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

Ichthyosis Focus

Spring 2014 *A Quarterly Journal for Friends of FIRST* *Volume 33, No. 1*

The Power of Art and Advocacy

By: Maureen Neville

This past November, we had the great pleasure of meeting Rick Guidotti, award-winning former fashion photographer turned "difference" activist, and founder and director of the education and advocacy organization, Positive Exposure.

Continued on page 15

Inside This Issue:

Photo by: Rick Guidotti

Vol. 33 No. 1 Spring 2014
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Ichthyosis Focus is published quarterly
by the Foundation for Ichthyosis &
Related Skin Types, Inc.®
2616 N. Broad Street Colmar, PA 18915

Requests to reprint information,
comments and correspondence
contained in the editor.

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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.

Executive Director Report

Jean R. Pickford,
Executive Director

In this very special issue of the Focus, we are sharing the thoughtful insight of our president, Mike Briggs, and our chief financial officer, Larry Silverman, as they relive the highlights from this past year. However, we are also shifting the focus, just a bit, to an event in the very near future. In fact, it is an event that I might say is the "quintessential" culmination of the past, present and future: The FIRST National Family Conference. We are so delighted to see how many new families we'll be meeting in Indianapolis, and how many returning members we will be reuniting with. There is a palpable "conference energy" stirring among staff and board members alike, as we are eager and excited to reconnect with this amazing community. Our roster of workshops, networking opportunities, and special events, is as robust and inspirational as ever. As always, attendees can expect to hear the most up-to-date medical information regarding skin care, as well as the latest advances in medical research…from the scientists themselves! Our world-class dermatologists will be available for one-on-one clinical screenings and our skin care product samples will be an added bonus. Moreover, attendees can expect new and innovative concepts like an alternative wellness workshop, life changing guidance from a "bullying expert," and of course, the wisdom and art of our keynote speaker, Rick Guidotti. If you are unable to attend the conference, we will be bringing as much of the conference to you as possible through our social media channels —straight from the Hilton—so please stay in touch during the conference weekend, June 20-22. We'll also be sharing insights, activities, and as much of the "Indy" experience as possible in the summer newsletter, e-news, FIRST website, and social media channels following the conference.

A long winter has come to an end (thank goodness), leaving a spectacular spring bouquet in its wake. Join me, and FIRST, as we open the windows, breath in the warm fresh air, and step into the brightest season yet.

All the best,

Jean Pickford

Correspondence Corner

Dear SR Lotion,

My 5 year old son has ichthyosis vulgaris. We are very fortunate that his major affected areas are his legs and scalp. Still the skin on his torso and upper arms is rough due to the dry skin hanging around and not sloughing off. I followed the directions for children and used 1 part SR lotion to 2 parts aloe based lotion. It has a lovely light lemon smell to it. If those scales didn't start to come off like magic! The bathtub water was full of little flakes (which never happens). Day 20 and it's like all new skin! I am one grateful Mama with tears in my eyes as I type!

(*****AMAZON partial customer review of SR Lotion)

Dear FIRST,

Thank you so much for the check from the Jane and Henry Bukaty Membership Assistance Fund! I was so shocked to receive it! Your gift is very helpful and I am so grateful!

Member Jennifer Andrews
Oxnard, California

RAREDISEASEDAY

FIRST goes to Washington DC for Rare Disease Legislative Advocate (RDLA) Conference

“Carry the Torch” was a message given to the participants at the Rare Disease Legislative Advocate (RDLA) Conference in Washington, DC, which was one of many events during Rare Disease Week held at the end of February. It was an appropriate symbolic message, considering the 2014 Winter Olympic Games had just come to a close, and the world watched the torch burn for over two weeks. But unlike the Olympic Games, rare disease will not end.

The word “rare” in the ichthyosis community seems minute and lonely, yet to use “rare” with over 150 represented diseases and disorders together in one room, “rare” becomes strong and familiar. The RDLA was not focused on one type of rare disease, but on all rare diseases and disorders. In attendance were parents of affected children, affected adults, and patient advocacy groups. magine being the family who learns only one other person has the disorder your child has and they live in another part of the world? Rare takes on a new meaning.

Lobby Day brought a new charge, which was to take our message of rare to the Hill and visit with senators and representatives, bringing a personal story and reinforcing the need for more funding for the National Institutes of Health. Three bills HR 1591; HR 3116; and HR 460 were introduced in the House, and the message was to ask Congress to co-sponsor these bills.

FIRST was fortunate to attend this event, and to share the few days in Washington, DC with the Zavitz family, whose daughter is affected with lamellar ichthyosis. Their daughter, Cate, was picked to represent Georgia at RDLA and Lobby Day, and she did a great job sharing her story with senators and congressmen. Also available to attend a visit on the Hill was Angela Godby, an affected adult with lamellar, and former board member at FIRST. FIRST carried the torch in Washington, DC, for ichthyosis and all rare disease; more families are needed to participate in Rare Disease Week 2015 to “Carry the Torch” for one another and many others affected.

Also, a big thanks to the Zavitz family for organizing the Gwinnett Gladiators fundraiser!

FIRST Members Took Action for Rare Disease Day!

In honor of Rare Disease day, an interview of FIRST member Laurie Anne Fiore, mother of Joseph and Faith, both affected with CIE (congenital ichthyosiform erythroderma), aired on 6 ABC Action News, Philadelphia on Rare Disease Day. Also a big thank you to Laurie for contacting Rep Tim Briggs of Montgomery County, Pennsylvania, whose staff wore blue jeans on Rare Disease Day, to show their support.

We’d also like to extend a heap of gratitude to Erin Burke Edwards and her family as they honored Rare Disease Day through several different coordinated FIRST fundraising events. They held a group fundraising dinner at Chick-fil-A, a donation box, and had a t-shirt sale. More than $625 was raised! Erin’s son Ethan, affected with lamellar ichthyosis, also helped create an awareness poster to display at Chick-fil-A and handed out ribbons and informed the public about ichthyosis.

Shirts were also donated to Ethan’s class, so when he arrived on Rare Disease Day, he would come in to a room of support! And Erin presented a lesson on recessive inheritance to Ethan’s second grade class, teaching them how to use a Punnet square to determine which children’s genotype would match with their parents’ for Rare Disease Day. Thanks to all for making a difference!

FIRST member Kelly Robinson, from Rhode Island, held a fundraiser at her place of employment, Paychex. Her beautiful daughter, Sienna is affected with epidermolytic ichthyosis. Kelly held a “Jean for Genes” day on Rare Disease Day and raised $563 through donations from her amazing coworkers. Thanks to everyone for all your support.

18th Biennial Conference - Connecting at the Crossroads – June 20—22, 2014

What Should I Expect?

The conference is an amazing, worthwhile, and moving event for the entire family. Registration begins early Friday morning and the workshops will end by 4:30 pm, so attendees are on their own for Friday night activities. Saturday will continue with workshops throughout the day until 5:15 pm. The dinner/dance party begins at 6:30 pm and features a live DJ who will play the latest hits, party games, and raffle/auction winners will be announced. Some people think this is the best part of the conference! Sunday workshops will end at 12:15 pm, and be followed by a closing session and farewell lunch. Friendships are made that are life-changing.

What's on the Agenda?

In addition to the exclusive opportunity to participate in a clinical screening appointment or research visit with the Yale Ichthyosis Research Project team, the agenda focuses on many different aspects related to living with ichthyosis. Disease and age appropriate discussions for adults and teens, genetics, research updates, group networking, specific care, skin management, and communications workshops are all featured. For the complete program, visit our website at www.firstskinfoundation.org and click on 2014 National Family Conference. Teenagers, ages 13-17, will also participate in a chaperoned offsite field trip to the Circle Centre Mall on Saturday afternoon of the conference.

Registration

Registration for the conference can be completed using the registration form or registering online at www.firstskinfoundation.org by June 2nd. Registrations without a completed form and payment will not be considered complete. Cancellations received prior to June 2nd will be refunded less a $25 per person administrative fee. No refunds issued after June 2nd. Please note: Registration does not include your hotel room. Accommodations at the Hilton Indianapolis must be made separately.

Kid's Camp

Social programs for all affected children and their siblings, ages 1—12, are an integral part of the conference. Participants will enjoy activities, entertainment, educational programs, and refreshments. A licensed childcare company will provide this service; a nominal fee is charged to confirm your participation.

Clinical Screening and/or Research Visits – Be a Participant!

Attendees have one of two options. Option 1 involves a 15 minute clinical screening with ichthyosis experts to review your medical and family history and to answer any questions you may have. Option 2 includes a clinical visit with ichthyosis experts to review your medical and family history and to answer any questions you may have, plus filling out a questionnaire about your medical and family history, signing informed consent, giving a blood sample for genetic testing (if you have not already had a blood test giving your genetic diagnosis), and taking photographs of your skin. Option 2 will take approximately one hour. Please note that appointments for Friday are filled, but Thursday afternoon/evening appointments are still available.

Hotel Room Reservations, Area Attractions, Transportation, and Dress Code

FIRST's discounted rate for an oversized room at the Hilton Indianapolis is $119 plus taxes and fees per night. This rate is available from June 17—25 and includes complimentary internet access. All attendees must make their own reservations at the Hilton Indianapolis by calling toll-free 1.800.315.1906 or going to FIRST's website and clicking on the 2014 National Family Conference link to reserve online. To receive the discounted room rate, you must identify our group name as "Foundation for Ichthyosis." Reservations must be received on or before midnight on May 18, 2014 to be guaranteed a room in the room block. Parking is $14 for self-park and $20 for valet parking. Other hotel rules and restrictions may apply.

Positioned in the heart of downtown Indianapolis, the hotel affords you multiple choices of activities. To learn more, visit the hotel website at www.indianapolishilton.com and click on Location & Attractions or visit the Visitors & Convention Center website for discounts and choices of things to do - http://visitindy.com/fnfc14.

Carey Limousine is the local shared ride service to and from the airport to downtown Indianapolis. The discounted cost for conference attendees is $16.95 per person one way. Please call toll-free: 800.888.INDY or use their website to make your reservation - https://careyindiana.hudsonltd.net/res. You may be eligible for free airfare using the Air Charity Network. To find out if you are eligible for free transportation to and from the conference, please contact Air Charity Network directly at 877.621.7177.

Conference attire is casual.

Registration Form

CONNECTING AT THE CROSSROADS
FIRST
2014 NATIONAL FAMILY CONFERENCE
INDIANAPOLIS, IN

Contact Information ______________________________

First Name ______________________________

Last Name ______________________________

Address ______________________________

City ______________ State ________ Zip ______________

Home Phone ______________ Cell Phone ______________

Email ______________________________

Registrant Information *(must include all names, ages and type of ichthyosis)*

First Name	Last Name	Age	Affected	Kid's Camp*	T-shirt Size
________	________	____	☐	☐	YS YM YL S M L XL XXL
________	________	____	☐	☐	YS YM YL S M L XL XXL
________	________	____	☐	☐	YS YM YL S M L XL XXL
________	________	____	☐	☐	YS YM YL S M L XL XXL
________	________	____	☐	☐	YS YM YL S M L XL XXL

Please indicate which type of ichthyosis affects your family: ______________________________

**For the safety of your children, the appropriate number of caregivers will be hired based upon the number of children signed up for the Kid's Camp. Therefore a nominal fee will be required to ensure we have an accurate number of participants.*

Clinical Screening Appointments

Meet privately with expert dermatologists who are extremely knowledgeable about ichthyosis to answer any questions or concerns that you may have. Currently, appointments are available on Thursday evening, June 19, from 3:00 – 9:00 pm. (Friday morning, June 20, from 7:00 – 10:00 am are filled and no longer available.) You will receive an email prior to the conference with your appointment time. Please note: There may be physician residents in-training observing during your appointment. This will help educate future leaders in dermatology about ichthyosis.

Name of person	Age	Male/Female	Type of Ichthyosis	Thurs Appt
________	____	________	________	☐
________	____	________	________	☐

FIRST Idols Talent Sign-Up *(ages 5-17)*

Back for its fourth year! This is a popular and heartwarming event for our kids to showcase their talents to our audience. Performances will take place on Saturday evening after dinner. A CD player and microphone will be provided. Please bring your own music, costume, props, etc. All performances will be limited to a maximum of two minutes.

Performers Name ______________________ Age ______ Grade ______________

Type/Description of Act: ______________________________

____

Teen Off-Site Field Trip

An organized trip has been arranged for teenagers (ages 13–17) to visit the Circle Centre Mall from 1:00–5:00 pm on Saturday, June 21. Licensed chaperones will accompany and travel to/from the mall with the teens. I give permission for my son/daughter to attend this trip and understand FIRST is not liable for any incident or injury while my son/daughter is not in my care.

Teen(s) Name ____

Signature of Parent/Guardian: ______________________________________

Permissions

☐ *I give permission to FIRST to publish the names, contact information, and type of ichthyosis in the conference roster, which will be distributed to all attendees.*

☐ *I hereby give my permission to FIRST to use and distribute any photos or video tapes taken at the 2014 family conference in which I or my family may be a part, including but not limited to use in newsletters, guides, documentaries, appeals, website and reports at their discretion.*

Signature ______________________________________

CONNECTING AT THE CROSSROADS
FIRST
2014 NATIONAL FAMILY CONFERENCE
INDIANAPOLIS, IN

Registration

Adults (Ages 13 and up) __________ *x $ 225.00 pp USD =* $______________
Children (Ages 1–12) __________ *x $ 75.00* pp USD =* $______________

Optional Add-Ons

Kids Camp (Ages 1–12) __________ *x $ 10.00 pp USD =* $______________
Donation to support the conference scholarship fund = $______________

Total Payment $______________

Method of Payment

Check, payable to FIRST (in US Funds)

Credit Card: Visa, Mastercard, Discover or Amex

*Credit Card #*____________________ *Expiration Date*_______ *Authorized Signature:*__________________________

In consideration of the acceptance of this registration entry, I/we the undersigned, assume full responsibility for any injury or accident which may occur while I/we am/are attending this conference. I/we hereby release and hold harmless the sponsors, promoters, and all other persons and entities associated with this event from any and all personal injury or damage, whether it be caused by the negligence of the sponsors, promoters or other persons or entity. Applications for minors will be accepted only if signed by a parent or guardian.

Signature ___________________________ *Name*_______________________________ *Date* __________

**Children's rate discounted through grant from the Lennox Family Foundation*

Grassroots Fundraising

Thank You Tinysuperheroes!

For the entire month of January, our friends at Tiny Superheroes held an online T-shirt sale in honor of their one-year anniversary, and also in honor of their very first cape recipient, FIRST member Brenna Westlake, affected with harlequin ichthyosis. The uplifting phrase splashed across the front of the shirt read: “Be Super in the Skin You’re In, Different is Beautiful.” Our members, staff, associates, and friends were thrilled and inspired by the special promotion and sales spiked almost immediately! Tiny Superheroes donated $5 for every T-shirt sold directly to FIRST, totaling an incredible $1,820! A sincere thank you to founder Robyn Rosenberger and her entire Tiny Superhero team!

Night with the New York Islanders

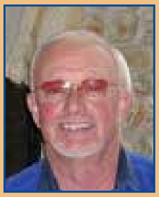
A big thanks to the Cimino family, whose son Nicholas is affected with lamellar ichthyosis, for taking a break from all of the holiday festivities to organize a FIRST Night at the New York Islanders game on December 28th! Pictured is 9 year-old Vanessa Bowman with Marc Benedetto. Vanessa is affected with lamellar/CIE and this was her first time meeting someone else with ichthyosis! The Bowman family was very thankful to the Benedetto family offering to meet with them. Proceeds from the game were over $350. A fun time was had by all!

Maria Tessinari raised $220 at a Touchstone Crystal online fundraising event! A BIG thanks for finding a creative way to have fun and support FIRST!

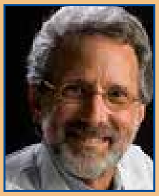
Dress Down Day at School

Teachers and staff at Paine Intermediate School in Trussville, Alabama, held a jeans day fundraiser on Wednesdays during the month of January. Their efforts were held in honor of 4 year-old Annalie Ekonen who is affected with lamellar ichthyosis. Many of the 1,000 students and staff members had not met little Annalie, so this was also a wonderful opportunity to educate the entire school community about ichthyosis, paving the way for a smooth transition when Annalie begins kindergarten in the fall. Many thanks to the entire staff, faculty, and students at Paine Intermediate School for their efforts!

FY 2013 board of directors

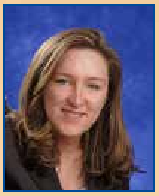


Michael W. Briggs
President
Grandfather of affected child, EI
Retired Vice President, United Parcel Service
Gainesville, GA



Moise L. Levy, MD
Vice President
Chief, Pediatric Dermatology
Physician-in-Chief
Dell Children's Medical Center
Austin, TX

Larry Silverman
Chief Financial Officer
BKR Cornwell Jackson Group
Frisco, TX



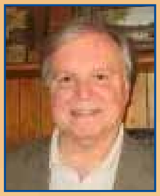
Jennifer F. Hillman, Esq.
Secretary
Affected, lamellar ichthyosis
Attorney, Ruskin Moscou Faltischek, P.C.,
Uniondale, NY

Denise Benedetto
Mother of affected child, lamellar ichthyosis
Teacher, F.X. Hegarty
Wantagh, NY

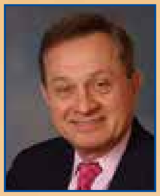
Jonathan A. Dyer, MD
Assistant Professor of Dermatology & Child Health
University of Missouri – Columbia
Columbia, MO

Jeff Hoerle
Father of affected child, CHILD syndrome
Managing Partner, Stone Run Capital, LLC
Stone Ridge, New York

Gabriele Richard, MD
Chief Medical Officer, GeneDx
Gaithersburg, MD



William B. Rizzo, MD
Professor of Pediatrics
University of Nebraska Medical Center
Omaha, NE



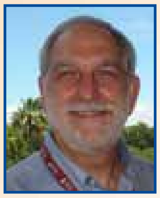
John Schoendorf
Affected, EI
Schoendorf Management Services
Coconut Grove, FL

Eric Schweighoffer
Affected, lamellar ichthyosis
VP Media Director
Cashman & Katz Integrated Communications
Southington, CT

Rachel See, Esq.
Affected and mother of affected children, ichthyosis en confetti
Lead Technology Council of the National Labor Relations Board
Washington, DC

Terry Tormey
Father of affected child, lamellar ichthyosis
President, TOTormey, Inc.
New Hope, PA

Board Members Emeriti



Philip Fleckman, MD
Professor, Division of Dermatology, University of Washington
Principal Investigator, The National Registry for Ichthyosis & Related Skin Disorders
Seattle, WA

Leonard Milstone, MD
Founding Member
Professor Emeritus of Dermatology
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Amy Paller, MD
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Professor, Pediatrics
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Grandfather of affected child, CIE
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Mary Williams, MD
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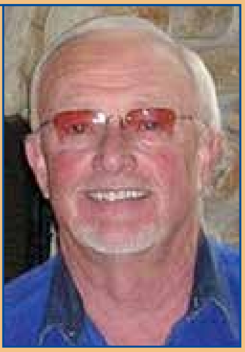
San Francisco, CA

General Counsel

Daniel J. Siegel, Esq.
Father of affected sons, x-linked ichthyosis
Law Offices of Daniel J. Siegel, LLC
Havertown, PA

President's Report



Dear FIRST Members:

This is my first letter to you as President of FIRST. Let me begin by extending our gratitude to Dave Scholl, past president, for his tireless efforts over the past six years to help bring us to the level of professionalism we have attained.

Our challenge for 2014 will be to expand on our successes of 2013, which was a very busy, energetic, and exciting year.

It was a very positive fundraising year as we saw unparalleled success in grassroots teams raising 21% more than 2012. More and more of our members are becoming involved and realizing that no matter how large or small their contributions are, every dollar counts. Additionally, we established a Major Gifts Committee to lead the mission of developing a multi-tiered major gifts campaign. We have also established an Investment Committee that works closely with SunTrust Bank to ensure our long-term stability and financial success.

Earlier in 2013, Maureen Neville was added to our team as communications director for FIRST, to help us strengthen our efforts and accomplish our mission of educating, inspiring, and connecting. Our means of communicating have been refreshed, and there has been dramatic positive communications added to our plan, including informational videos, enhanced social media activity, and additional electronic communications.

As for the research grant program, established in 2006, we continue to have three active medical research grants being funded, enabling the progress of ichthyosis research to continue an upward climb toward better treatments and, hopefully, an eventual cure.

We have also added new members to our Medical & Scientific Board, lead by Dr. Leonard Milstone, totalling 32 members. Four new board members were welcomed this year to FIRST's Board of Directors. We are also fortunate that Dave Scholl agreed to remain on as Board Member Emeritus.

We have a very sound structure to help guide us and continue our positive growth following our long-term strategic plan. There is no doubt we have become the leading source of information and research in the world for ichthyosis and with that comes great responsibility.

I look forward to our continued success in 2014, and I am always open to your suggestions for improvement. Hopefully, I will see many of you in Indy this summer!

Best wishes,

Mike Briggs

Chief Financial Officer's Report

Dear Members and Friends:

This is my first year in this honorable position and I want to thank all of the fine people at FIRST for their incredible support. John Schoendorf may have left this post, but he has continued to be a strong presence and always ready to help; he made the transition move seamless. Jean and her professional staff have an amazing capacity and great enthusiasm in their commitment to this wonderful organization. They help ensure that our finances and resources are protected and used for the ultimate goals of FIRST. I enjoyed my first FIRST board meeting last November in Philadelphia. I was truly amazed at the dedication and enthusiasm from fellow board members.It was a real treat to develop new friendships around this important cause.

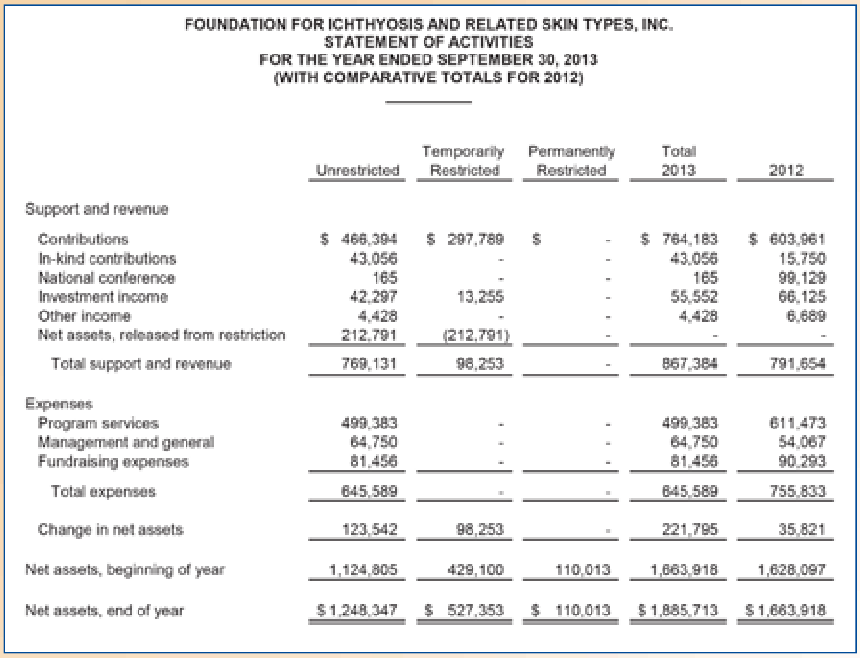
Now to the state of financial affairs. We had a solid year for the period ended Sept. 30, 2013. Based on our audited financial statements, net assets were up $239,301. In-kind donations were up $27,306 and other fund revenues increased by over $75,000. While administration expenses were up, designated funds were favorable over the prior year by over $119,000. The administrative expenses are being held nicely in check; we did add a Communications Director in 2013, which was the only significant increase in expenses over 2012. Our expenses as a percentage are still very low as compared to other similar organizations. Once again, the lion's share of contributions is spent on FIRST's programs and services.

We continue to manage our assets through SunTrust and have a strong investment management team there. Our Investment Committee continues to closely monitor all aspects of our progress and performance with the SunTrust organization. The new investment policy has been fully integrated and operational since 2013. The results have been solid and we continue to enhance the value of our assets. I hope to see all of you this June at the family conference in Indianapolis. This is a terrific event where education and connection can inspire us all.

Please feel free to reach out at any time should you have any questions or concerns about our financial affairs. I wish all of you a continued year full of great health, peace, and happiness.

Warmest regards,

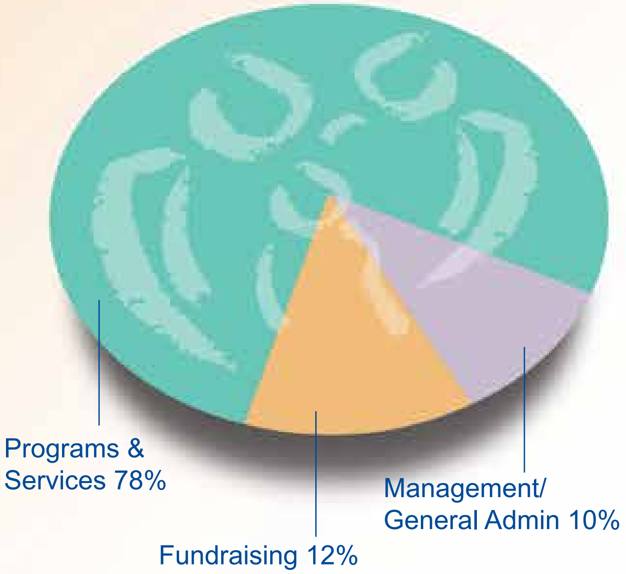
Larry Silverman, CPA, CFP



FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC.
STATEMENT OF ACTIVITIES
FOR THE YEAR ENDED SEPTEMBER 30, 2013
(WITH COMPARATIVE TOTALS FOR 2012)

	Unrestricted	Temporarily Restricted	Permanently Restricted	Total 2013	2012
Support and revenue					
Contributions	$ 466,394	$ 297,789	$ -	$ 764,183	$ 603,961
In-kind contributions	43,056	-	-	43,056	15,750
National conference	165	-	-	165	99,129
Investment income	42,297	13,255	-	55,552	66,125
Other income	4,428	-	-	4,428	6,689
Net assets, released from restriction	212,791	(212,791)	-	-	-
Total support and revenue	769,131	98,253	-	867,384	791,654
Expenses					
Program services	499,383	-	-	499,383	611,473
Management and general	64,750	-	-	64,750	54,067
Fundraising expenses	81,456	-	-	81,456	90,293
Total expenses	645,589	-	-	645,589	755,833
Change in net assets	123,542	98,253	-	221,795	35,821
Net assets, beginning of year	1,124,805	429,100	110,013	1,663,918	1,628,097
Net assets, end of year	$ 1,248,347	$ 527,353	$ 110,013	$ 1,885,713	$ 1,663,918

Expense Allocation Percentage



2013 Donor Listing

$100-$249

4th Annual Power in the Park Event
5 Star Walt's LLC
Mr. and Mrs. Richard Abbott
Abbott Laboratories
Dr. and Mrs. Harvey Adams
Mr. Gregory Adams
Adaptive Driving Access, Inc.
Mr. and Mrs. J.R. Aguila
Mr. and Mrs. Luis Aguilar
Mr. and Mrs. Chris Alexander
Mr. and Mrs. Kyle Alexander
Mr. and Mrs. James Amdahl
Rex Amonette, MD
Johnnie Dacus Amonette
Mr. Clement Amore
Ms. Amneet Anand
Mr. and Mrs. Herbert Anderson
Mr. and Mrs. Paul Anderson
Okey Anderson
Mr. and Mrs. Kevin Anderson
Ms. Catherine Andrade
Ms. Merritt Andrews
Ot Annie
Anonymous(15)
Ms. Amber Antheunisse
Mr. and Mrs. Nicholas Anzalone
Mr. Mario Anzano
Tyler Arendt
Mr. and Mrs. Robert Ash
Mr. and Mrs. Douglas Auw
Mr. and Mrs. Thomas Bachand
Ballet Royale
Mr. and Mrs. James Bangsund
Mrs. Annette Barbash
Ms. Linda Barney
Mr. and Mrs. Jared Barney
Mr. Randy Barr
Ms. Jennifer Bartlett
Mr. Todd Bartlett
Baum, Smith & Clemens, LLP
Mr. and Mrs. Terry Beard
Mr. and Mrs. Marco Benedetto
Dr. Latanya Benjamin
Mr. Nathan Bennett
Ms. Annie Bennett
Mr. and Mrs. Lynn Bernard
Ms. Debbie Best
Mr. and Mrs. Robert Bialer
Mr. Robert Bier
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Peterson Commercial LLC
Mr. and Mrs. James Phillips
Pittsburgh Associates
Mr. and Mrs. Robert Ponzo
Mr. Anthony Poselenzny
Mr. and Mrs. Joseph Proscia
Mr. and Mrs. David Purcell
Hugh and Margaret Reid
Mr. and Mrs. Victor Rice
Mr. John Riley
Riverbend Mobile Home and RV Park Comm
Mr. Eric Schweighoffer
Mr. and Mrs. Stephen Schweighoffer
Drs. Pedro and Lucy See
Jennifer See
Rachel See
Mrs. Janet Showers-Patterson
Mr. Day Lewis Patterson
Mr. and Mrs. Elliot Shulman
Ms. Krystal Summers
Mr. and Mrs. Harry Sundik
Mr. and Mrs. Ronald Swenson
Texas Gauge & Controls, Inc.
Ms. Janie Thompson
Tibbs Paving Inc.
J. Derek Tieken, DDS
Mr. and Mrs. Andrew Trees
Mrs. Jeannie Nina Trezevant
Ms. Shelley Trojanowski
Dr. and Mrs. Joseph Trombley
Ms. Alexandra Valsamakis
Mr. Andy Golden
Mr. and Mrs. Werner Vavken
Vestal Varsity Club Volleyball Tournament
W. E. Barrett, Inc.
Mamie Webb
Ms. Mary Anne Wegmet
Mr. and Mrs. Thomas Wornom

$1,000 - $4,999

Mr. and Mrs. Robert Adamo
Adobe Equipment Houston, LLC
Mr. Mark Ajjouni
Almaden Valley Athletic Club
Altered Images Color Salon & Day Spa
American Tube Products
Anacor Pharmaceuticals, Inc.
Anonymous(3)
Barney - Running for Research
Gioia Mia Bianchi
Mr. Brian Brager
Dr. and Mrs. David Bryson
Mr. Daniel Carroll
Mr. and Mrs. Rodney Chapin
Cheveron Humankind
Cina - Wine Tasting Event
Mr. Jim Costello
DBG Services, L.P.
Dermal Therapy Research, Inc.
Deutsche Bank Americas Foundation
Mr. Mike Donohue
Dr. and Mrs. James Stark Draper
Elliott - Bake Sale
Fasciano - T-Shirt Sales
Mr. Alexander Forrest
Raymond Funada, DDS
GE Foundation
Ms. Diana Gendotti
Sally and Donald Haugk
Health & Medical Research Charities
Po-Han Huang
Mr. and Mrs. Joseph Hugenberg
Iott Pumpkin Paint & Bake Sale
Iott's Softball & Pork Feed
Mr. and Mrs. John Jessiman
Mr. Martin Kahn
Kohl's
Kurt Filiopvitch, Trustee
Dr. and Mrs. Moise Levy
M & J Hall, Inc.
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Mr. and Mrs. Michael Miller
Drs. Ellen and Leonard Milstone
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Mr. and Mrs. David Norris
Northwestern University
Ms. Marcia Ohlwiler
Our Lady of Peace Columbiettes Council 11378
Dr. Amy Paller
  Mr. Etahn Cohen
Mr. and Mrs. James Pate
Pittsburgh Pirates Ticket Sales
Ms. Marylynne Pope
Mr. and Mrs. Michael Potack
RDA ProMart
Dr. Gabriele Richard
Mr. Rory Riggs
Dr. William Rizzo
Royals vs. White Sox Ticket Sales
Mr. and Mrs. Steve Schumacher
Schumacher - Wine Tasting Event
Ms. Michelle Shannon
Siemens Caring Hand Foundation
Ms. Nomi Silverman
Mr. and Mrs. Lawrence Silverman
Sovereign Bank Community Development
Ms. Margaret Stewart
Mr. Henry Stewart
Summers Laboratories
Tastefully Simple Event
Team Brenna
The Enchanted Ball
Mr. and Mrs. John Tierney
Tim Horton's Café & Bake Shop Event
Top MD, Inc.
Torrington School Dress Down Day
Toyota Motor Sales, USA
Mr. and Mrs. Brian Turecek
Upsher Smith Laboratories, Inc.
US Raceworks, LLC
Mrs. Margaret Vernet
Mr. and Mrs. Evan Westlake
Dr. Mary Williams
  Dr. Peter Elias
Mr. and Mrs. Andy Wohlgang
Mr. Kevin Wood
Ms. Denise Yong
Dr. and Mrs. Ruey Yu

$5,000 - $9,999

Allergan Foundation
Anonymous(1)
Beiersdorf, Inc.
Mr. and Mrs. Jason Cohen
Flint Center
General Motors Foundation
Mr. Mark Hawn
Hodgkinson Dance-A-Thon
Madelyn Lyon's Garage Sale
Merz Pharmaceuticals LLC
Mr. and Mrs. Michael Saccente
Select Equity Group Foundation
Select Equity Group, Inc.
Tang Family Foundation
Triangle Skinsational Sip
Tundidor - Zumba Event
Valeant Pharmaceuticals Intl.
Dr. Eugene Van Scott

$10,000 - $99,999

Ace in the Hole Foundation, Inc.
Mr. and Mrs. Michael Briggs
Dane's Friends for FIRST Concert
Galderma International S.A.S.
Mr. and Mrs. Robert Hoerle
Lido West Beach Run/Walk
Mr. George Loening
Monster Dash Fun Run
New York Mets Ticket Sales
Dr. and Mrs. David Scholl
Mr. and Mrs. Vincent Sellechia
UPS Foundation

$100,000 +

Jane's 5K for a Cure
Lennox Foundation

Jane & Henry Bukaty Skin Care Fund

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 a demonstration of the financial need for this product/treatment.

Awards will not exceed $250. 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 the application from FIRST's website and email to the national office at jpickford@firstskinfoundation.org, fax to 215.997.9403 or mail to the attention of:

Jane & Henry Bukaty Skin Care Fund Foundation for Ichthyosis & Related Skin Types, Inc.®
2616 N. Broad Street, Colmar, PA 18915
The deadline for submitting an application is July 31, 2014.
You will be contacted by the office if you have been awarded aid from this fund.

2014 Testimonial Dinner

On Saturday September 6, 2014, FIRST will be honoring members Dave and Valerie Scholl, at our 2014 Testimonial Dinner. The dinner will take place at the Heritage Club in Mason, Ohio, and all proceeds will benefit FIRST's mission to educate, inspire, and connect those touched by ichthyosis and related skin types. As they are long-time members of the FIRST family, we are privileged to pay tribute to the Scholls and their countless contributions to FIRST.

The Power of Art and Advocacy *...continued*

By: Maureen Neville

We met Rick at his studio in downtown Manhattan. And although in this very same space he had photographed many “celebrity” models in the 80s and 90s, for a variety of high-profile clients including Yves St. Laurent, Revlon, L’Oreal, Elle, Harper’s Bazaar, and GQ—now this quiet studio, accessorized by perfect photos of the “imperfect” and drenched in the warmth of the sun and a friendly dog named Buster, seemed as far away from the glitzy world of high-fashion as one could be.

In his former career, Rick took photographs of what were considered “the world’s most beautiful people:” chic, striking images used in publications all over the world. But one day, on a break from a photo shoot, a chance encounter on a Manhattan street changed everything—he not only redefined his life’s path, but redefined the meaning of beauty.

Rick had been feeling disillusioned by the high-fashion industry and in this moment of serendipity, he walked by a young woman with albinism (a genetic condition that results in loss of pigmentation in the hair and eyes) at a New York City bus stop. He found her to be breathtaking, and wondered why she wasn’t considered beautiful in his other world.

Upon returning home Rick began a process of discovery—about albinism, about people with genetic differences, and about himself. What he found was startling and upsetting. The images that he saw were sad and dehumanizing. In medical textbooks children with a difference were seen as a disease, a diagnosis first, not as people.

He could not disagree more.

This exploration resulted in a show-stopping magazine spread for Life Magazine featuring young women with albinism smiling out from under the headline “Redefining Beauty” —Rick Guidotti, photographer.

But his mission didn’t stop there. In fact ,it had only begun.

His foundation called Positive Exposure, an innovative arts, education and, advocacy organization, working with individuals living with genetic, physical, cognitive, and behavioral difference, was soon born. For 15 years now, Rick has been photographing people with genetic differences, redefining beauty, and introducing the world to an entirely new movement: the human movement.

He spends his days photographing members of the genetic, physical, cognitive, and behavioral difference community, giving self-esteem workshops, lecturing to medical students, parent groups and conferences, corporations, nursing and genetic counseling programs, universities, and elementary schools worldwide. His lectures focused on the motto of Positive Exposure: CHANGE HOW YOU SEE. SEE HOW YOU CHANGE. SEE WHO YOU CHANGE. They are delivered with such resonance, such passion, they are often punctuated by standing ovations. His message, a continuous drum beat throughout his presentation, is individuals living with a genetic difference are first and foremost human beings.

Photographer:
Rick Guidotti

Rick also has a unique knack for doing the impossible—connecting deeply with teenagers. FIRST member Marc Benedetto (affected with lamellar ichthyosis) and his mom, Denise, had joined us at Rick’s studio for the afternoon. Within minutes of his arrival, it was clear—any self-consciousness Marc may have been feeling had leaped out the window of the 6th floor loft, alongside any reservations he may have had of being photographed by a former fashion photographer. Marc was excited to share the stories of his life, his plans for the future, and his newly found appreciation for self-advocacy.

“Just being here today, you are your own advocate. That’s fantastic,” Rick told him.

Rick is also the subject of a documentary of the unflinching new film On Beauty, directed by Joanna Rudnick (In the Family). And, his photographic exhibition, Positive Exposure; The Spirit of Difference, premiered at the People’s Genome Celebration in June 2001, at the Smithsonian’s National Museum of Natural History in Washington, DC. Positive Exposure: The Spirit of Difference continues to exhibit in galleries, museums, and public arenas internationally.

We are pleased to also announce Rick will be the keynote speaker at the FIRST National Family Conference June 20-22, in Indianapolis, Indiana!

SEE WHO WE CHANGE.

FIRST
Foundation for Ichthyosis & Related Skin Types®
Educate • Inspire • Connect
2616 N. Broad Street • Colmar, PA 18915

FIRST to Know Calls Taking Place

May 18	**Vacation and Ichthyosis** Traveling and Managing Ichthyosis Away From Home
June 1	**PRP** Families Connecting Together
June 22	**Teens** What's Up?
July 6	**XLI** Families Connecting Together
July 27	**College 101** What to Expect When You Get to Campus