellen Davis (Forbus) Betts

February 23, 1928 – June 6, 2010

FIRST regrettably announces the passing of Georg'Ellen Betts, a long-time member, and former treasurer of the Foundation. Georg'Ellen is the mother of long-time first member, and former Board President, Ellen (Rowe) Clemmer.

The daughter of Elizabeth Knox Burger and Wiley Davis Forbus, M.D., Mrs. Betts was born in Baltimore, Maryland. She grew up in Durham, North Carolina, but was a resident of Raleigh, North Carolina for more than 50 years. She touched many lives as a community volunteer and an advocate for people in need.

Georg'Ellen began her career in advocacy after her graduation from Duke University with a degree in sociology in 1949. She received many awards for her volunteer and advocacy efforts.

Georg'Ellen and her husband Wilmer had 4 children, three of whom are affected with ichthyosis. Georgie, as she was affectionately known, and Wilmer raised all of their children to be very confident adults and recognize that it is a person's character that is important.



The Betts siblings as children

Mrs. Betts began her involvement with FIRST in 1991. She jumped in and helped in the office in Raleigh before being elected treasurer, a position she held until 1994.

The Betts family generously included FIRST as a recipient of donations in Georg'Ellen's memory.



Awareness All Year-Round

Pittsburgh resident Hunter Steinitz has been very busy lately!



Hunter with her proclamation

In June, the National Geographic Channel aired a special, featuring Hunter, titled "Extraordinary Humans: Skin." The episode was very well done and did a great job of describing ichthyosis and what life is like for those affected. It also featured FIRST Medical and Scientific Advisory Board member Dr. Philip Fleckman from the University of Washington in Seattle. Dr. Fleckman described what happens to ichthyotic skin and current research being explored to find better treatments or a cure.

In conjunction with this television episode, The Pittsburgh Post Gazette, featured Hunter in several articles prior to and following the airing of this episode. Pittsburgh City Council President, Darlene Harris read one of the articles about Hunter in the paper and was moved to invite Hunter to Pittsburgh City Council to receive a proclamation. Pittsburgh declared Tuesday, July 20, 2010 Hunter Steinitz day. Quite an honor indeed!



Friends and family gathered for Hunter's big day



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Jane Bukaty Membership Assistance Fund

FIRST recognizes that living with ichthyosis is not only a medical issue, but a financial one as well. Maintaining the daily regimen of treatments required can become very expensive. Many insurance companies will not provide coverage for the many creams and lotions required to maintain a patient's skin.

This is your opportunity to receive financial assistance for your ichthyosis treatment.

Since the fund is limited, the following criteria must be met by the applicant in order to be eligible for MAF aid:

- The applicant must be a member of FIRST.
- The applicant is required to submit a letter indicating his/her need for funding.
- The letter must include the amount of funding requested, the specific product/treatment for which funds are required, and a demonstration of the financial need for this product/treatment.

Awards will generally not exceed \$200.00. Applications will be awarded two times per year. Applicants will be eligible to receive one award every two years.

Applications are currently being accepted, with grants being awarded in December. Applications are available by contacting the national office at 800.545.3286 or info@firstskinfoundation.org. Once completed, the application requests can be emailed to the national office or mailed to the attention of the Jane Bukaty Membership Assistance Fund at: 2616 N. Broad Street, Colmar, PA 18915.

Donate through the United Way or Combined Federal Campaign Programs

Donating to the Foundation through the United Way or Combined Federal Campaign is an easy and convenient way to support the important work of the Foundation.

A small deduction of \$5.00 per paycheck can add up to over \$200 per year for the Foundation. It's simple, convenient, and can really make a difference.

The United Way of America is the national organization dedicated to leading the United Way movement in making a measurable impact in every community across America. The United Way movement includes approximately 1,400 community-based United Way organizations. Each is independent, separately incorporated, and governed by local volunteers. The Foundation for Ichthyosis is the recipient of funds from many of the United Way community-based organizations. Through the Donor Choice Program, you can designate all or a portion of your donation to the Foundation. Simply write in "Foundation for Ichthyosis & Related Skin Types" on

the Donor Choice Option form, and your gift will be sent to our office. Be sure to include our mailing address and phone number, 2616 N. Broad Street, Colmar, PA 18915, 215-997-9400. Our federal tax identification number is 94-2738019.

The Combined Federal Campaign (CFC) is the annual fund-raising drive conducted by federal employees in their workplace each fall. Federal employees and military personnel raise millions of dollars each year through the CFC to benefit thousands of non-profit charities. The Foundation is the recipient of funds from many CFC organizations throughout the country. The Foundation's CFC code is 10322, which is listed in the charitable organizations directory.

Contact your Human Resources Department to find out how you can support the Foundation using United Way or Combined Federal Campaign.



Executive Director's Report



Dear Members and Friends of FIRST,

The past three months have been very eventful and exciting for FIRST. Between the launching of our new website, our first-ever international scientific meeting, the national family conference, and moving the office, we all have been very busy educating, inspiring and connecting!

As you will see on pages 13 - 15, this year's National Family Conference was amazing! Four hundred and three people attended, making it the most attended conference in our history. Members came from as far away as Nigeria and Saudi Arabia. Many attendees rekindled former friendships while even more members made new friends. Special connections were forged and many of these families vowed to reconnect again next year at our smaller, regional meetings (see page 2).

Special thanks to the Vaseline® Skin Fund for generously donating \$50,000 to sponsor 23 families to attend the conference. Fourteen of these families have never attended a conference before. For some, it was life – changing to meet other affected individuals and families for the first time. FIRST is very grateful to all the conference sponsors (see page 14) for their generous support. Their generosity enabled FIRST to keep registration fees affordable.

In addition to the educational workshops and networking opportunities, the conference attendees enjoyed a visit from Mickey Mouse and Cinderella, celebrating the spirit of DisneyWorld. The smiles on the faces of the children were incredible! The smiles on their parents' faces were just as inspiring. Also included in the program were recognition awards presented by Dave Scholl, president of FIRST. Dave recognized many volunteers for their outstanding accomplishments over the past two years in raising awareness and funds for FIRST. Congratulations to all!

Every two years as I plan and attend these family conferences, I reflect on the impact of how these events affect those who attend. So many individuals personally come up to me with words of thanks and gratitude. For a few short days, everyone is part of a large extended family. You may pass someone in the hallway and say hello. Before you know it, you're talking for fifteen minutes with each other and have become instant friends. Everyone shares the common bond of ichthyosis. It is hard to put into words how the energy and togetherness makes you feel when you attend a conference. I can only hope that every affected person and their family will have an opportunity to attend a conference in their lifetime.

As we were organizing the family conference and the *Frontiers in Ichthyosis Research* Meeting, we were also working hard behind-the-scenes to create our new website for its "official debut" at the family conference. Brian See, board member and website chairperson, along with Lisa Breuning, Public Relations Coordinator, in the national office, and Joe DeMicco at Accurate Imaging, Inc. (AIMG), gathered forces and created the new site. All information was migrated over from the old site and new information was added. The layout and navigation is much more user-friendly. Congratulations and thank you to the Brian, Lisa, Joe, and the committee for all their hard work!

Two weeks after our conferences ended in Orlando, we moved our national headquarters to 2616 N. Broad Street, in Colmar, PA. After four years in our North Wales office, our landlord was raising our rent. We took some time to look around in the area and found a larger, more professional space for the same rent. Our new office has a lot of room for growth, so we should be staying put for many more years to come!

As I look toward the next few months, my focus will be setting our goals for fiscal year 2011, both financially and programmatically. Please continue to donate to FIRST and think of us often with your generosity. And, as always, contact me or someone in the office if you have anything you'd like to share or ask. We are here to help you.

Best wishes.

Sincerely yours,
Jean R. Pickford
Executive Director

Now is the time to begin planning your awareness campaign

Ichthyosis Awareness Week

October 3 - 10, 2010

One week out of each year, members and volunteers host awareness campaigns and fund raising activities to benefit FIRST and educate the public about ichthyosis. This year, Ichthyosis Awareness Week will be formally celebrated October 3—10, 2010, although, ichthyosis awareness can take place at any time during the year. Educating your local community is very important as it can make day-to-day life much easier for those affected. The simple knowledge that ichthyosis is a genetic skin disease and not contagious, a bad sunburn, or the result of poor bathing habits, can help the public understand the disease and its symptoms.

The possibilities are endless ... Events can take any form, from a car wash, to a bake sale, to a golf tournament. One of the easiest ways to spread the word in your community is to do an interview for your local newspaper. Share your personal story with them.

Another option is to hold a grassroots fundraising event. Grassroots events offer not only the opportunity to increase awareness, but also raise funds for FIRST. FIRST has a complete Grassroots Fundraising Guide available to assist you with your event. It provides step-by-step information in planning and organizing your event. The Grassroots Fundraising Guide is available free of charge to anyone who requests it.

Please contact the national office at (800) 545-3286 or e-mail development director, Greg Wilson, at gwilson@firstskinfoundation.org to receive this useful tool.



Fundraising Ideas:



- Auction • Bingo • Book Sale • Bake Sale
- Candy Sale • Car Wash • Dance
- Donations in lieu of birthday/anniversary gifts
- Submit a personal story to local newspaper, radio, or TV stations
- Dress Down Day at work or school • Garage Sale
- Golf Tournament • Halloween Costume Contest
- Raffle • Skate-a-thon • Walk-a-thon



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. If you are interested in hosting your own grassroots event, contact Greg Wilson, Development Director.

Atlanta holds “Find a Cure” event

Foundation Board member Mike Briggs, grandfather of 8-year-old Adam who is affected with EHK, called on his friends and family to join him to help find a cure for ichthyosis.

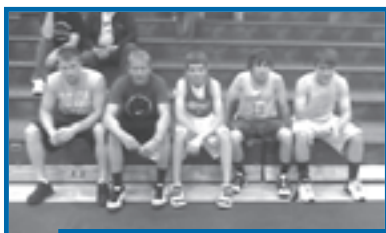
Mike partnered with Ron Wallace, co-owner of The Olde Blind Dog Irish Pub in Milton, Georgia, to create this fun-and friend-filled evening.

Friends and family answered the call on Thursday evening, April 8. Forty people joined Mike for great food and socializing. Mike’s son-in-law and Adam’s father, Mark Klafter, provided the participants with an update on important research being conducted on EHK in Colorado by Dennis Roop, PhD.

More than \$10,000 was raised during this terrific evening. FIRST is very appreciative to Mike, Ron, and all of the participants for their generosity.



Ron Wallace and Mike Briggs enjoy the evening



*Top: JR and his teammates
Bottom: Danielle with her team*

Basketball Tournament Another Success!

J.R. Drouhard and his sister Danielle, along with their mother, Jill Kimple, held their annual basketball tournament. It was another great success! This year’s event was hosted at Newman University in Wichita, KS, where Danielle attends as a graphic design major. She marketed the event on the campus website and developed a facebook event page advertising the tournament. Newman University added an article about the event in their newspaper. This really created awareness throughout the campus about ichthyosis and FIRST.

Participants paid \$15 each to play and received a t-shirt that was designed by Danielle. The winning team received movie tickets to a local theater. Each year this basketball tournament grows. Plans are beginning for another year at Newman University.

More than \$500 was raised at this great tournament.

The Foundation is very appreciative to the Drouhard family and Newman University for their efforts.

Penn Wynne Elementary School Walk-a-thon

The students at Penn Wynne Elementary school have sponsored a walk-a-thon each year for the past 20 years in memory of former student Jimmy Sullivan. This year, the students chose FIRST as the recipient of the funds they raised with this event. Laurie Anne Fiore and her husband, Daniel, have 2 daughters who attend the school, and 2 pre-school age children, Joseph and Faith affected with CIE.

The children walked the property around their school, located in Wynnewood, PA and raised more than \$4,000. Recently, FIRST Development Director Greg Wilson, visited the school where he was presented with the proceeds from the days efforts.

This event is the perfect example of how a grassroots fundraiser can make a difference.



Greg visits Penn Wynne Elementary

EDITOR’S NOTE:

In the article printed about Madison Hoffman’s Barbeque in our last issue, we mistakenly printed that Emily and Jeremy Hoffman didn’t know about ichthyosis. Emily Hoffman is actually affected with EHK and has been a long-time member of FIRST. We apologize for the error.

Community Yard Sale Benefits FIRST!

Foundation members Derek and Jennifer Hotchkiss recently moved into the Bucks County area. The family has been warmly welcomed by a wonderful community of friends and neighbors. Every year, the residents of the Mountain View neighborhood in Warwick Township hold a community-wide yard sale. The participating families designate an organization to which to donate their proceeds. This year, after meeting Jennifer and her 4 year old daughter, Grace, who is affected with Lamellar Ichthyosis, the yard sale organizers decided that the proceeds of this yard sale be donated to FIRST.



Grace Hotchkiss

The sale was a tremendous success raising almost \$1,400 for FIRST!

Even the youngest participated. Grace and her sister Claire had a lemonade stand at the sale and raised money on their own.

FIRST is very grateful to the Hotchkiss Family and the Mountain View neighbors for their generosity.



Marley Roberts

Roberts Fishing Rodeo

Nine year old Marley Roberts, with help from his grandparents, Hank and Janice Roberts and Sonny and Peggy McBride, organized a fun-filled fishing tournament to help raise money for FIRST and awareness about ichthyosis.

The 1st Annual Marley Roberts Fishing Rodeo was held at the Harbor Landing Yacht Club in Ocean Springs Harbor, Mississippi on June 19th. More than 60 children participated in the event, where 1st, 2nd, and 3rd place prizes were awarded in seven different categories. One youngster caught a 28 pound black drum. What a fish! There was also a "strangest fish" category which had many unusual entries.

This was a fantastic day for all participants and a great way to help FIRST.

In addition to the event, local TV station WLOX interviewed Marley and aired a story about him and the event. If you would like to view the video, you can go to the FIRST website and click on the article about Marley. There is a link to the video in the article.

A very sincere thank you to the McBride and Roberts families for all of your efforts.

Shamrock Shuffle

Erin Egesdal, sister of Shauna Egesdal who is affected with EHK, is the Executive Director of Outdoor Sports Events, LLC (OSE). OSE, along with Paul Horan, co-owner of *Gear Running Store* in Edina, MN, and *All Sport*, sponsored a 5K race and a portion of the proceeds were donated to FIRST.

Coinciding with St. Patrick's Day, the **Shamrock Shuffle 5K** was held on **Saturday, March 13, 2010** at Chanhassen High School in Chanhassen, MN.

More than 370 people came out on a cloudy, windy, 35 degree day to participate in the race. Author *Terry Hitchcock* was on hand as the honorary starter of the race, and also donated signed copies of his book, "A Father's Odyssey: 75 Marathons in 75 Days," to each of the age-group winners.

FIRST appreciates the efforts of Erin and the event sponsors on our behalf.



Participants line up to start the race.



Erin Egesdal and Terry Hitchcock

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.

A Crafty Idea to Raise Money

FIRST member Sarah Hodgkinson is an avid scrapbooker and very good at crafts. Since her family was not able to attend this year's conference because school was still in session in her area, she came up with an idea to be there "in spirit". Sarah, along with some help from her family and good friends, designed an "Ichthyosis Awareness Bookmark." She designed it and then set out creating them for FIRST to sell at our kiosk at the Family Conference. Sarah and her team worked marathon hours over the course of a weekend putting together the bookmarks. She then shipped them to Orlando where they were available for purchase for \$2 each or 3 for \$5. All of the proceeds from the sale of the bookmarks have been donated directly to FIRST. The bookmarks were very well received at the conference. There are still some available for sale at the FIRST office. If you are interested in making a donation to receive a bookmark, you may call the office at 800.545.3286.



Burger Bash During the Indy 500

A FIRST member partnered with an old friend during race week at the Indianapolis 500. A friend of his who works at the Indianapolis Star approached our member about participating in a fundraising event that would benefit multiple charities. They hosted the "96th Street Burger Bash," which was a festival of food and games taking place during Race Week in Indianapolis. The event was a tremendous success for several charities, including FIRST. The Burger Bash raised \$1,500 for the Foundation. Our sincere thanks to our member and friend for their work on our behalf.

Young Students Join Together ...

Students at Valley Christian Elementary School in San Jose, California were given a unique opportunity. A member of their community donated \$10 to several students at the school. The 12 students were charged with selecting a worthy recipient of their money. They pooled their money and decided to donate it to FIRST.

The group was spearheaded by Chandler Phelps, who attends the school, along with her brother, Cade. Chandler and Cade are the siblings of Dane Christian Phelps, who passed away 2 years ago at the age of 3 ½ years. Dane had a very rare, unknown type of ichthyosis, which had never been officially diagnosed. Their parents, Eric and Suzanne, have been instrumental in helping FIRST apply for funding from the Lennox Family Foundation, grants from which funded the following initiatives; the tele-ichthyosis website and FIRST's Marketing plan.

Another group of youngsters was also active on behalf of FIRST. Darcie Kuzik, mother of 3 sons affected with X-linked Ichthyosis, runs *Kuzik Family Child Care* out of her home in Virginia. Her 9 students, ages 7 months to 5 years, held a lemonade stand for 1 ½ hours and raised \$72 for FIRST.



Darcie helps her students sell lemonade

The 2010 FIRST National Family Conference

The 2010 FIRST National Family Conference was recently held in Orlando, Florida. As expected, this was the best attended and most exciting conference to date!

Over 400 registrants gathered in Orlando to be a part of this fantastic event. Thanks to the sponsorship of the Vaseline Skin Fund®, 14 families attended the conference for the very first time. It was so heart-warming to see affected children meet other children with the same skin condition for the first time.

The conference weekend kicked off with a pre-conference meeting



of ichthyosis researchers from around the world. Leading experts in ichthyosis research met to identify new opportunities for research collaboration.

On Friday morning, before kicking off, first-time participants had the opportunity to gather together and gain information from veteran conference attendees about how to make the most of their conference experience.

During the opening program, everyone participated in ice-breaker activities to get to know one another. This paved the way for strong friendships to be formed over the course of the weekend.

Child care was provided so that parents could attend the workshops and gain as much knowledge as possible. The children had a great time playing games. The older teens participated in a trip to Disney Quest on Saturday afternoon.

At the very beginning of the Child Care Camp, FIRST member Merritt Andrews arranged for a baby alligator from Gatorland to be brought to the conference. Merritt explained that many times children with ichthyosis are called "alligator skin" in addition to other cruel names. She wanted to

give the children an opportunity to touch an alligator. Its skin is actually smooth! This will arm the children with clever retorts when faced with name-calling.



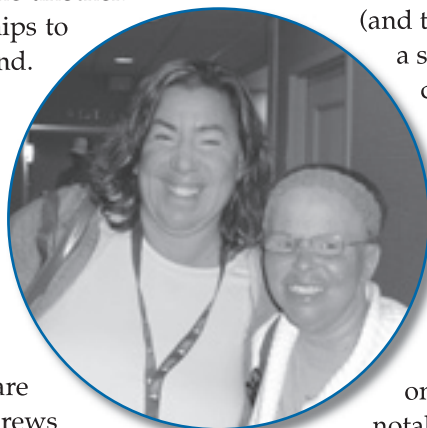
The weekend featured a broad array of workshops designed to help affected families with school issues, doctor/patient concerns, and skin care ideas. Break-outs for moms, dads, affected adults, spouses, and young adults are always a popular feature at the conference and provide individuals the opportunity to share encouragement and concerns with their peers.

Of course, the highlight of the conference is the Saturday night dinner dance, and this year was no exception. The excitement began with visits from Mickey Mouse and Cinderella, to the delight of every child, and some of the adults, in attendance. The 2nd Annual FIRST Idols Revue was a tremendous success with great performances by our aspiring singers and dancers.

This year's raffle, chaired once again by Jennifer See, was very successful and participants were excited to hear their names called when they won a prize.

FIRST President Dave Scholl presented the "Volunteer of the Year" awards. The 2008/2009 Volunteer of the Year award was presented to Jennifer See for the tremendous job with 2008 Family Conference Raffle (and this year's raffle as well), coordinating a scrapbooking fundraiser, initiating and chairing the new Ambassador program, and being our "eyes and ears" on the internet, spreading the word about FIRST's services.

The 2009/2010 Volunteer of the Year was Jolie Cina for her efforts hosting a wine tasting party, facilitating the "Pancakes for Santa" fundraiser, serving on the Marketing Committee, and most notably, connecting with Senator Richard Codey from New Jersey. Her connection with Senator Codey facilitated legislation in the New Jersey legislature seeking additional funding for ichthyosis research.





Dave also presented the Frances Bernsteil Award recognizing outstanding efforts in Grassroots Fundraising.

Josh and Amie Jo DeGarmo were recognized for the golf tournament that they have organized for the past 4 years. People in their community of Napa know all about ichthyosis because of the DeGarmos events which have raised more than \$40,000 for FIRST.

Shelly and Lucas Trojanowski, while not present at the conference, were recognized with the Frances Bernsteil Award for their fund raising campaign mailing letters to family and friends, e-mailing friends and business associates, and cooking a lunch at their local deli called "Lunch for Lucas." Their campaign raised over \$5,000 for FIRST for Lamellar/CIE research.

After the awards, the dance party was in full swing. With a fantastic DJ, adults and children alike danced long into the night.

After lunch on Sunday, some participants reluctantly parted ways, while others stayed on to enjoy the



Disney World attractions. Whether going home on Sunday or staying a while longer, everyone left the conference armed with information, lotion samples, and life-long friendships and memories to take with them.

So much information, so many ideas, friends, and fun.

Every year this experience changes my views on life and makes me a more positive and comfortable person.

Thank you to our 2010 Family Conference Sponsors!



A very special thanks to the Vaseline Skin Fund for providing the funds to offer conference scholarships for families to attend this year and for underwriting a majority of the cost of every child.

Thank you to the following companies that donated samples for our conference.

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EDIE WOHLGANG





CHECK OUT FIRST'S NEW WEBSITE!



As part of the 4-year strategic plan, the Foundation developed a new website. For the past 6 months, the Website Committee, chaired by board member Brian See, met via bi-weekly teleconference to design and implement FIRST's new website. Working with Accurate Imaging (AIMG), who has been donating their services to host FIRST's website for the past 10 years, the committee formulated design and implementation plans to improve our internet visibility.

The website has been designed with a fresh new look and feel, and all FIRST publications are easily available and downloadable. It is now much easier to navigate and find information. **Please check out the new site with our new URL www.firstskinfoundation.org.**