



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

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Positive Exposure

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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.*



*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](mailto: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.

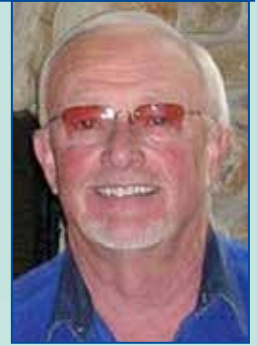
Additionally, we added 471 new families in 2014, to bring us to a total of 4,036 affected families in our database. Many of these additions were a direct result of the numerous innovative communication techniques introduced during the year.

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.

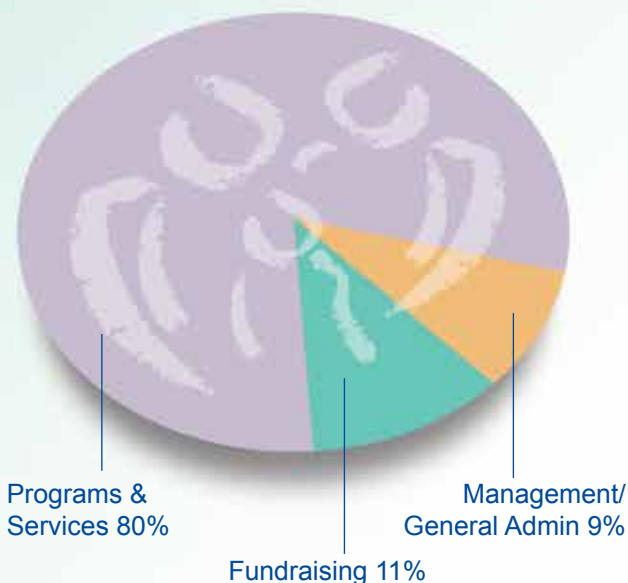
Please feel free to reach out at any time should you have any questions or concerns about our financial affairs. I wish all of you a continued year full of great health, peace, and happiness.

Sincerely yours,

**Larry Silverman, CPA, CFP**  
**CFO, Board of Directors**

FOUNDATION FOR ICHTHYOSIS AND RELATED SKIN TYPES, INC. STATEMENT OF FINANCIAL POSITION SEPTEMBER 30, 2014 (WITH COMPARATIVE TOTALS FOR 2013)			
	2014	2013	
<b>ASSETS</b>			
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	
<b>LIABILITIES</b>			
Current			
Accounts payable and accrued expenses	\$ 28,143	\$ 21,216	
Total current liabilities	28,143	21,216	
<b>NET ASSETS</b>			
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. Jeffrey Peterson  
 Mr. and Mrs. Nicholas Petry  
 Ms. Patricia Pfeiffer  
 Dr. and Mrs. Charles Ping  
 Mr. and Mrs. Michael Pinnisi  
 Mr. and Mrs. Raymond Pirrello  
 Ms. Kay Pitts  
 Ms. Laurie Porter  
 Mr. and Mrs. Anthony Poselenzny  
 Power Hour, LLC  
 Ms. Priscilla Alta Pratt  
 Mr. and Mrs. Mark Preston  
 Mr. Alan Prince  
 Ms. Carol Quintal  
 Ms. Nancy Rabb

Ms. Suzanne Ragg  
 Ms. Ella Rajnys  
 Mr. and Mrs. Keith Raterink  
 Mr. and Mrs. Eugene Ravizza  
 Ms. Dawn Rege  
 Regional School District 36  
 Ms. Cathy Register  
 Mr. and Mrs. James Register  
 Mr. and Mrs. Jon Reid  
 Mr. and Mrs. James Renner  
 Ms. Jennifer Reynolds  
 Mr. John Richardson Jr.  
 Mr. and Mrs. Mark Rieger  
 Mr. and Mrs. James Riestenberg  
 Ms. Paula Rivers  
 Mr. Steven McConnell  
 Mr. Michael Roberto  
 Ms. Bonnie Robertson  
 Mr. Phil Rodas  
 Ms. Barbara Rogers  
 Mr. and Mrs. Mark Rogers  
 Ms. Kathryn Rogers  
 Ms. Susan Roper  
 Mr. Mark Rose  
 Mr. and Mrs. Phillip Rosenberg  
 Mr. Jason Ruck  
 Mr. and Mrs. Michael Ryan  
 Sabux, Inc.  
 Mr. and Mrs. Michael Saccente  
 Mr. John Safos  
 Mr. and Mrs. Gregory Saggio  
 Mr. and Mrs. Angelo Sampona  
 Mr. and Mrs. Gordon Sanders  
 Ms. Mary Ann Sanders  
 Dr. and Mrs. H. G. Sawyer  
 Mr. and Mrs. James Schaus  
 Ms. Sharon Schee  
 Mr. and Mrs. Barry Scheiner  
 Mr. and Mrs. Eric Schneider  
 Susan and Paul Schumacher  
 Mr. and Mrs. Allen Schwartz  
 Mr. and Mrs. Michael Scirica  
 Sea World San Antonio  
 Ms. Chrissy See  
 Select Spine and Sports Med PLLC  
 Mr. and Mrs. James Seman  
 Mr. Thomas Shaer  
 Ms. Lisa Shelnitz  
 Kara Shah, MD, PhD  
 Mr. Joseph Shields  
 Pat Shiffner  
 Mr. Anthony Shope  
 Mr. and Mrs. Ted Sidenstricker  
 Mr. and Mrs. David Simon  
 Mr. and Mrs. Ross Sinclair  
 Mr. and Mrs. John Sipe, Jr.  
 Mr. Jesse Sipper  
 Dr. and Mrs. Michael Sisack  
 Ms. Cynthia Smith  
 Mr. Gregory M. Petrick  
 Mr. and Mrs. Richard Smith  
 Ms. Anne Smith  
 Ms. Tammy Smith  
 Ms. Kathleen Smith  
 Ms. Ethel Sorgatz  
 Southwest Refractory of Texas, LP  
 Mr. Larry Spruill  
 St. Mark's United Methodist Church  
 Ms. Gayle Steele  
 Mr. and Mrs. Kurt Stenn  
 Mr. and Mrs. Lauren Stephens, II  
 Mark Stepovich, DDS  
 Ms. Kelle Stevens  
 Ms. Regina Stottlemeyer  
 Mr. and Mrs. Ronen Strassburg  
 Ms. Lori Strejlau  
 Ms. Kathleen Strick  
 Ms. Emily Strunk  
 Sun & Ski  
 Mr. and Mrs. Kenneth Sundberg  
 Mr. and Mrs. George Swan  
 Mr. Mark Tanner  
 Mr. and Mrs. Marc Taranto  
 Teale Machine Company, Inc.  
 Douglas Thomas, MD  
 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 Torney  
 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 Zugerger

## \$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  
 Drs. 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 Huetton  
 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 Klaffer  
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 Ohlwiler  
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. Brianna 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 Curton, 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 Ohlwiler  
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 Waldsham  
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 Consler  
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**

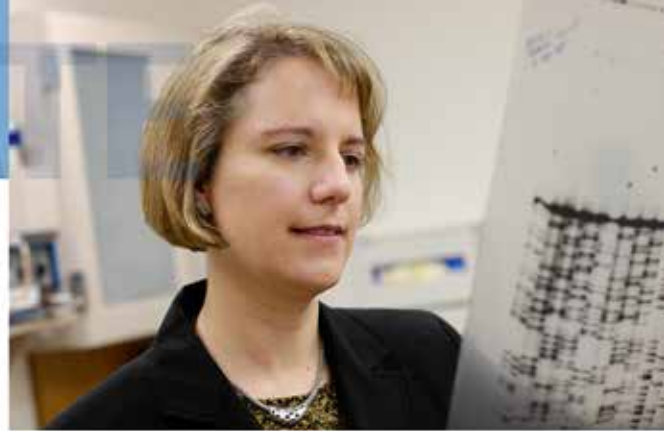
Newest member of the FIRST Board of Directors Kimberly Cole is the mother of 3-year-old Harper, who is affected with erythrokeratoderma variabilis (EKV). Kim has been very active in fundraising for FIRST since Harper's birth, participating in bake sales and craft fairs to create awareness and raise funds. 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](http://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](mailto: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](http://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](mailto: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](mailto:mneville@firstskinfoundation.org).***



## Ask Dr. John

John C. Browning, MD, FAAD, FAAP  
Assistant Professor, Baylor College of Medicine  
Chief of Dermatology, Children's Hospital of San Antonio



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](mailto: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](http://www.firstskinfoundation.org), or by emailing the research team at [choatelab@yale.edu](mailto: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.

# MicrodermaMitt

## FAST – EASY – NATURAL

*Removes dry skin cells and scaling instantly using only water!*



Before

After one use

"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."

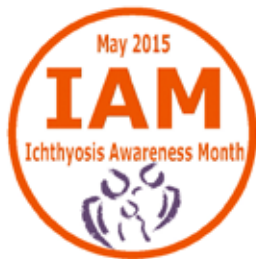
"The MicrodermaMitt is AMAZING!! I cannot tell you enough how happy I am that I found this mitt for my daughter. After our first bath using it, I was speechless! Her skin was soft, smooth, shiny and so healthy looking. Her skin has been wonderful since we started using the Mitt. It looks so much smoother 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](http://www.MicrodermaMitt.com)



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*May is Ichthyosis Awareness Month! Check the FIRST website for awareness raising activities in your area, or contact Chris Wassel [cwassel@firstskinfoundation.org](mailto: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](http://campdiscovery.org) or contact Janine Mueller at [jmueller@aad.org](mailto:jmueller@aad.org).