

FIRST Celebrates RARE Disease Day with Positive Exposure & the FRAME Project...

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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.*

CEO Report



In many ways 2014 was a very memorable year. However, for me, it marked a particularly special milestone as I celebrated my 15th anniversary at FIRST. And, as each year has been filled with great passion for supporting our families and the privilege of collaborating with the world's leading medical and science experts, I am continually inspired by the hope for a better future for all those affected. Thanks to science, technology, and many dedicated people, the horizon is filled with even more hope than ever before! In fact, if I had to sum up the journey, there is one single word that comes to mind: flourish.

After months of collaborating with a unique and talented team of individuals, comprised of not only FIRST staff, but affected family members, ichthyosis investigators, and FIRST Board members, I am delighted to announce the completion of our next four-year strategic plan, (2015-2018). There are many exciting initiatives that will be unveiled over the next few weeks, months and years. Members will note that our overall strategy greatly aligns with the evolving landscape of communications, outreach, and medical research

Due to our enhanced communication efforts this year, and our overall embracement of technology and social media, 2014 will no doubt also be remembered as the year of connection. We hit our highest reach on Facebook with our inspiring "IAM selfie campaign" – empowering members to use their voices, photos and messages to share their stories and raise awareness. We also produced the highest attended National Family Conference to date, with 407 attendees in Indianapolis. We are looking forward to moving the conference to the West Coast for 2016 - San Diego! In the interim, we have planned many opportunities for in-person connection and support at our Regional Patient Support Forums in Toronto, Minneapolis, Phoenix and Miami.

In 2014, the FIRST Research Grant Program awarded \$50,000 to Dr. Brittany Craiglow of Yale University for her collaborative study of newborn and early childhood complications and comorbidities that accompany the ichthyoses. FIRST anticipates that the results will be particularly helpful in counseling newly diagnosed families, which represents a significant part of FIRST's work as a patient support organization. Additionally, Dr. Ryan O'Shaughnessy received \$50,000 from the grant program to continue his work in targeting the scaling pathways in ichthyosis. This research specifically focuses on understanding the mechanisms that cause scaling, and subsequently increasing the options for treatment.

As we move into the next phase of our journey with the ichthyosis community, we are inspired and motivated by this extraordinary group. On behalf of Moe, Mo, Chris, Lisa and myself, the depth of our gratitude for each and every one of the members is truly bottomless, and we would like to extend a warm thank you to everyone (members, physicians, investigators, staff, Board members) for their continued commitment to FIRST.

Best Regards,

Jean R. Pickford
CEO, FIRST



Please join us in welcoming our newest staff member, Madeline Bergman. "Maddy" has joined FIRST as our new Director of Development and we are delighted to have her on board! Madd previously held the positions of Communication and Development Specialist at the North Penn School District and the Lead Program Manager at Best Buddies in Wilmington, DE. She is a graduate of Drexel University and a native to Lansdale, PA. Feel free to send her a note and say hello! mbergman@firstskinfoundation.org.

President's Report

Dear FIRST Members:

This will be my last letter to you as my two-year term as President and 10-year membership on the Board of Directors has expired. It has been an honor and a privilege to serve such a fine organization and I want to thank Jean Pickford, her wonderful staff, and the Board for their hard work and assistance during my tenure.

There were many achievements during 2014, beginning with our continued improvement in grassroots activities that raised over \$184,000. More and more families are becoming involved and realizing that this activity is the backbone of our fundraising and EVERY dollar counts.

Of course, the highlight of the year was our 18th biennial FIRST National Family Conference in Indianapolis, where a record 407 attendees - including 65 new families from all corners of the globe - arrived. We continue to be the leading source of information and research in the world for ichthyosis. I certainly hope to see you in San Diego in 2016.

Additionally, we added 471 new families in 2014, to bring us to a total of 4,036 affected families in our database. Many of these additions were a direct result of the numerous innovative communication techniques introduced during the year.

Our Investment Committee has again been successful through their diligent work with SunTrust to place us in a very favorable financial position for the years ahead.

Lastly, I am pleased to introduce Jeff Hoerle, our new President. We are very fortunate to have such a talented, dedicated person helping guide us into the future. We wish Jeff, his wife Allison, and children Katharine, Nicholas and Sasha all the best!

Best wishes,

President, Board of Directors
Mike Briggs





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Dear Members and Friends:

We have had a great year and our results from a financial perspective reflect a strong and stable organization. Once again, I would like to thank Jean and her professional staff for their continued commitment to excellence and their enthusiastic support to all. Mike Briggs has been an inspiration, as well. He helped lead this group to incredible heights never even imagined. Thanks for all you do, Mike, and for your incredible leadership. Jeff Hoerle, our incoming president, should also be recognized for his tireless energy and effort directed to our organization; he is always there to help.

Now to the state of financial affairs. We had a solid year for the period ending September 30. Based on our audited financial statements, net assets were up \$175,237. Overall contributions were up \$12,718. We enjoyed \$34,735 of increased investment income over last year's earnings. Administration expenses were up, but only slightly - mostly related to payroll costs. We did significantly decrease our website management expense. The administrative expenses continue to be held in check. Our expenses as a percentage of income 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 managing our portfolio. 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.

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.

Sincerely yours,

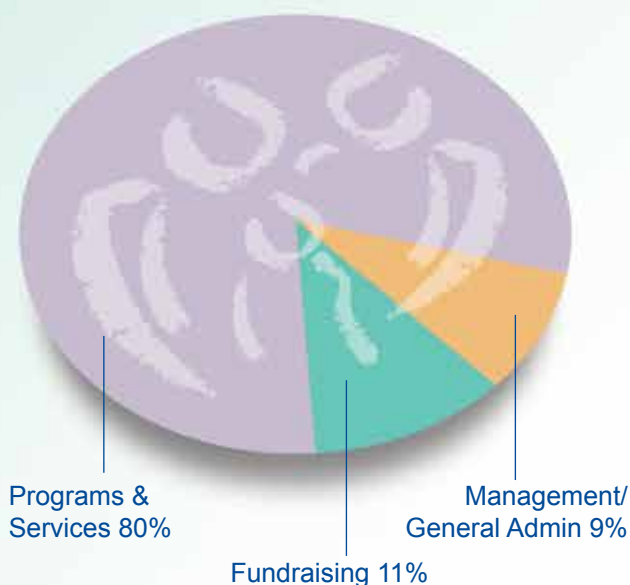
Larry Silverman, CPA, CFP
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FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC.
STATEMENT OF FINANCIAL POSITION
SEPTEMBER 30, 2014 (WITH COMPARATIVE TOTALS FOR 2013)

	2014	2013
ASSETS		
Current		
Cash and cash equivalents	\$ 120,578	\$ 187,791
Investments	1,747,780	1,571,672
Prepaid expenses and miscellaneous	3,115	3,115
Unconditional promise to give	50,000	-
Receivables	20,527	25,866
Total current assets	1,942,000	1,788,444
Cash, permanently restricted	110,013	110,013
Furniture and equipment, net	9,080	5,472
Other assets		
Unconditional promise to give	25,000	-
Deposits	3,000	3,000
	28,000	3,000
Total assets	\$ 2,089,093	\$ 1,906,929
LIABILITIES		
Current		
Accounts payable and accrued expenses	\$ 28,143	\$ 21,216
Total current liabilities	28,143	21,216
NET ASSETS		
Unrestricted		
Unrestricted	1,083,266	1,029,974
Board designated	294,649	218,373
Total unrestricted	1,377,915	1,248,347
Temporarily restricted	573,022	527,353
Permanently restricted	110,013	110,013
Total net assets	2,060,950	1,885,713
Total liabilities and net assets	\$ 2,089,093	\$ 1,906,929

Expense Allocation Percentage



The Statement of Financial Position is excerpted from the Foundation's audited financial statements as of September 30, 2014. 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.



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Mr. and Mrs. Scott Thompson
Mr. and Mrs. James Thorn
Mr. and Mrs. Douglas Thornton
Ms. Catherine Tiemeyer
Ms. Melissa Tierney-Osterloth

Ms. Shelley Tobey
Mr. Ted Tonn
Pouya Torabi
Mr. Terrence Tormey
Dr. and Mrs. Joseph Trombley
Mr. and Mrs. Sam Unruh, Jr.
Mr. and Mrs. Jason Ura
Valeant Pharmaceuticals Int'l.
Ms. Shannon Simmons VanderSwaagh
Ms. Rochelle Vaughn
Vaughn Duffy Wines
Ms. Irene Velasquez
Hazel Vernon, MD
Fulvia Veronese Marino DeMarzo
Ms. Peggy Viehweger
Reverend and Mrs. Franklin Vilas
Mr. and Mrs. Phillip Vitali
Mr. and Mrs. Thomas Voll
Volume Salon
Mr. and Mrs. John Allen Waldrop, III
Mr. and Mrs. Jimmy Wall
Wallaroo Hat Company
Mr. and Mrs. Scott Wallwork
Mr. and Mrs. Samuel Walters
Ms. Mary Jo Ward
Mr. Michael Wasieleski
Ms. Gladys McCarter
Mr. and Mrs. Joseph Weldon
Mr. Charles Wells
Mr. and Mrs. Bill Westlake
Bobbi Wiercioch
Mr. and Mrs. Richard Wiese
Mr. Joe Williams
Mr. and Mrs. Peter Williams
Ms. Lisa Wilps
Mr. Thomas Wilson
Mr. Edward Yahner
Albert Yan, MD
Mr. Jonathan Young
Mr. and Mrs. Mike Young
Mr. Scott Zailer
Mr. Mark Zarrabian
Mr. and Mrs. Edward Zawacki
Mr. Eric Zugerma

\$250 - \$499

Mr. and Mrs. Richard Abbott
Ms. Nancy Abrams
Mr. and Mrs. Leonard Adamson
Ms. Maureen Albert
Dr. and Mrs. Christopher Anadale
Okey Anderson
Andrew Sander's Half Marathon
Mr. and Mrs. Joseph Andrews, Sr.
Anonymous (3)
Mr. and Mrs. Robert Averill
Bacliff Dental Clinic, PA
Mr. Ryan Bankhead
Mrs. Claudia Barillas
Mr. Stephen Barker
Mr. and Mrs. Christopher Barta
BCCNS Life Support
Mr. Michael Beard
Mr. Kenneth Beck
BelleCore, LLC
Mr. Patricio Benavente
Mr. and Mrs. Marco Benedetto
Mr. and Mrs. Christopher Bentson
Ms. Jody Berg
Ms. Debbie Best
Beth Hampshire's ThirtyOne Party
Ms. Jane Graves Blackford
Mr. and Mrs. Christopher Block
Ms. Carol Blue
Mr. and Mrs. Brandon Bond
Hon. and Mrs. Barry Brandt
Ms. Cara Brook
Mr. and Mrs. Rodney Brown
Anna Bruckner, MD
Mr. and Mrs. Richard Campisi
Ms. Ellen Carroll
Mrs. Sonal Chandar
Mr. and Mrs. Charles Clare
Ms. Kathryn Forrest Clark
Mr. and Mrs. Ronald Clark
Ms. Marcia Clayton-Hollimon
Cleveland Indians Baseball Company
Cleveland Indians Game
Mr. and Mrs. Jason Cohen
Cole's Cookie Sale
Brittany Craiglow, MD
Dale and Deborah Crawshaw
Ms. Krista Dauner
Mr. and Mrs. James Dawson
Mrs. Howard and Charlotte Dean
Mr. and Mrs. John Deering
Mr. and Mrs. Carl DePiano
Ms. Mary Dillon
Double M Distribution
Ms. Paulette Dudley
Ms. Anne Dunipace
Mr. Steven Eccher
Edward and Norah Blum, Inc.
Mr. and Mrs. Charles Ethan Edwards
Ms. Denise Eiser
Mr. and Mrs. Roy Farmer
Mr. and Mrs. David Fasanella
Mr. and Mrs. Joseph Femminella
Mr. and Mrs. Alan Fershtman
Mr. and Mrs. Michael Fevola
Mr. and Mrs. Lucas Fiore, Jr.
Ms. Holly Friddle
Ms. Lucille Furka
Mr. and Mrs. Nezmi Gad
Ms. Lisa Gigli
Steve Gonzalez, PLLC
Mr. and Mrs. Victor Goodman
F. O'Neil Griffin
Ms. Veronique Hager
Ms. Stacy Hall
Mr. and Mrs. John Hamill
Ms. Judith Hartmann
Helamia, LLC
Ms. Amber Hiner
The House of Adonai
Houston Astros Game
Mr. James Huetson
Ms. Katherine Huggins
Mr. and Mrs. Roger Huntington
Indianapolis Indians First Night Out
Indians, Inc.
Industrial Packaging Systems
Rusty Ingram
INT Topical Steroid Addiction Network
Mr. and Mrs. Richard Keathley
Samira Kirmiz, MD
Mr. and Mrs. Stephen Klaffer
Ms. Carmen Klaffer
Dr. and Mrs. W. R. Konneker
Mr. John Kopchick
Ms. Char Kopchick
Mr. Michael Kornmiller
Ms. Kelli Kotowski
Mr. Matt Kozinski
Mr. Harry Lancaster
Mr. and Mrs. Andre Landry, III
Ms. Lynette Limosnero
Imran Younas Malick
Mrs. Margaret Manning
Mr. and Mrs. Simon Martin
Erin Mathes, MD
Mr. and Mrs. Richard Maurer
Mr. and Mrs. Ian McCurrach
McGinnis Chiropractic
Mrs. Jean Melton
Ms. Denise Merritt
Michael G. Moore, DDS
The Honorable & Mrs. Gary Mills
Mr. Andrey Mukin
Mr. and Mrs. Thomas Murphy
Nancy Osentoski IAM
New York Islanders Hockey Club, LP
Diana Nordlund
Ms. Juditha Ohlmacher
Mr. and Mrs. John Oswalt
Paine Intermediate School Dress Down Day
Ms. Mimi Patterson
Pearland Pediatrics, PA
Ms. Erin Peterfeso
Ron and Carolyn Phillips
Ms. Elsie Pickens
Mrs. Virginia Pickles
Ms. Esther Pinto
Pratt's Wear Jeans on Friday Event
Prevention Pharmaceuticals, Inc.
Rare Kids, Inc.
Mr. Christopher Raschke
Mr. and Mrs. Tim Reisinger
ReNew You Laser Skin Center
Mr. and Mrs. Joseph Roberts

Ms. Gladys Roden
Mr. John Roden
Ms. Victoria Rotondo

Sax Roscoe Construction, Inc.
Mr. and Mrs. David Schell
Mrs. Debra A. Scholl
Sharlet Selinger
Mr. and Mrs. Craig Shaffer
Mrs. Kerry Shaw
Mr. and Mrs. Elliot Shulman
Mr. and Mrs. William Shute
Mr. and Mrs. Daniel Siegel
Mr. Mike Sieron
Mr. and Mrs. Robert Simmons
Ms. Samantha Sizemore
Mr. Terry Smith
Mrs. Jordan Brooks Flake
Ms. Robin Smith
Mr. and Mrs. Dennis Sopher
Mr. and Mrs. Eric Stafford
Mr. and Mrs. Keegan Steele
Mr. and Mrs. David Stenseth
Mr. and Mrs. David Stevenson
Superheros Reading Month
Mr. and Mrs. Ronald Swenson
Marc Swerdlick, MD
Mr. and Mrs. Robert Taylor
Mr. and Mrs. Thomas Theaker
Mr. and Mrs. Scott Thompson
Ms. Melanie Thorpe
Mr. and Mrs. Andrew Trees
Mr. Carl Trindle
Ms. Barbara A. Body
Mrs. Cara Tundidor
Tupperware/Tastefully Simple
Mr. and Mrs. Richard Vedder
Mr. and Mrs. Charles Wagner
Mr. and Mrs. Jerome Wagner
Ms. Judith Watts
Mr. and Mrs. Eric Wegmet
Mr. and Mrs. Tom Weihe
Mr. and Mrs. Richard Weinert
Mr. and Mrs. Bud Wheeler
Mr. and Mrs. Robert White
Mr. and Mrs. Robert Willcox
Mr. and Mrs. Sammy Williams
Mrs. Kellie Wilson Mr. Jose Ragel
Ms. Elizabeth Wirstrom
Mr. Lowell Wright
Ms. Megan Wright
Wrinkle, Gardner & Co., PC
George and Sherry Zailer

\$500 - \$999

5th Annual Power in the Park Event
Mr. and Mrs. Kyle Alexander
Amcap Mortgage
Dr. Rex Amonette
Johnnie Dacus Amonette
Anonymous (1)
Kjartan Armann, MD
B.F. Ascher & Company, Inc.
Ms. Jacquelyn Bach
Bailey Pretak Premier Designs Event
Mr. and Mrs. Glenn Balog
Mr. and Mrs. Marc Benedetto
Ms. Reba Benson
Ms. Christine Booe
Ms. Kristi Bowden
Ms. Meshell Boydston
Mr. and Mrs. Mark Breen
Mr. and Mrs. Lewis Brinkley
Caravan Beads, Inc.
Mrs. Christine Chan
Ms. Martina Cheung
Keith Choate, MD, PhD
Mr. and Mrs. Jeremy Chunick
Circle City Photobooth Rentals, LLC
Mr. and Mrs. Roland Coates
Ms. Kimberly Cole
Dr. and Mrs. John Compton
Mr. and Mrs. Salvatore Corbo
DeBartolo Family Foundation
Ms. Quinn Deloughary
Ms. Teresa Delprete
Mr. Michael Diamond
Ms. Amy Miller
Russell and Carla Dietz
Ms. Alicia Dortch
Double Helix Development US, Inc.

Mr. and Mrs. Mark Dunkin
Edward's Chick-fil-A Event
Erin Peterfeso's 100 Mile Run

Mr. and Mrs. Mark Evans
F.O.E. Kane Aerie 307
Mr. and Mrs. Joseph Fasciano
Ms. Marcia Ferguson
FLIR Commercial Systems, Inc.
Mrs. Linda George
Kelly Gerland
Gerland Team, Inc.
Shari Gilevich
Mr. and Mrs. Carlos Godby
Mr. and Mrs. Jack Grams
Grams Holiday Challenge
Mr. and Mrs. Mike Green, Jr.
Mr. and Mrs. Mike Hall
Mrs. Beth Hampshire
Mr. and Mrs. John Havrilla
Mr. and Mrs. Leo Hecke
Mr. and Mrs. Jason Hedley
Jill Hirschfeld
Mr. and Mrs. Scott Hollenbeck
Mr. and Mrs. David Hoon
Mr. and Mrs. D. A. Hopkins
Mr. William Horton Jr.
Mr. and Mrs. Yung Huang
Ms. Tiffany Jackson
Jason International, Inc.
Mr. and Mrs. Joe Johnson
Agnieszka Kapelewska
Mr. and Mrs. Jonathan Kimmelman
Mr. and Mrs. Mark Klafter
Mr. and Mrs. Mark Klima
Mr. and Mrs. Matt Kocher
Mr. George Kollias
Mr. and Mrs. Rene Latreille
Gary Lau, DDS
Mr. and Mrs. Paul Licursi
Kyle and Deann Look
Mr. and Mrs. Bruce Lynch
Mr. and Mrs. Jeffrey Lyngaas
Mr. Tom Lyons
Mr. and Mrs. Patrick Lyons
Mr. and Mrs. Rick Malatesta
Ms. Nancy Mantel
Mr. and Mrs. Peter Markwald
Mr. and Mrs. John McCoy
Mr. Peter McHugh
Ms. Louise R. McNamee
Mr. and Mrs. Andrew McNelly
Mr. Thomas Messner
Mr. Harrison Miller
Ms. Clare McCamy
Ms. Alicia Morales
Mr. and Mrs. Simon Morris
Ms. Denise Morrone
Mr. Joseph Morsman, III
National Health Council, Inc.
Mrs. Heather Newland
Mrs. Dawn Nolet
Mr. and Mrs. Warren O'Brien, Jr.
Mr. Timothy Ohlweiler
Mr. Paul Olivo
Ms. Dorothy K. Grange, MD, PhD
Mr. Roy Palenbaum
Patagonia Pharmaceuticals, LLC
Mr. and Mrs. Richard Pedtke
Mr. and Mrs. Thomas Petelin
Mr. and Mrs. Brent Pfeiffer
Mr. Darren Phelps
Ms. Kate Piche
Mr. and Mrs. Stephen Pickford
Premier Insulation Services Corp.
Mr. and Mrs. Joseph Proscia
Mr. and Mrs. David Purcell
Ms. Glenda Randall
Jason and Angela Reister
Mr. and Mrs. Victor Rice
Mr. and Mrs. Kyle Robinson
Robinson's Jeans for Genes
Running for Brews, LLC
Mr. and Mrs. Kenneth Schaap
Mr. and Mrs. Charles Schaffer
Mr. and Mrs. Justin Scholl
Mr. and Mrs. Stephen Schweighoffer
Mr. and Mrs. William Scully
Ms. Jill Selinger
Mr. Ray Perez
Sempra Energy Utility

Mrs. Janet Showers-Patterson
Mr. Day Lewis Patterson
Mr. and Mrs. Mike Soper
South Troy Timing Association
Mr. and Mrs. Larry Staton
Mr. Mark Steinitz
Ms. Camilla Strickler
Mr. and Mrs. Harry Sundik
Suntrust
Superhero Cape Dash
Susan Cauthen Travel, LLC
Mr. and Mrs. Chris Swisher
Texas Gauge & Controls, Inc.
The Theraplex Company, LLC
Ms. Jennifer Thoele
Mr. Michael Schulze
Ms. Janie Thompson
Mr. and Mrs. John Tierney
TWWC, Inc.
Anthony Vitarelli, DDS
Ms. Mary Anne Wegmet
Ms. Brianne Wopperer
Wopperer's Jeans for Genes
Mr. and Mrs. Thomas Wornom
Mr. and Mrs. Brian Zavitz

\$1,000 - \$4,999

American Tube Products
Anonymous (3)
Mr. and Mrs. James Babcock
Sherri Bale, PhD
Beach Bonfire Event
BeAed
Mr. George Bianchi
Gioia Mia Bianchi
Mr. and Mrs. Merle Blanton
Boston Celtics Shamrock Foundation 50/50
Raffle
Boston Red Sox Game
Mr. and Mrs. James Brown
Dr. and Mrs. David Bryson
Mr. and Mrs. Rodney Chapin
Brian Cheng, MD
Mr. and Mrs. Sean Cina
Cina Wine Tasting Event
City of Campbell
Mr. and Mrs. Tom Clemmer
Mr. Doug Copple
Mr. and Mrs. Russ Cossel
Mr. and Mrs. Jack Cox
Mr. Ralph Curtin, Jr.
Mr. Tim Dang
Dr. and Mrs. Clifford Daugherty
DBG Services, LP
Dermal Therapy Research, Inc.
Dr. and Mrs. James Stark Draper
Dugan's Golf Outing
Mr. and Mrs. Jack Ellis
Episciences, Inc.
Evan Fasciano's T-shirt Sale Event
Mark Fagan, MD
Wen Fan
Mr. Qazi Fazal
Dr. and Mrs. Phil Fleckman
Ms. Bobbi Florian
The Gaffney Foundation
Mr. and Mrs. Ken Gendotti
GeneDx, Inc.
Giovanna & Diego
GL Group
Gleason's Event
Mr. Irving Goldberg
Mr. James Griffin, Jr.
Mr. and Mrs. David Heyson
Mrs. Stacey Horr
Mr. and Mrs. Joseph Hugenberg
Iott Pumpkin Paint and Bake Sale
Iott Softball and Supper Event
Jackie Osowski Chicago Marathon Event
Mr. and Mrs. John Jessiman
Johnson & Johnson/Aveeno
Meera Kamdar
Mr. and Mrs. Richard Kass
Ms. Nancy Kennedy
Mr. and Mrs. Wolfgang Knabe
Kohl's
Jaehee Koo
Dr. and Mrs. Moise Levy
Luna's Mexican Restaurant
Mr. and Mrs. J. David Mast
Ms. Carol McCutcheon

Mr. and Mrs. Robert Melton
MicrodermaMitt, Inc.
Drs. Ellen and Leonard Milstone
Todd and Rachael Mooney
Mr. and Mrs. Steve Naber
NeoStrata Company
Ms. Edie Nordlund
Mr. Bob Nordlund
Ms. Marcia Ohlweiler
Mr. and Mrs. Frank Osowski
Our Lady of Peace Columbiettes Council 11378
Amy Paller, MD
Etahn Cohen
Mr. and Mrs. James Pate
William Perry, MD
Mr. and Mrs. Michael Potack
Mr. and Mrs. Roger Pretak
Raising the Balloon for Brenna
Gabriele Richard, MD
Mr. and Mrs. Alex Riedel
William Rizzo, MD
Sami Sada
Athar Saeed
Sadaf Saeed
Mr. John Schoendorf
Mr. and Mrs. Aaron Scholl
Mr. Eric Schweighoffer
Drs. Pedro and Lucy See
Jennifer See and Rachel See
Mr. and Mrs. Vincent Sellechia
Bhavleen Sethi
Shirley's Donuts
Siemens Caring Hand Foundation
Ms. Nomi Silverman
Mr. and Mrs. Lawrence Silverman
Robert Silverman, MD
Summers Laboratories
Synergia One
Ms. Lauren Thoma
TinySuperheroes, LLC
TinySuperheroes Event
TopMD, Inc.
Toyota Motor Sales, USA
Upsher Smith Laboratories, Inc.
Vestal Central Schools
Vestal Central Volleyball Tournament
Mr. and Mrs. Benjamin Waldshan
Washington Nationals Game
Dr. Mary Williams
Dr. Peter Elias
Mr. and Mrs. Andy Wohlgang
Ms. Denise Yong
Dr. and Mrs. Ruey Yu

\$5,000 - \$9,999

Tang Family Foundation
Eugene Van Scott, MD
Mr. Richard Bauman
Dana Conslor
Mr. Robert Kraybill
Ms. Durreen Shahnaz
The Driven Race & Club
Beiersdorf USA
Pittsburgh Pirates Game
Mr. and Mrs. Bob Dubanski
Mr. and Mrs. Brian Turecek
Mr. and Mrs. Chris Phillips
Lautus Pharmaceuticals

\$10,000 - \$99,999

5th Annual Lido West Beach Run/Walk event
Ace in the Hole Foundation, Inc.
The Ambrose Monell Foundation
Anonymous (1)
Mr. and Mrs. Michael Briggs
Dane's Friends for FIRST Concert
Mr. and Mrs. Robert Hoerle
Mr. Jeff Hoerle
Ms. Allison Draper
Mr. George Loening
Merz Aesthetics
Monster Dash Run
NY Mets Game
Mr. Frank Perano
Dr. and Mrs. David Scholl
Select Equity Group Foundation

\$100,000 up

Anonymous (1)
Lennox Foundation

Grassroots Fundraising

Thirty-One Gifts Online

Longtime FIRST member and volunteer Beth Hampshire took to the Internet to help raise funds for FIRST. During November 2014, Beth held a Thirty-One Gifts online fundraiser. Beth was so happy with the response from family, friends, and even strangers, for her event. Beth stated, "I was surprised by the amount of people that I didn't know, who were willing to participate because they took the time to check out FIRST's website and felt moved enough by the stories they saw to participate in the fundraiser." This was the first time that Beth planned a fundraiser for FIRST, but she is hoping to hold another event in 2015. Many thanks to you Beth for your support!



Superheroes Come to Life at a Birthday Party

When you celebrate a birthday, it is such a fun occasion, surrounded by family and friends. Some people make the celebration even more special when opting to donate their presents to a good cause. Such is the case for Craig Hodgkinson. Recently, Craig's wife, Sarah, and his family surprised him with a superhero-themed celebration for his 45th birthday. Everyone came dressed up as superheroes. They hosted the party at the Enchanted Theater Company, where their 10-year-old daughter Ema takes drama classes, and Craig and Sarah attend improv nights. Rather than having attendees bring a gift, the Hodgkinson family asked each participant to instead make a donation to FIRST in honor of Ema, who is affected with ARCI-CIE type ichthyosis. The evening was so much fun for all who joined in the celebration and more than \$300 was raised for FIRST. Many thanks to the Hodgkinsons, their family, and their friends for your continued support over the years!

GoFunding for FIRST

Mikael Palmer and his wife, Lisa Anderson Palmer, are the parents of baby, Ally, who is affected with ARCI-CIE ichthyosis. Originally from Stockholm, Sweden, the Palmer family is currently living in Los Angeles, California. They wanted to host a fundraiser and create awareness about ichthyosis, but with family and friends spread around the world, they needed to do something online. Mikael created a GoFundMe page with a photo of Ally and shared their story. The response was overwhelming! The campaign was shared more than 500 times and almost \$6,000 was raised for FIRST. We can't thank the Palmer family enough for this amazing effort.



A Half-Marathon with Full Results

FIRST member Andrew Sanders had competed in a half-marathon a couple of years ago, as had his wife Heather. They playfully competed with each for the better time. Parents to 2-year-old Ruairi, who is affected with epidermolytic ichthyosis, Andrew decided that the Houston Half Marathon was the perfect opportunity to raise funds for FIRST. Having attended the 2014 National Family Conference – Indianapolis, and participating in the FIRST Facebook pages, the Sanders family has received so much support from FIRST and the ichthyosis community, that they wanted to give back. And give back they have! This is the second fundraiser that they have organized on behalf of FIRST. Almost \$1,000 has been raised because of this Houston Half Marathon fundraiser. Many, many thanks to Andrew and Heather for everything they've done for FIRST.

Fort Collins is FIRST on the Dance Floor

Michelle and Allan Schell of Fort Collins, Colorado, gathered their family and friends for a fun night of dancing in support of FIRST. Affected with X-linked ichthyosis, Allan attended the 2012 National Family Conference-Denver, forging connections and gaining valuable information about ichthyosis. After receiving support from the FIRST community, Allan and Michelle wanted to give back. They decided that a dance would be a fun way to gather together, spread awareness, and raise funds. FIRST on the Dance Floor was planned for February 21. Even with a snowstorm on the day of the event, 55 people attended and had a fantastic evening.

A silent auction added to the fun of the night. The Schells raised more than \$3,500 and the owners of the ballroom space were so impressed, that they offered back a portion of the payment to add to the event proceeds. FIRST is so grateful to Allan and Michelle for their tremendous efforts on our behalf.



Jeans for Genes Fundraising for FIRST

Brianne Wopperer and Andrew Costantino are the parents of 16-month-old Andrew, who is affected with ARCI-CIE type ichthyosis. For the second year, in celebration of Rare Disease Day, Brianne and Andrew teamed up with Tony Walker & Company, a retailer in Williamsville, New York, that specializes in high-end denim-perfect for Genes for Jeans Day! TW&C donated 10% of sales on February 28 to FIRST. Andrew and Brianne even had little Andrew at the store and answered questions about ichthyosis! What a wonderful way to create awareness. Last year's event raised more than \$500 for FIRST and this year's event will prove to be just as successful. Many thanks to Andrew, Brianne and young Andrew, for their efforts on behalf of FIRST.



Jamberry Nail Wraps

Newest member of the FIRST Board of Directors Kimberly Cole is the mother of 3-year-old Harper, who is affected with erythrokeratoderma variabilis (EKV). Kim has been very active in fundraising for FIRST since Harper's birth, participating in bake sales and craft fairs to create awareness and raise funds. Kim's latest endeavor targeted Rare Disease Day. Kim sold decorative nail wraps during the

month of January to create excitement and offer participants a way to display their Rare Disease Day pride. The wraps were decorated with logos and designs for Rare Disease Day and sold online, with a portion of the proceeds going to FIRST. The wraps continue to be available for sale to raise ichthyosis awareness anytime. Visit FIRST's website to purchase yours. Much gratitude to Kim for her work on this effort!



Educate

The Phenotype Spectrum of X-linked Ichthyosis Identified by Chromosomal Microarray

FIRST Medical and Scientific Advisory Board member Jennifer Hand, MD, of the Mayo Clinic, discusses the process and conclusions of her latest research endeavor.

Is it possible that a milder form of X-linked ichthyosis is more common than we thought?

Chromosomal Microarray (CMA) is usually a blood test that has become a common method to test babies born with multiple birth defects (congenital anomalies) for a genetic, underlying cause. CMA is very effective at screening the whole genome of an individual for chromosome deletions. The question about X-linked ichthyosis arose because most cases of X-linked ichthyosis (over 90 percent) are caused by a small deletion on the X-chromosome that is spotted easily by routine CMA. Our clinical laboratory at Mayo receives a high volume of infant blood specimen, usually for questions that don't have anything to do with the skin or ichthyosis. However, the laboratory was recognizing cases with a deletion of the steroid sulfatase gene that causes X-linked ichthyosis, but the referral indications mentioned nothing about the skin. We wondered if it was possible that a case of X-linked ichthyosis could be so mild that a physician wouldn't even mention it in the reason for testing.

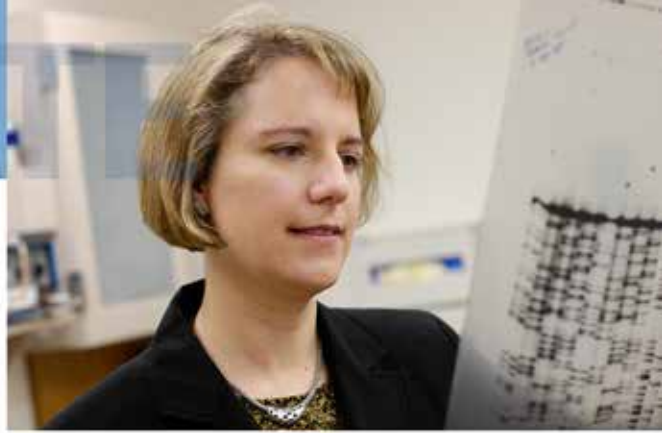
We were able to contact physicians of patients who had a laboratory diagnosis of X-linked ichthyosis for permission to review the medical records more closely. We were a little

surprised that none of the patients we reviewed were described as having "polygonal" or "dirty, brown" scale that is typically associated with X-linked ichthyosis. Rather, some were described as having dry skin or eczema and some were not noted to have prominent changes in their skin typically associated with X-linked ichthyosis. Other authors in the past have described that a milder type of X-linked ichthyosis with yellowish, dry scale is possible. We described that in all the cases diagnosed in the laboratory, for which follow-up was available, and the skin changes were fairly mild.

Our sample size of patients for whom we were able to obtain medical records was small, but in line with the known incidence of X-linked ichthyosis in 1 out of every 1,500 male births. These results don't show that all cases of X-linked ichthyosis are expected to be mild, but that in cases diagnosed in a laboratory, it is possible that the skin of the affected person will not show prominent "dirty brown" or "polygonal" scale described as typical in the existing literature.

Full research abstract can be found at www.jaad.org The phenotype spectrum of X-linked ichthyosis identified by chromosomal microarray.

**Research Authors: Jennifer L. Hand, MD,
Cassandra K. Runke, CGC Jennelle C. Hodge, PhD**



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. It's an opportunity to apply for a small grant to try a new ichthyosis product, for which you would be reluctant to spend the money if it didn't work. Since the fund is limited, each applicant must be registered in our database and is required to submit an application indicating what the small grant would be used for. The application can be downloaded from FIRST's website. Awards will not exceed \$200 and will be awarded two times per year as determined by the Review Committee. Applicants will be eligible to receive one award every two years. Applicants receiving funds from the Diya & Aliya Friends Fund will not be eligible to also receive funds from the Jane & Henry Bukaty Skin Care Fund.

Please download the application from FIRST's website and email to the national office at cwassel@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 August 2015. Recipients will be contacted by the office. The deadline to submit an application for this fund is July 31, 2015.



FIRST Goes to Capitol Hill for Rare Disease Week

In addition to other awareness raising activities, Strategic Planning Committee Member Sam Zavitz and FIRST Program Director Moureen Wenik joined more than 200 rare disease advocates in Washington, DC, for the 4th annual Rare Disease Week on Capitol Hill, February 23 to 27. "During Lobby Day, advocates are given the opportunity to meet with legislators on the Hill to share their stories and concerns, and discuss what they hope will change in the future for those affected with rare disease," said Moureen.



FIRST and Positive Exposure Celebrate RARE Disease Day in NYC!

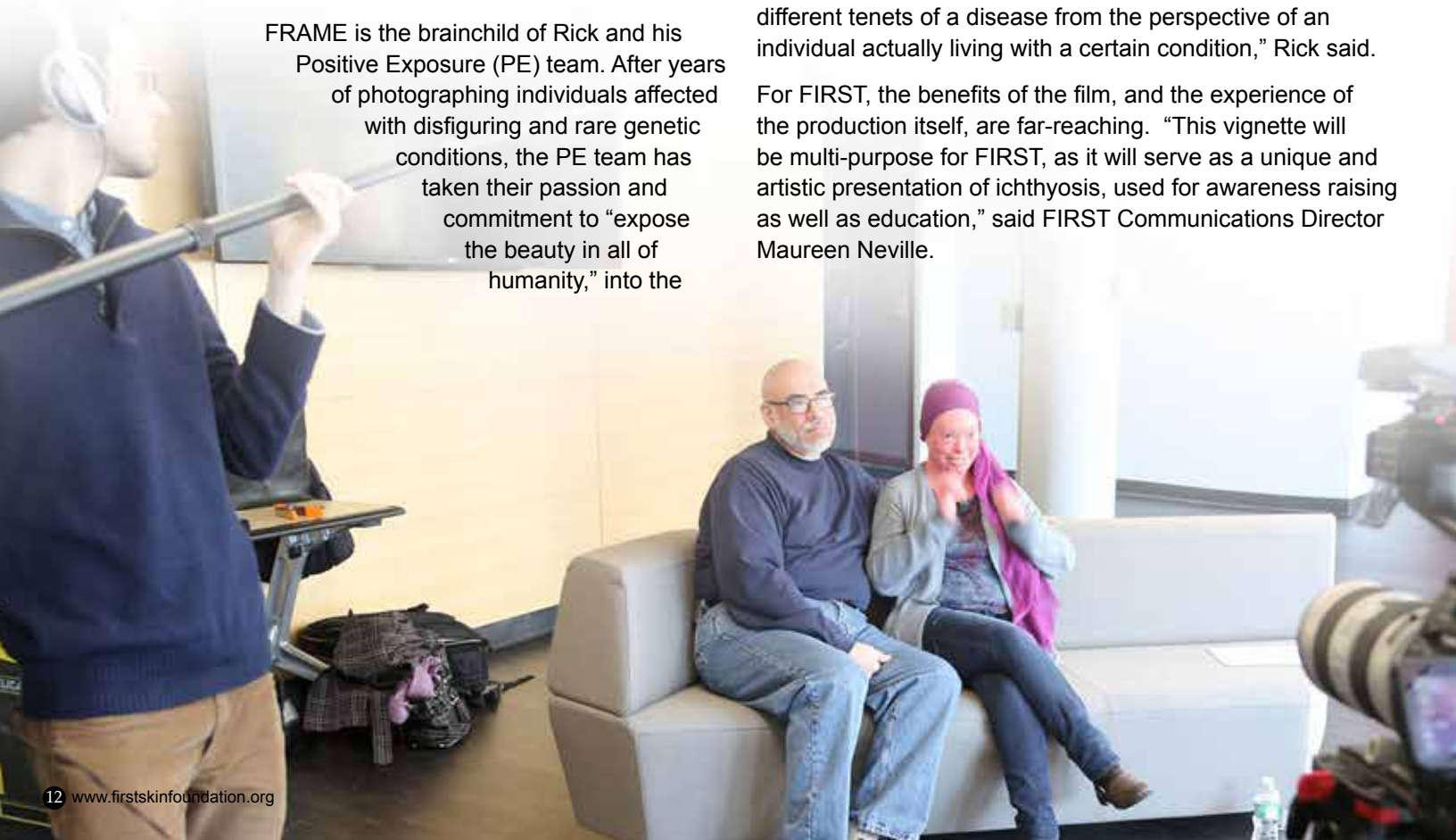
On February 28, World Rare Disease Day, FIRST was the center focus of the FRAME film series (Faces Redefining the Art of Medical Education), created by the innovative arts and advocacy organization, Positive Exposure (www.positiveexposure.org). As many members of the FIRST community are aware, Positive Exposure was founded by award-winning photographer Rick Guidotti, keynote speaker at the 2014 FIRST National Family Conference-Indianapolis, and supporter of the mission of FIRST.

FRAME is the brainchild of Rick and his Positive Exposure (PE) team. After years of photographing individuals affected with disfiguring and rare genetic conditions, the PE team has taken their passion and commitment to "expose the beauty in all of humanity," into the

storytelling arena of film. FRAME is a series of brief vignettes that will serve as an online resource for medical students and other healthcare providers-in-training, medical professionals, teachers, and families. The films highlight the basic characteristics or hallmarks of each condition with a focus on the humanity of every individual.

"FRAME allows us to teach healthcare providers about the different tenets of a disease from the perspective of an individual actually living with a certain condition," Rick said.

For FIRST, the benefits of the film, and the experience of the production itself, are far-reaching. "This vignette will be multi-purpose for FIRST, as it will serve as a unique and artistic presentation of ichthyosis, used for awareness raising as well as education," said FIRST Communications Director Maureen Neville.



FIRST is deeply grateful to the five affected families and individuals who generously gave their time and enthusiastically participated in the production: the Steinitz, Grady, Krips, Evans and Cina families. They traveled to New York City on World Rare Disease Day and, with very little guidance, used their "voices" in the most remarkable of ways. Enlightening interviews, thoughtful storytelling and heartfelt "performances" (yes, there are future superstars among us!) energized the room for the entire afternoon. These families and individuals are certain to educate and inspire FRAME audiences for years to come.

The FRAME series is scheduled to be released in Spring 2015. Stay tuned for details!



Upcoming FIRST Events

Patient Support Forums

Minneapolis, Minnesota – Saturday, April 25

Phoenix, Arizona – Saturday, June 6

Miami, Florida – TBD

2016 National Family Conference, San Diego - June 24-26, 2016

Regional Ichthyosis Picnic at Northwestern University - Sunday, June 14th 2-5 pm

Regional Ichthyosis Picnic (tentative location is Northwestern University Campus in Evanston). We hope that all individuals and families with ichthyosis will come for the fun and networking. There will be fun projects for kids and an opportunity for both kids and adults to participate in our research, related to ichthyosis and quality of life. Make new friends at the Northwestern/ FIRST ichthyosis spring picnic! Check the FIRST website for more details regarding location or contact Dr. Amy Paller (apaller@northwestern.edu).

FIRST Turns Up the Tech in Austin!

From March 3-6, FIRST Communications Director Maureen Neville attended the annual Nonprofit Technology Conference in Austin, Texas, to learn how FIRST can best utilize the ever-changing technical landscape of communications.

According to Maureen, "In addition to networking with a wide range of nonprofits from around the globe, the conference included presentations from some of world's top technology companies. There were also plenty of mentors available for one-on-one consults and on-the-fly 'concept workshoping.' The environment nurtured the opportunity to rethink what technology means to fundraising, education, and nonprofit growth and to share those thoughts with peers and leaders in the field."

Over the upcoming weeks and months, FIRST will incorporate numerous conference-inspired concepts and tactics into our communications content and deployment strategy across all divisions.

Have a "techy" idea to share for our marketing communications strategies?

Contact mneville@firstskinfoundation.org.



Ask Dr. John

John C. Browning, MD, FAAD, FAAP
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Have a question about living with ichthyosis? Now you can ask Dr. John. Each issue of the newsletter will feature a common (or sometimes not-so-common) question regarding living with ichthyosis. The questions are submitted directly from a member, and an answer will be provided by FIRST Medical and Scientific Advisory Board member, Dr. John Browning.

Do you have question for Dr. John?

Send your inquiry to Maureen Neville at mneville@firstskinfoundation.org.

Question:

Our daughter has ARCI-lamellar ichthyosis. She recently married and wants to find out if her husband is a carrier of this recessive gene before they have children. Can you give her any guidance?

Answer:

Thank you for your great question. I am sure that other families with ARCI-lamellar ichthyosis are also pondering the same thing. It is actually quite easy for your son-in-law to figure out if he is a carrier of the same recessive gene as your daughter. First, your daughter needs to know which gene she carries. This should be easily attainable from the physician who initially made the diagnosis. However, if no genetic testing has been performed, then that will need to be done first. This can be done by sending her blood sample to a commercial lab such as GeneDx. Alternatively, she could consider enrolling in the Gene Discovery Project at Yale University. You can find more out about the Gene Discovery Project at the FIRST website at www.firstskinfoundation.org, or by emailing the research team at choatelab@yale.edu for more information.

Once her genetic mutation is known then her husband can be screened for the same mutation by a CLIA-certified lab, such as GeneDx. The test for a known mutation is much cheaper than full gene sequencing and usually costs a few hundred dollars.



Now you can be a part of FIRST's biggest national fundraiser ever! RAISE is FIRST's new national online fundraising campaign, encouraging people from all across the country to join together and raise awareness, funds, and hope for all those affected with ichthyosis. If you would like to participate "offline," now you can! Simply fill out the form below and include it with your donation. It will be added toward the RAISE campaign goal of \$100,000! Use your voice and join our committed team of fundraisers! RAISE deadline is July 3, 2015.

Ready. Set. RAISE!

Name _____

Address _____

Phone _____ Email _____

Affected Individual _____

Donation Amount _____

Investigators & Patient Advocates

The new research power couple

Engagement with patient advocacy organizations is an impactful initiative to advance scientific research. FIRST, the global leader in ichthyosis patient advocacy, has witnessed tremendous growth within the patient advocate/medical investigator relationship. FIRST's Research Grant Program has independently funded over \$1.6 million in ichthyosis related research. FIRST's support has been instrumental in finding new genes that cause ichthyosis, unlocking the genetic basis for these diseases, supporting siRNA technology to directly target specific mutations, and helping the development of new topical products currently in clinical trial.

The physician-scientists funded by FIRST have also enthusiastically partnered with our organization. Many have joined the Board of Directors, as well as the Medical and Scientific Advisory Board. Additionally, these physician-scientists are actively involved in patient communications, family conferences and patient support forums, and have welcomed the opportunity for advising and supporting the entire ichthyosis community

Meet 2015 Research Grant Recipient and FIRST Partner Dr. Brittany Craiglow

FIRST proudly announces our first research award recipient of 2015, Brittany Craiglow, MD, of Yale University. Dr. Craiglow was awarded a \$50,000 research grant for her collaborative study of newborn and early childhood complications and comorbidities that accompany the ichthyoses.

"Dr. Craiglow has been a pivotal asset to the ichthyosis community. Her warmth and willingness to connect with families at our conferences and support meetings, advise FIRST staff, and always lend a hand to those in need, is truly inspiring. Not to mention, she is a tireless trailblazer and one of the leading investigative scientists in the field of ichthyosis," said FIRST Executive Director Jean Pickford.



Dr. Brittany Craiglow

Dr. Craiglow notes, "At present, there is no standard of care for the management of babies and children with these disorders and therapeutic options are limited." This enhanced understanding will help these investigators establish accepted clinical standards of care that could be tailored to the genetic diagnosis. The study may also ultimately provide a foundation for the development of targeted therapies.

A thorough evaluation of infants and children with ichthyosis will help to fill a large void in the understanding of these disorders. FIRST anticipates that the results will be particularly helpful in counseling newly diagnosed families, which represents a significant part of FIRST's work as a patient support organization.

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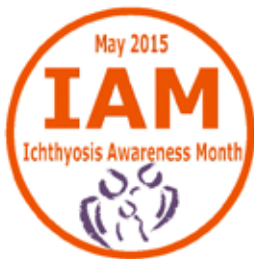


"My daughter asked me to buy a lifetime supply! It is the best her skin has ever looked. Prior to using the Mitt she was using green scouring dish pads, loofahs and exfoliating gloves. The MicrodermaMitt is incredible! The scaling is much less everywhere...but some places, like her arms especially, look almost like normal skin."

"We have been using it about 6 days a week. It has done wonders for her! Nothing else I've used even comes close to getting the amount of dry skin exfoliated from her body. I've tried spa mitts, loofah pads, and scrub brushes. The Mitt works SO MUCH BETTER than anything I've used before. Since using the MicrodermaMitt, her skin doesn't dry out as fast and she doesn't get nearly as itchy during the day."

"The MicrodermaMitt is AMAZING!! I cannot tell you enough how happy I am that I found this mitt for my daughter. After our first bath using it, I was speechless! Her skin was soft, smooth, shiny and so healthy looking. Her skin has been wonderful since we started using the Mitt. It looks so much smoother and virtually flake free. The skin also comes off so easy without much effort."

**Discounts available by contacting FIRST @ 800.545.3286
To Order: www.MicrodermaMitt.com**



May is Ichthyosis Awareness Month! Check the FIRST website for awareness raising activities in your area, or contact Chris Wassel cwassel@firstskinfoundation.org for assistance planning an event.

Camp Discovery 2015 Dates!



The American Academy of Dermatology's (AAD) Camp Discovery program is for children ages 8-16 who have a chronic skin disease. Under the expert care of dermatologists and nurses, Camp Discovery gives campers the opportunity to spend a week with other young people with skin conditions having fun and participating in activities such as swimming, horseback riding, arts and crafts and many more.

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

- **June 21-26,** Camp Little Pine - Crosslake, Minnesota (ages 10-14)
- **June 22-26,** Camp Reflection - Carnation, Washington (ages 9-16)
- **July 5-10,** Camp Big Trout - Crosslake, Minnesota (ages 14-16)
- **August 9-14,** Camp Dermadillo - Burton, Texas (ages 9-15)
- **August 9-14,** Camp Horizon - Millville, Pennsylvania (ages 8-13)
- **August 9-15,** Camp Liberty, Andover, Connecticut (ages 8-16)



Camp Wonder

June 22-27,
Camp Arroyo -
Livermore, California

For more information about attending, volunteering or donating, please visit campdiscovery.org or contact Janine Mueller at jmueller@aad.org.