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.

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
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
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

Expense Allocation Percentage

<table>
<thead>
<tr>
<th>Programs &amp; Services 80%</th>
<th>Management/General Admin 9%</th>
<th>Fundraising 11%</th>
<th>Net Assets 9%</th>
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</thead>
<tbody>
<tr>
<td>Current</td>
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<tr>
<td>Accounts payable and accrued expenses</td>
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<td>$21,216</td>
<td></td>
</tr>
<tr>
<td>Total current liabilities</td>
<td>$28,143</td>
<td>$21,216</td>
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<tr>
<td>Net Assets</td>
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<td>Unrestricted</td>
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<td></td>
</tr>
<tr>
<td>Total liabilities and net assets</td>
<td>$2,060,950</td>
<td>$1,885,713</td>
<td></td>
</tr>
</tbody>
</table>
Michael W. Briggs  
*President*  
Grandfather of affected child, EI  
Retired Vice President, United Parcel Service  
Gainesville, GA

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

Larry Silverman  
*CPA, CFP*  
Chief Financial Officer  
Comprehensive Financial Planner  
Partner, Silverman LeGate Advisory Group, LLC  
Frisco, TX

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

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

Kimberly Cole  
Mother of affected child, EKV  
Digital Specialist, Froedtert & the Medical College of Wisconsin  
Wauwatosa, WI

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

Greg LiCalzi, Jr.  
Affected, ARCI-lamellar ichthyosis  
Vice President, Gates Capital Corporation  
New York, NY

Tracie Pretak  
Mother of affected child, ARCI-lamellar ichthyosis  
Owner/Teacher, Grace Notes Studio  
Wilcox, PA

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

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

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

Eric Schweighoffer  
Affected, ARCI-lamellar ichthyosis  
VP Media Director, Cashman & Katz Integrated Communications  
Soutthington, CT

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

Robert Silverman, MD  
Pediatric & General Dermatology, Private Practice  
Fairfax, VA

Board Members Emeriti

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

Leonard Milstone, MD  
Founding Member  
Professor Emeritus of Dermatology  
Yale University School of Medicine  
New Haven, CT

Amy Paller, MD  
Professor and Chair, Dermatology  
Professor, Pediatrics  
Feinberg School of Medicine Northwestern University  
Chicago, IL

David Scholl  
Grandfather of affected child, ARCI-CIE  
Former President, Diagnostic Hybrids, Inc.  
Mason, OH

Mary Williams, MD  
Founding Member  
Adjunct Professor of Dermatology & Pediatrics, Dermatology Service  
University of California San Francisco, CA

General Counsel

Daniel J. Siegel, Esq.  
Father of affected sons, X-linked ichthyosis  
Law Offices of Daniel J. Siegel, LLC  
Havertown, PA
Our mission is to improve lives and seek cures for those affected by ichthyosis and related skin types.

FY14 Support & Revenue - $1,018,642
FY14 Functional Expenses - $843,405

Programs & Services, $677,748

Fundraising, $93,542
Administrative, $72,115

24% - Research & Assistance
21% - Family Conference
55% - Education & Support