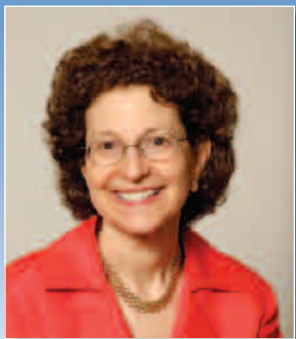


## Testimonial Dinner Planned

to Honor Long-time,  
Renowned Member of  
FIRST's Medical & Scientific  
Advisory Board

*Dr. Amy Paller* is the Walter J. Hamlin Professor and Chair of Dermatology and Professor of Pediatrics at Northwestern University's Feinberg School of Medicine. She has served on the *Board of Directors of FIRST* for nine years and is now an emeritus member. Additionally, she serves as a member of the Foundation's *Medical & Scientific Advisory Board*. FIRST is extremely proud to announce that Dr. Paller, a long-time supporter of FIRST's activities and a renowned researcher and clinician, will be honored by FIRST at our 8th Annual Testimonial Dinner on **Friday evening, July 12**, at the University Club in downtown Milwaukee, Wisconsin.

Details about the evening will be posted on our website as the date approaches.



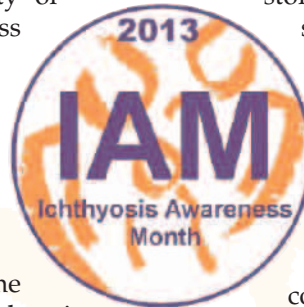
*Dr. Amy Paller*

## INSIDE Ichthyosis Focus...

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## Ichthyosis Awareness Month

It's spring and time to think about Ichthyosis Awareness Month, celebrated each year in May. Members and friends of FIRST from across the nation plan and participate in a wide variety of events to create awareness about ichthyosis in their community and to raise funds for FIRST. These events can be anything from placing a jar for collecting coins in local businesses, to hosting a golf tournament, and anything in between. The most important part of Ichthyosis Awareness Month is the awareness. You can simply pass out FIRST brochures to members of your community to educate them about ichthyosis and FIRST or you can contact your local newspaper, tell them your story, and ask them to write an article. Be creative and have fun!



In celebration of Ichthyosis Awareness Month, FIRST will once again feature our members and friends in an email and online campaign to share their stories. If you would like to share your story with the ichthyosis community, please contact Lisa at [lbreuning@firstskinfoundation.org](mailto:lbreuning@firstskinfoundation.org), and she will be happy to help you.

If you are planning a fundraising event, please contact Chris at the national office at [Cwassel@firstskinfoundation.org](mailto:Cwassel@firstskinfoundation.org), and she will help you with information and supplies that you may need for your event. If you think you might like to host an event, but are not sure what type of event, you can also reach out to us for help at 215.997.9400.

## Spotlight On... Stephanie Turner

At 19 years old, my mom went to the hospital because she was leaking amniotic fluid. She was told it wasn't amniotic fluid and that I was just sitting on her bladder so it was normal. She knew something wasn't right. A day later, she went into labor and I was born 4 weeks early on March 19, 1993. Everyone expected a healthy baby. She had had two ultrasounds and they both came back great, showing no complications at all!

As soon as I was born, the doctor called other doctors to the hospital STAT. I was rushed to an incubator before my mom even got to see me. She was wheeled to a nearby room where a nurse entered with a medical encyclopedia and let my mom read the ONE and only paragraph that mentioned anything about Harlequin ichthyosis. Luckily, medicine has come a long way in twenty years, and there's much more information than there was at that time. After the nurse left, a counselor entered the room to "prepare" my mom for my death, since everyone was saying there was no chance of survival for me. My mom was told repeatedly that I wouldn't make it past a few minutes due to a number of things, including: infection, dehydration, and breathing problems since my skin was so tight and it severely restricted my chest. Simple answer, I wasn't going to live because babies born with this skin disorder just didn't live.



*Continued on page 2*

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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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## Rare Disease Day Celebrations



*Faith and Joseph Fiore*

FIRST is an active participant in Rare Disease Day annual activities. As a Rare Disease Day partner, FIRST joins hundreds of other patient organizations, government agencies, and medical societies in focusing attention on rare diseases. Celebrated on February 28 during non-leap years, and on February 29 during leap years, members of FIRST organize activities to draw attention to ichthyosis and all rare diseases.

This year, FIRST member **Laurie Ann Fiore**, of Wynnewood, Pennsylvania planned a "Wear That You Care" campaign at her children's elementary school, Penn Wynne Elementary. Students and staff wore jeans or blue to show their support of Rare Disease Day. Laurie also made awareness ribbons for participants to wear for the day. The Fiore children, **Joseph** and **Faith**, are both affected with congenital ichthyosiform erythroderma (CIE). In this digital age, word of Laurie's efforts spread, and she has people participating from 14 states across the country! She also asked participants to support FIRST with a donation. Laurie's efforts raised awareness about Rare Diseases and more than \$350 for FIRST.

In Cumming, Georgia, FIRST member **Sam Zavitz** asked her daughter **Cate's** school, Kelly Mill Elementary, to support Rare Disease Day. Usually reserved for Fridays, teachers at the school were encouraged to wear jeans on Thursday February 28th in celebration of Rare Disease Day. The school principal Ron McAllister said, "Certainly we can do this! Thanks for bringing it to our attention." Teachers and students spent the day wearing jeans and denim awareness ribbons to call attention to the many people fighting rare diseases, many of them genetic. Cate is affected with lamellar ichthyosis, an autosomal recessive congenital, form of ichthyosis.



A rare disease is one that affects fewer than 200,000 Americans; there are nearly 7,000 of these diseases.

*Cate, center, with her teachers, showing off their Jeans for Genes.*

### Spotlight On...Stephanie Turner *Continued from page 1*

My mom just knew I'd be okay. She kept asking the nurse each time she came in, "Is she still alive? How is she?" Each time the nurse would reply, "Yes, she's still alive but don't expect her to be much longer. Babies born with Harlequin ichthyosis just don't make it." Eventually, my mom pointed out to the nurse that I wasn't expected to live past a few minutes; now it's been over night and I'm still alive. My mom never has been one to give up, thank God.

A month after I was born, my mom brought me home, April 27, 1993! She kept me wrapped in bandages because I had deep fissures. She needed to keep a Vaseline-type of lotion on me, (Aquaphor®) and it would protect me a little more from infections. She had to

change the bandages multiple times a day. Weeks went by, and I was steadily progressing and the bandages came off! I looked like a baby instead of a little mummy.

A lot of care went into taking care of me; eye care, skin care, cleaning out ears, etc. God definitely pairs kids and parents together for a reason; no ordinary woman could deal with the stress or responsibility of taking such great care of a Harlequin-affected baby. Especially not at 19 years old! My mom and my grandparents have done a fantastic job.

With the exception of a few hospital trips due to skin infections, I was just like any other child starting

*Continued on page 4*

# Correspondence Corner



Hi All!

I wanted to share some insights. When my daughter Anna (age 30) and I attended the summer meeting in Atlanta in 2011, we were greatly encouraged by everyone there. We tried new products, but this is what we have settled upon.

While at that meeting, we came to realize that Anna has a much milder case of EI (formerly called EHK). She now regularly applies Vaseline Intensive Rescue Repairing Moisture Lotion, fragrance free. She bathes, scrubs with a pumice stone, and then puts on the lotion. Her skin is clear and incredibly soft! I am having trouble finding the wonderful pumice stone that we always used. I would love to hear of suggestions from our FIRST family.

I had been experiencing severe itching and allergic reactions to the above-mentioned lotion when treating my skin.

I have realized that I do have confirmed sensitivities/allergies to the following: corn, peanuts, soy (these products are literally IN everything), and chlorine. Whenever I eat the following products, I break out in itchy bumps and my skin becomes very splotchy. The chlorine is another story.

We love going to the beach, but on one of those trips, I began itching horribly. The itching seemed to calm down when we returned home. Five years ago, we moved to a nearby town; the itching became year round. I went to several doctors: dermatologists, internists, allergists, and gynecologist during that time, and no one could help. I went to the meeting in Atlanta searching for an answer. Whenever I tried the recommended chlorine bath, I realized that solution was not for me. After doing some research on my own, I finally realized I was allergic to the chlorine in my water. I decided to try a filtered showerhead that removed the chlorine (Sprite at Lowe's) and I couldn't believe the difference! My skin was incredibly smooth and the itching was greatly reduced. We considered a whole house water treatment system, but then I stumbled onto another piece of information: Vitamin C is a natural water de-chlorinator! Simply run the bath water, crush 2 tabs of 1000 mg of Vitamin C and sprinkle in the water. I have been doing this for several months: my skin is smooth and soft, and my bank account hasn't suffered.

Realizing that there is much MIS-information out there, I found items #1 & #2 to be the most convincing and items #3 & #4 to be quite interesting:

1. The Journal of Orthomolecular Medicine Vol. 15, 2nd Quarter 2000 The Negative Health Effects of Chlorine, Joseph G. Hattersley
2. Using Vitamin C To Neutralize Chlorine in Water Systems by Brenda Land, Sanitary Engineer, Project Leader. Electronic copies of SDTDC's publications are available on the Internet at: [www.fs.fed.us/eng/pubs/](http://www.fs.fed.us/eng/pubs/) (taken from Recreation Management Tech Tips)
3. Healthy Child Healthy World (search chlorine in Chemical encyclopedia)
4. Retrieved from [www.greenoptions.com/t/2058/disposable-sanitary-pads-a-silent-health-threat](http://www.greenoptions.com/t/2058/disposable-sanitary-pads-a-silent-health-threat) (This may seem a bit "odd", but it has some information regarding chlorine in sanitary pads & toilet paper)

*Continued on page 14*



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kindergarten at 5 years old. I went to a very small public school (my whole town is small) and made fantastic friends that remained right up until 12th grade! I went out at recess, played in the gym, and was a kick-ball professional... at least I was in my head. I did have to rest a little more than the other kids, and I had to stay in the classroom and play inside when it was too hot outside.

From 3rd through 7th grade I was homecoming maid. I was also a cheerleader for four years, in girl scouts, and was even in ballet for a whopping 2 weeks! My dance career didn't last long because I was a momma's girl and didn't want her to leave me there by myself, but they wouldn't let her stay!

In junior high and high school, everyone knew me. After all, I was the only red cheerleader on the field (haha!) I never had a problem with bullies. High school drama, yes, but not bullies. Just typical boy drama and drama with friends. No one ever really treated me any different. I had my first boyfriend at 14 years old. We went on a date to a pizza place and a movie. Double dates with your parents at 14 weren't the coolest thing, but now that I look back, I'm glad it happened.

After high school, I met the man of my dreams! He had the cutest dimples and big brown eyes. Immediately he shocked me with how sweet he was and how much of a gentleman he was. He even laughed at my corny jokes! We started dating and three months later we were married. When you know God has let you come face-to-face with the man that you were meant to spend the rest of your life with, why wait? We were young, crazy, but completely in love!

Soon after we married, we got a little puppy, an apartment, and moved an hour away from our family to be closer to my husband's job. It wasn't easy being away from my family, since my mom and I are best friends, but we still made a point to see each other whenever we could.

We had everything a young married couple needed; a place of our own, a puppy, love, and a flat screen TV. I mean, what else did we need? A BABY! We eventually started discussing kids and whether it was even safe for me to have a baby since I have this skin disorder. Of course, there was no way of knowing, since I'm the oldest girl in America with Harlequin ichthyosis. No one else has ever been pregnant according to doctors. We talked about it millions of times; prayed about it constantly. We talked to our families, friends, doctors, each other, but mainly to God. We decided we were going to go for it! I've never let my skin hold me back. I've proven statistics wrong my entire life with the help of God, Momma, and doctors. I told my husband this and he agreed. If I felt that strongly about it and knew the risks, and were willing to take them, then he'd be behind me every step of the way. After all, he wanted to be a daddy too.

We began to pray every night that God would let whatever He wanted to happen, happen; whether that

meant getting pregnant or adopting. Within the first month I had missed my period! I was so nervous because before we tried getting pregnant, we had been irresponsible before and we had a pregnancy scare but then a few days later I started my period.

Even though we weren't trying then I still couldn't help but get a little excited. This time, I realized I missed it; so after I was a week late, I took a test and told only my momma. It came back POSITIVE. All seven of them did, haha! Curt and I were both overwhelmed with excitement, crying like crazy, kissing, and hugging.

Months later we found out our little angel is going to be a BOY! His name will be William Curtis Drake Turner. I go to a high risk obstetrician because everyone thought I'd have to have special care. I've eaten more (I ate a lot before...mainly because I'm a pig!). I apply lotion after my morning bath and most nights I apply Baby Oil Gel. I go to the doctor just as regular as every other pregnant woman. I did lose two pounds, and I was instantly worried, but as soon as we went back to the ultrasound room, we discovered my little angel weighed two pounds. He was even a week ahead of what he's supposed to be, and they moved my due date from May 24th to May 10th. I'm losing and he's gaining? I'll take it!

We had a birth plan from visit one: C-section! My doctor figured it'd be much safer and that we could take my little man out at around 30 weeks or a little after so my skin wouldn't have to stretch any more than needed to have a healthy baby.

Much to my surprise, our last doctor visit I found out that was no longer the plan he had in mind. I've been banking on him giving me a little medicine, cutting a little then sewing me up and my baby would be here! That may not be the case. Since I'm doing so perfect and Will's growing amazingly, he asked if I wanted to do a natural birth. I'd love to because I'm almost positive the healing would be much smoother and I'd rather stay away from infections. The only way we'll go back to the C-section idea is if he's a very big baby or if my skin starts acting up.

I thank God everyday that he's blessed me with so much. A wonderful family, husband, and now he added on a perfect little boy! There's always something negative you can dwell on in life, let it hold you back, make it an excuse to slack, but you've got to be stronger than that "set back" and realize someone always has it worse than you no matter what. God doesn't give you anything you can't handle, I believe that with my whole heart!

**Jeremiah 29:11** *11 For I know the plans I have for you, declares the Lord, plans to prosper you and not to harm you, plans to give you hope and a future.*





## President's Report

### Dear FIRST Members:

This year, I begin my sixth Annual Letter with a pop quiz – what are the fundamental tenets that explain our behavior and propel our mission at FIRST? You know, like those credit card commercials, those three words that no family or friend of FIRST “should leave home without.”

Think about them; I will return for your answer. In the meantime, and in the midst of a painfully slow economic recovery worldwide, I am excited to share with you some terrific news. FIRST has continued to thrive in 2012 and exert its major impact on the lives of our members. Through expanded service and communication programs, creative research oriented toward translating discoveries from the laboratory bench to bedside, growing financial strength, and continued outstanding leadership, FIRST is positioned to be a strong point of pride to individuals and members with ichthyosis and related skin types now and for years to come. The ingredients for future successes are surely in place, and I wish to thank you for your continued and persistent support of YOUR organization.



Shifting back to my question about mission, one of the three words is to *educate*. Of the three, it is perhaps my favorite. A call to education implies a sense of knowing about something and teaching it to others. For example, we know ichthyosis is a family of rare genetic disorders, and it causes dry, red, scaly skin. In check-out lines, at school, restaurants, anywhere for that matter, we patiently educate those who are open to learning by teaching them about ichthyosis. The need to educate certainly takes on a compelling urgency when we serve as an educational resource to new parents of a child born with ichthyosis. We want to be there, we need to be there, we will be there, and beyond, to educate!

What do we really know about fixing the “real problems” underlying the disorder? We know quite a bit, but not nearly enough. To overcome this, we must remain steadfast in our emotional and financial support of those “teachers” who can better educate us. The clinical researchers and skilled scientists who are heavily associated with FIRST are our partners to help us solve the problem. They are real heroes in so many ways. These extraordinary professionals hold out tremendous hope for us. Their knowledge of dermatology, genetics and metabolism, and their enthusiasm for finding solutions to problems converge in a very positive way for our organization. For rare disorders, these wonderful people are pivotal to all hope, and we must support them!

Later this year, FIRST will announce a new, exciting, and multi-year fundraising campaign that will establish a research endowment as part of a major effort to strengthen these relationships. As the FIRST Research Program enters its seventh year, the experiment has been a big success and akin to a start-up small business, ready for expansion. The time has come to stabilize and expand our commitment to ongoing research of innovative and creative solutions to problems that affect our members.

Noted essayist and poet Ralph Waldo Emerson described the basis for success when he wrote, “Every great achievement is the victory of a flaming heart.” Victory for FIRST’s Research Program is not hard to define, but more difficult to imagine. Yet we must imagine a future defined by the discovery of new and effective treatments and cures for ichthyosis.

There is no greater imperative. Affiliated researchers are doing their part. In fact, we are turning several interested researchers away for lack of sufficient funds. All are extremely passionate about what they are doing on our behalf. Effectively, they are dedicating their professional lives to changing ours!

So, how do we complement their passion the best? By *inspiring* philanthropy and generosity from FIRST members, friends, family, and corporate sponsors, we *connect* dollars to answers and fulfill our supportive role in the march to that victory! In the future, and as we reach out to our members and ask for your thoughtful support throughout the campaign, please consider ways that you can contribute in meaningful ways to this special campaign achievement and the ultimate victory ahead. In fact, we are searching for the most descriptive and inspirational title for the campaign—please write to Jean at FIRST with your suggestions. Your “inspiration” could be selected as the moniker to lead us forward for generations to come.

In closing, and upon completing my sixth year as president of FIRST, I look forward to supporting the three fundamental principles that bind us all: FIRST’s never-ending mission to *educate, inspire, and connect* our members with each other and to a thriving future. Have a prosperous and healthy 2013. Together, we will board the fast track to Indy and produce a record-breaking attendance at our 2014 National Family Conference!

Sincerely,

*Dave Scholl*

# Chief Financial Officer's Report

Fiscal Year End 09/30/12

**Dear Members and Friends:**

As this is my last report, I want to give thanks to my finance committee for hanging in there with me for so many years and, most importantly, until we could put our new investment policy to bed. I am pleased to report that the investment committee has met four times now with our new investment manager at SunTrust Bank, and we are all pleased they are living up to our expectations, both from a communication standpoint and an investment standpoint. Although only a short time has passed from an investment standpoint, we believe the process will be rewarding for FIRST over the long term.



I want to wish our new CFO, Larry Silverman, the best in his efforts to watch over our finances. Larry is a certified public accountant and his firm also manages investments for others, so he begins his tenure at a most advantageous time. We are very fortunate to have him join our foundation, and I am certain he will do us well.

From an overall performance standpoint, FIRST had another good year. Our audited financial statements illustrate Net Assets increasing by almost \$36,000, and this was done while increasing research grant expenditures by \$75,000 to a total \$225,000. Very exciting when you look back not too far and there were no expenditures for research grants!

From a revenue standpoint, we also did exceptionally well. Not counting our national conference income, revenue increased by \$170,000. Most of this was from unrestricted contributions. I would like to believe this is a good indication that our member base, friends, family, and knowledgeable givers continue to increase, and not just the funding they provide. I am also inclined to believe, this is not just a result of Jean Pickford and her staff doing a great job but also a result of your efforts especially from grassroots efforts. Let's all keep up the good work moving on this track so we can help more people with more services and research.

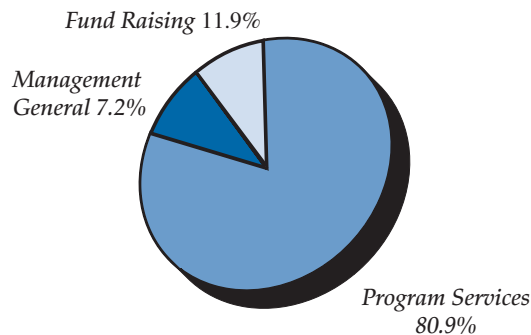
On the operating expense side, Jean has continued to run a very tight ship. If we carve out our national conference and grant expenditures, our spending is virtually the same as last year. Just as important, we continue to be very much in line with national standards for program, fundraising, and administrative categories. I continue to mention this because from a fund raising perspective, corporate and institutional contributors watch these ratios in addition to what we spend our money on.

In closing, I want to thank everyone that helped our fund raising efforts and challenge others to look for a way you too can help. Come to our next family conference and talk to those that have walked the walk and see how much fun they had. And if that is not your cup of tea, I hear a prayer or two can work wonders! Finally, as always, please feel comfortable in approaching me with any questions you may have regarding our financial results for the past year. Oh, and you are not completely getting rid of me, I will serve on FIRST's Investment Committee so I can hopefully be around

when we get our first big endowment. Gotta keep the dream alive!

Sincerely,  
**John J. Schoendorf**  
*(EI [formerly called EHK] member)*  
 CFO, Board of Directors

**Fiscal Year 2012 Expense Allocation**



The statement of Financial Position is excerpted from the Foundation's audited financial statements as of September 30, 2012. Complete copies of the audited financial statements and the independent auditor's report are available and can be obtained by calling the national office at 215.997.9400 or 800.545.3286.

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC.			
STATEMENT OF FINANCIAL POSITION			
SEPTEMBER 30, 2012			
(WITH COMPARATIVE TOTALS FOR 2011)			
	2012	2011	
<b>ASSETS</b>			
Current			
Cash and cash equivalents	\$ 1,224,002	\$ 1,279,085	
Investments	324,043	265,533	
Prepaid expenses and miscellaneous	1,735	7,930	
Total current assets	1,549,780	1,552,598	
Cash, permanently restricted	110,013	70,203	
Furniture and equipment, net	4,833	7,083	
Other assets	3,000	3,000	
Total assets	\$ 1,667,626	\$ 1,632,884	
<b>LIABILITIES</b>			
Current			
Accounts payable and accrued expenses	\$ 3,708	\$ 4,787	
Total current liabilities	3,708	4,787	
<b>NET ASSETS</b>			
Unrestricted			
Unrestricted	907,173	776,689	
Board designated	217,632	223,947	
Total unrestricted	1,124,805	1,002,636	
Temporarily restricted	429,100	555,258	
Permanently restricted	110,013	70,203	
Total net assets	1,663,918	1,628,097	
Total liabilities and net assets	\$ 1,667,626	\$ 1,632,884	



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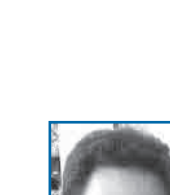
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 Affected and mother of  
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**Terry Tormey**  
 Father of affected child,  
 lamellar ichthyosis  
 President, TOTormey, Inc.  
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This listing includes all donations made during the 2012 Calendar Year.

**\$100 - \$249**

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 Mr. and Mrs. Roger Pretak  
 Mr. and Mrs. Joseph Proscia  
 Mr. and Mrs. Chuck Ransom III  
 Mr. and Mrs. Victor Rice  
 Mrs. Marcia Richmond  
 Rock Roofing and  
 Construction LLC  
 Ms. Kathryn Rogers  
 Mr. and Mrs. Ben Romero  
 Mr. and Mrs. Robert Ross  
 Ms. Allison Sanford  
 Santa Rosa Golf & Country Club  
 Mr. Mark Santoro  
 Mr. and Mrs. Charles Schaffer  
 Mr. and Mrs. Stephen  
 Schweighoffer  
 Mr. Eric Schweighoffer  
 Mr. and Mrs. William Scully  
 Ms. Lynna Search  
 Mrs. Kerry Shaw  
 Mrs. Janet Showers-Patterson and  
 Mr. Day Lewis Patterson  
 Mr. and Mrs. Daniel Siegel  
 Simi Winery  
 Ms. Barbara Smith  
 Softball/Pork Feed (SD)  
 South Troy Timing Association  
 Starbucks Coffee  
 Mr. and Mrs. Larry Staton  
 Summers and Sons Electric  
 Mr. and Mrs. Harry Sundik  
 Doug Takeuchi DDS and  
 Ellen Takeuchi  
 Ms. Jennifer Thoelke and  
 Mr. Michael Schulze  
 Mr. Rob Thompson  
 J. Derek Tieken DDS  
 Mr. and Mrs. Roland Unruh  
 Mr. and Mrs. Dietmar Urbat  
 UW Fundraising Event (FL)  
 Ms. Margaret Valdez  
 VMV Hypoallergenic  
 Mr. and Mrs. Eric Wegmet  
 Mr. and Mrs. Brian Wetzel  
 What's New Fair (OH)  
 Mr. and Mrs. Robert White

## \$1000 - \$4999

Alcon Labs  
 American Title Services Company  
 American Tube Products  
 Mr. Glenn Anderson

Anonymous(1)  
 Mr. and Mrs. Glenn Balog  
 Bassett Elementary Fun Day/  
 Applebees (OH)  
 Mr. Brad Bawmann  
 Beiersdorf, Inc.  
 Mr. Gary Bellis  
 Mr. and Mrs. Merle Blanton  
 Blueprint Personal Training  
 Brandt/Tanner Wedding (PA)  
 Dr. and Mrs. David Bryson  
 Mr. and Mrs. Randall Caddell  
 Jovita Carranza  
 Mr. and Mrs. Rodney Chapin  
 Children's Hospital of Colorado  
 Cina Wine Tasting (NJ)  
 Mr. Timothy Croasdaile  
 DBG Services, L.P.  
 Dermablend Professional  
 Dermal Therapy Research, Inc.  
 Dr. and Mrs. James Stark Draper  
 Dugan Golf Outing (NY)  
 Mr. and Mrs. Donald Elliman Jr.  
 Mrs. Lee Everding  
 Dr. Robert Freedman  
 Ms. Katy Frost  
 The Gaffney Foundation  
 Galderma International S.A.S.  
 Mr. and Mrs. Steve Gray  
 Mr. Mark Hawm  
 Hi-heels & Handbags (GA)  
 Jill Hirschfeld  
 Mr. and Mrs. Craig Hodgkinson  
 Mr. and Mrs. Scott Hollenbeck  
 Mr. and Mrs. Alex Howard  
 Mr. and Mrs. Joseph Hugenberg  
 Robert Hyde DDS  
 Mr. and Mrs. Zachary Hyman

It Makes Cents (CT)  
 Mr. and Mrs. John Jessiman  
 Ms. Dana Johnson  
 Mr. Derek Johnson  
 Josh Ridings Band Benefit (SC)  
 Kansas State University  
 Mr. and Mrs. Richard Kass  
 Mr. Matthew Keyser DDS  
 Ms. Carol Kong  
 Mr. Robert Kraybill and  
 Ms. Durreen Shahnaz  
 Mr. and Mrs. Paul Licursi  
 Ms. Terri Ly  
 Mrs. Carolyn Marquardt  
 Mr. and Mrs. John McCoy  
 Merck Partnership for Giving  
 Drs. Leonard and Ellen Milstone  
 More Than Skin (NJ)  
 Nordby Construction  
 Mr. and Mrs. David Norris  
 NY Mets Game  
 O'Keeffe's Company  
 Mr. and Mrs. Frank Osowski  
 Dr. Amy Paller and  
 Mr. Etahn Cohen  
 Mr. and Mrs. James Pate  
 Dr. and Mrs. Eric Phelps  
 Phillies Game  
 Mr. and Mrs. Chris Phillips  
 Mr. and Mrs. Michael Potack  
 Price Waterhouse Coopers  
 Pumpkin Paint & Bake Sale (SD)  
 Release the Butterfly (PA)  
 Dr. William Rizzo  
 Dennis Roop PhD  
 Ms. Ramona Schiller  
 Mr. John Schoendorf  
 Mr. and Mrs. Aaron Scholl

Jennifer See and Rachel See  
 Shahnaz Half Marathon  
 Sovereign Bank Community  
 Development  
 Mr. and Mrs. George Swan  
 Ms. Janie Thompson  
 Mr. and Mrs. John Tierney  
 The TJX Companies, Inc.  
 Triangle Skinsational Sip (NC)  
 Mr. and Mrs. Brian Turecek  
 University of Colorado  
 Cancer Center  
 University of Colorado  
 Foundation  
 Upsher Smith Laboratories, Inc.  
 US Raceworks, LLC  
 Vaughn Duffy Wines  
 Mrs. Margaret Vernet  
 Mr. and Mrs. Benjamin Waldshan  
 Dr. Mary Williams and  
 Dr. Peter Elias  
 Mr. and Mrs. Andy Wohlgang  
 Ms. Denise Yong  
 Dr. and Mrs. Ruey Yu  
 Zumba (FL)  
  
**\$5000 - \$9999**  
 Chicago White Sox Game  
 Ms. Nancy Cohen  
 Mr. Gregory Erwin  
 Mr. John Gates  
 General Motors Foundation  
 Mr. and Mrs. Charles George  
 Mr. and Mrs. Peter Grant  
 Health & Medical  
 Research Charities  
 Links Medical Products  
 NFC Fundraising Event (Ireland)

Mr. James Wason  
 Penny Drive (Canada)  
 Phelps & Cohen  
 Orthodontics Practice  
 Summers Laboratories  
 Swan Benefit Dinner (CA)  
 Ms. Diane Wallach  
  
**\$10,000 - \$99,999**  
 Accurate Imaging  
 Ace in the Hole Foundation, Inc.  
 Mr. and Mrs. Michael Briggs  
 Dane's Friends for FIRST  
 Concert (CA)  
 Mr. and Mrs. Robert Hoerle  
 Mr. and Mrs. Jeffrey Hoerle  
 Mr. George Loening  
 Monster Dash Run (TX)  
 NeoStrata Company  
 Dr. and Mrs. David Scholl  
 Sherlock Half Marathon (DE)  
 University of Colorado  
 Anschutz Medical  
 Dr. Eugene Van Scott  
  
**\$100,000 +**  
 Lennox Foundation

*Thank you  
 to all our  
 generous  
 donors!*

## A message from the incoming President...



*Dear Friends and Members of FIRST:*

I would like to take this opportunity to introduce myself to you. I retired from UPS in 1999, after 36 years as Region Manager/Vice President. I grew up in upstate New York, graduated from Mohawk Valley Community College, attended Utica College and Syracuse University. My wife Lynn and I were transferred numerous times to all parts of the country. We have two children and five grandchildren. I have served on the FIRST Board of Directors for 8 years and have participated in a number of committees.

I became involved with FIRST after the birth of my grandson, Adam, who was born with epidermolytic ichthyosis (formerly called EHK).

While witnessing significant progress in the last number of years, we are only scratching the surface of our true potential. I believe we have seen what technology can do for us in an effort to communicate with more people on a timely basis, as well as assist us in fundraising to reach our goal of endowment funds to financially support our organization in the coming years.

Continuing our mission to Educate, Inspire, and Connect while enabling ourselves to continue our journey in research to finding a cure is who we are!

Sincerely,  
**Mike Briggs**  
 President 2013-2015

# Executive Director's Report



*Dear Members, Friends, and Donors of FIRST,*

Fiscal year 2012 turned out to be a good year for FIRST. Although the recovery of our economy has been slow, we experienced solid growth at FIRST in three key areas: programs/services, fundraising, and membership.

The highlight of our programs this past year featured our national conference in Denver. We had an excellent turnout in attendance. Investigators and scientists associated with the Gene Discovery Project at Yale University were able to meet with more than 80 families who contributed to finding the genetic basis of ichthyosis and understanding how mutations in specific genes (genotype) give rise to unique physical findings in each person (phenotype).

In the fundraising department, we saw our best year ever in terms of local, grassroots events around the country. Our gross revenue totaled over \$100,000! More and more members, family and their friends are joining the efforts to raise awareness and dollars for FIRST. From small bake sales to large community concerts, FIRST is reaching people far and wide. In addition to these FIRST supporters, our direct mail campaigns, corporate appeals, and grants have all seen slight increases as well. This is a sign that FIRST is important to our members and their families and reinforces that we are armed with the resources to continue to educate, inspire, and connect.

Over the past eight months, our staff, key volunteers, and board members have focused their attention on how FIRST is "getting the word out"—in essence, our public relations and marketing strategies. With today's new social media phenomenon, it is clear we can reach more and more people with less and less time and money. And in the world of a rare disease, this is a tremendous asset. Over the past four years, our membership has grown over 20%, with last year seeing the biggest jump of 8% over the previous year.

Because we now know that approximately 200-400 babies are born each year with some form of moderate to severe ichthyosis, our mission is even more important to educate, inspire and connect those touched by ichthyosis and related disorders through emotional support, information, advocacy, and research funding for better treatments and eventual cures.

Warm regards,

Jean R. Pickford  
*Executive Director*



## JANE & HENRY BUKATY SKIN CARE FUND

*Applications Now Accepted*

Thanks to the generosity of *Jane and Henry Bukaty*, FIRST has established the Jane & Henry Bukaty Skin Care Fund to help alleviate some of the financial burden that may be facing our members. 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 and requests the specific product/treatment for which funds are needed, and also requests a demonstration of the financial need for this product/treatment.

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

Please download this application from FIRST's website and email to the national office at [jpickford@firstskinfoundation.org](mailto:jpickford@firstskinfoundation.org), fax to 215.997.9403, or mail to the attention of:

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

The next cycle of funds awarded will take place in July 2013. You will be contacted by the office if you have been awarded aid from this fund.

# Regional Support Networks

## Are You the FIRST to Know?

Would you like to speak to knowledgeable clinicians and other FIRST members about topics specific to your disease type? If so, the FIRST to Know conference calls are the answer for you. The foundation designed this opportunity so that you can call into the designated number and listen and communicate with others who are “in the know” about topics specific to you.

The FIRST to Know calls are a great way to “meet” other families and individuals. Sharing tips, stories, and challenges makes living with ichthyosis easier. RSVP to a call by emailing Moureen at [mwenik@firstskinfoundation.org](mailto:mwenik@firstskinfoundation.org), or call the National office at 1.800.545.3286. A call-in number will be sent to you. All calls are held in Eastern Time, and are phone calls only, so you only need a phone, not a computer.

**Thursday, April 25**

Teens Rock: An Open Dialogue for Teens, with Teens

**Tuesday, May 7**

Aging Skin: How is Your Skin Changing?

**Wednesday, May 22**

Darier Disease: Bringing a Community Together

**Thursday, June 6**

Vulgaris: Connecting with One Another

**Tuesday, June 20**

Time for College: Transitioning from High School to College

**Wednesday, July 10**

Infections: What Are They?

## 2013 Patient Support Forums Are Scheduled

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 and 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 the following events:

June 8, 2013 - Dallas, Texas

June 29, 2013 - Cincinnati, Ohio

August 3, 2013 – New Jersey

September 7, 2013 - San Jose, California

September 21, 2013 - Kansas City, Missouri

## Free Health Planners Are Available

The NIAMS created the multicultural health planners with information and resources about staying healthy and managing conditions of the bones, joints, muscles, and skin. FIRST still has planners available for distribution. The planners FIRST has available are for the following audiences: African American, Asian Americans, and Hispanic/Latinos. To receive your free Health Planner, contact Moureen at [mwenik@firstskinfoundation.org](mailto:mwenik@firstskinfoundation.org) or contact the FIRST office at 215.997.9400.



### Do you have an idea for a FIRST to Know topic?

Email Moureen at [mwenik@firstskinfoundation.org](mailto:mwenik@firstskinfoundation.org)

#### What we heard about the Netherton call:

*Thank you for setting this up yesterday. It was great to have this time for us to talk intimately with other families and a doctor about Netherton. I think we are all just reaching out for any hope for our kids, and yesterday's talk certainly gave us that.*

*If it is possible to have these specific chats more frequently, I'd definitely be interested; perhaps every few months.*

*Anita A.*

*Thank you so much for letting me know about the Netherton conference call. I was thrilled to not only see something about Netherton, but it was comforting to know that there are really others “out there!” Ten years ago, I learned that one in a million people have it; it was great to speak with and listen to a few of them!*

*Fran R.*

#### About the lamellar call:

*The call was quite interesting. Thanks again for sharing the link with me. Along with other tidbits, I found the Camp Horizon info especially interesting. Hanna has just turned two, but it is something to keep in mind as she gets older.*

*Thanks for all you do!*

*Alan B.*

Though our own FIRST doctors have recommended putting chlorine in our bath water, I would strongly recommend that each family do their own research. One last bit of information that I found helpful came from [ichthyosis.com](http://ichthyosis.com). It was a testimonial from a then-60-year-old ichthyosis vulgaris (IV) patient whose own mother used chlorine in her bath water. Once on the site, click on Ichthyosis Information, Alternative Therapies, click onto Alternatives for Daily Baths & Showers go to Pg. 2 and read the post by G.F. Foodie.

Forgive the lengthy explanation, but it was written in hope that someone else in our ichthyosis community could benefit. I would welcome your responses.

Respectfully Submitted with Hugs,

**Andrea Thorn**

Madison, Mississippi  
[athorn59@yahoo.com](mailto:athorn59@yahoo.com)

*Editor's Note: Always check with your physician before trying any new treatments or products.*

### Hi Everyone,

I have a skin care regimen that works very well for me, and I would like to share it with you in case it works for others.

When I bathe, I add salts from the Dead Sea to the water as well as lathering with a Dead Sea salt shower gel, imported from Israel, and scrubbing off scales with a ceramic pumice stone/sponge. Another topical product that has made a remarkable difference is 100% natural, unrefined African Shea Nut Butter. The smell of it is not appealing, so I mix it with lotions of my favorite perfume scents or essential oils. However, I'm now utilizing much less expensive over-the-counter products to manage this disorder and rarely rely on prescription medication, which has cost me thousands of dollars over my lifetime.

I get the Dead Sea salts on ebay. I use 8 oz. per tub full. I usually purchase either White Treatment Dead Sea Bath Mineral Crystals Salt in a Box or Dead Sea Mineral Bath Salt Mix Course Bulk.

I purchase the African Shea Nut Butter on the streets of Harlem from African Vendors. I am willing, however, to become a distributor, shipping by USPS Priority Mail and receive payment via pay-pal. Members can email me at [nessa11434@yahoo.com](mailto:nessa11434@yahoo.com) and mention ichthyosis or African Shea Nut Butter in the subject line.

Take care!

**Vanessa Jennings**

## 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.

### Another Successful Zumba Event in Florida

**Cara Tundidor** is the mother of 5-year-old **Teo**, who is affected with CIE. She is also a Zumba instructor and held a wonderful Zumba event last year to raise awareness about ichthyosis and funds for FIRST. She decided to once again hold this high-energy event and had even more success, raising more than \$4,000 for FIRST! Many thanks to Cara and her friends and family for their tremendous support.



### Wonderful Wine-Tasting Event in Ohio

At the beautiful Grand River Cellars Winery and Restaurant in Madison, Ohio, **Susan Schumacher** hosted a wine tasting and silent auction fundraiser. Susan's nephew **Mark Klima** and his wife, Lisa, are the parents to 8-year-old **Emma Klima** who is affected with epidermolytic ichthyosis (formerly called EHK.)

This was Susan's first time hosting an event for FIRST and it was a tremendous success! More than 80 people attended and the event raised nearly \$4,000. Susan's grand total is sure to climb because, in the near future, she will also run an e-Bay auction of a Kirby vacuum (valued at \$1,600). A few days after the event, while discussing the fun night, Susan became emotional talking about what a special night it was. Not only did she enjoy herself, but she was overwhelmed with such a wonderful feeling that she received from all of the people who came and supported her efforts.

# Grassroots Fundraising

## 11th Annual Monster Dash Fun Run

*Joe and Dawn Johnson*, parents of 14-year-old *Jordan*, organized the 11th Annual Monster Dash Fun Run in Friendswood, Texas last fall. A total of 250 runners signed up for a 5k Run, 1 mile kids run, or a 1 mile walk. Jordan is affected with epidermolytic ichthyosis (formerly called EHK) and the Johnson family have been ardent supporters of the Foundation ever since.



*Dawn registers some of the 250 participants*

It was a gorgeous day in Friendswood and many runners showed up in full costume to celebrate Halloween! Aside from all of the fun, over \$14,000 was raised for FIRST to advance our mission to Educate, Inspire, and Connect! Thank you, Johnson Family.



*Participants decked out in costume or wearing their race day t-shirts.*

## Wine Tasting Evening in North Carolina

Long-time FIRST member, and a past president, *Ellen Clemmer* teamed up with FIRST member *Teresa Hedley* to host a wonderful wine tasting event in North Carolina. Ellen, who is affected with lamellar ichthyosis, was president of FIRST from 1988 to 1992. Teresa is the mother of 14-year-old *Jelani* who is affected with **KID syndrome**.



*Ellen and Teresa hosted a wonderful evening*



*FIRST members Jennifer See and Richard and Lynette Sapienza support Teresa's and Ellen's efforts*

Ellen and Teresa cohosted the Triangle Skinsational Sip wine tasting and silent auction which was held at the North Ridge Country Club in Raleigh, North Carolina. Over 80 people attended this wonderful event, and they enjoyed several different high-end wines and nibbled on delicious hors d'oeuvres while also learning about ichthyosis.

Ellen's nephew, *Sean*, manned the coat check for the evening. He then took the tips that he earned and donated them to FIRST! What a generous act.

Ellen and Teresa hosted a beautiful event and raised great awareness for ichthyosis at this, their first attempt at a grassroots fundraiser. We walked them through each step of the fundraising process. However, it was their eagerness, determination, and creativity that made it such a huge success.



*Friends and family of Ellen and Teresa enjoy the evening and support FIRST.*



*Sean Betts works the coat check*



## REMINDER...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 info about attending or volunteering, visit [www.campdiscovery.org](http://www.campdiscovery.org) or contact Janine Mueller at 847.240.1737 or [jmueller@aad.org](mailto:jmueller@aad.org). 2013 dates are listed below.

- Little Pine, Crosslake, MN** – ages 10-14, June 23-28
- Camp Horizon, Millville, PA** – ages 8-13, August 10-17
- Camp Reflection, Carnation, WA** – ages 8-16, June 24-28
- Camp Dermadillo, Burton, TX** – ages 9-15, August 11-16
- Big Trout, Crosslake, MN** – ages 14-16, July 7-12
- 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](mailto:ftenconi@csdf.org) or call 925.947.3825



## FALL WEEKEND CAMPS OFFERED FOR CHILDREN AND THEIR FAMILIES



*The Roundup River Ranch*, located in Gypsum, Colorado hosts camps for children diagnosed with chronic or life-threatening medical conditions. Camps are offered for children during the summer months, and specialized camps for families are offered during the fall.

These camps are completely free to the child and their immediate family members, but applications are required and the family would need to provide their own transportation to various pick-up points within the state of Colorado. The deadline to apply for the summer camps is May 1, 2013 and for the fall family camps is August 1, 2013.

For details and more information visit their website at [www.roundupriverranch.org](http://www.roundupriverranch.org) or call Eileen Hall at 970.524.5713.