

# Changing World, Changing Ways...

**FIRST's Mission Statement:** *To improve lives and seek cures for those affected by ichthyosis and related skin types.*

*"Never underestimate the power of a small group of committed people to change the world. In fact, it is the only thing that ever has."* –**Margaret Mead**



So, what did we accomplish in 2015? Lots! Many of our accomplishments have been featured in our publications, website, and social media posts. However, there is one significant highlight that I'd like to expand upon, as I believe this milestone may be the most significant of the year – we have refined our approach on how we communicate and serve our members.

As you know, we have been supporting our mission and connecting our community for over 35 years. And each year, our community has grown, flourished and brought us one step closer to where we stand today – as the global leaders in ichthyosis advocacy. In 2015, we not only continued to embrace and serve the needs and requests of our members, but we've taken a deeper look at each individual's personal connection with FIRST. The insights we've collected through surveys, member enrollment, event participation, donations and specific relationships, has helped us to better understand our membership on a more personal level. We've drawn new conclusions about our support channels and recognize emerging data, like the fact that FIRST's largest group of supporters, is also our patients' most vital support system – their family.

Through a pointed approach to data analysis, we've deepened our knowledge of who our members are, and what they precisely need from FIRST. For instance, we are learning that a family's first contact with FIRST is most often through an extended family member, or that our medical professional members have the longest retention rate of active involvement in FIRST. All of this information is leading us to a path of more relevant programs and communications, expansion of our potential for patient advocacy, and enhanced service to our entire community throughout their lives. Our new approach is a true result of a changing world. We are reformulating how and to

whom we communicate, reaching targeted audiences with messages that are relevant to their own personal connection to FIRST.

A key player in this new communications effort is a long-time member of our staff, Lisa Breuning. Lisa is a familiar face to many of our members, as she has been a dedicated member of our team for nearly nine years. In addition to her analytical eye and technical savvy, over the years, Lisa has gained a keen and comprehensive understanding of our membership base and the technology to manage their relationships. Last year, Lisa's role shifted from Communications Coordinator to Director of Member Relations, which has proved to be an invaluable transition for our members and for FIRST.

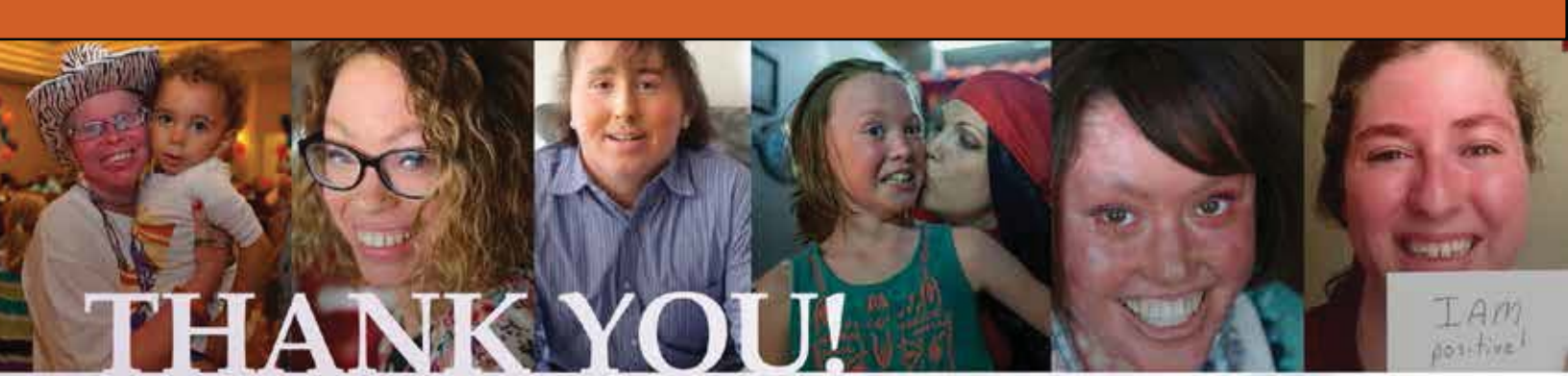


*"My role as Director of Member Relations is completely different than my role as Communications Coordinator. I am a more linear thinker, so this is a good fit for me. My goal for the database is to maximize all of the functionality that is available and better utilize the information that we collect. If our information is up-to-date, consistent, and comprehensive, then we can better advocate on behalf of our members. Streamlining some of the day-to-day tasks has also been a focus, enabling the staff to get the information that they need as expediently as possible."* – **Lisa Breuning**

Conversations and feedback from our members are an integral part of our success. On behalf of our staff, we look forward to connecting on a greater level with as many of you as possible, and learning more and better ways to serve this amazing community.

**All the best,**

**Jean Pickford**  
CEO, FIRST



# THANK YOU!

Your volunteer activities, financial gifts, and support of our programs assured that **4,983 affected individuals** benefitted from FIRST education, support, and research.

## THE CHALLENGE

- **250 – 400** babies are born with some form of moderate to severe ichthyosis in the US each year.
- **50** newborns and their families contact FIRST annually.
- Genetic tests are available for **32** different gene mutations that are known to cause ichthyosis.
- **0** known cures for ichthyosis.

## MISSION PROGRESS

- 132** Regional Support Volunteers.
- 2,472** donors.
- 633** Affected families joined in 2015.

**205** nationally and internationally recognized experts in the field of dermatology serve on the Medical & Scientific Advisory Board and Physician Referral Listing.

**\$14,750** awarded through UFIRST scholarships in 2015 to 11 young adults with ichthyosis.

## EDUCATE

**55** people participated in this year's FIRST to Know Calls.

**124** educational, informative and inspirational e-communications were sent to over **7,320** affected families, friends, and medical professionals.

**4** quarterly issues of FIRST *Ichthyosis Focus* were delivered to **4,350** affected households each quarter of **2015**.

In **2015**, the FIRST blog, *Voices in our Community*, received **5,900** visits from 19 different countries.



## INSPIRE

*"Member stories we read on the website help us to realize we are not alone. They are a true gift for our affected son."*

**- FIRST Member Donna Kober**

**267,679** users viewed our website in **2015**.

**51 RAISE** partners generated **\$66,417** from **768** donors worldwide in our inaugural year.

**62** events were held in communities across the globe, raising **\$155,000**.



## CONNECT

**4** Patient Support Forums held in the US and Canada, connecting over **150** individuals or families with leading dermatologists and the ichthyosis community.

**221** Regional Support Network referrals.

**195** physician referrals.

**322** people tried a new product thanks to the product listing.

## RESEARCH

**\$50,000** research grant was awarded to Dr. Ryan O'Shaughnessy to continue his work in targeting the scaling pathways in ichthyosis.

**\$50,000** research grant was awarded to Dr. Brittany Craiglow for her study standards of care for newborns with ichthyosis.

# LOOKING AHEAD TO 2016 - 2018

## GOALS

**Membership Engagement** - Trustworthy and compassionate support, reliable information and useful resources through engaging relationships throughout a person's lifetime

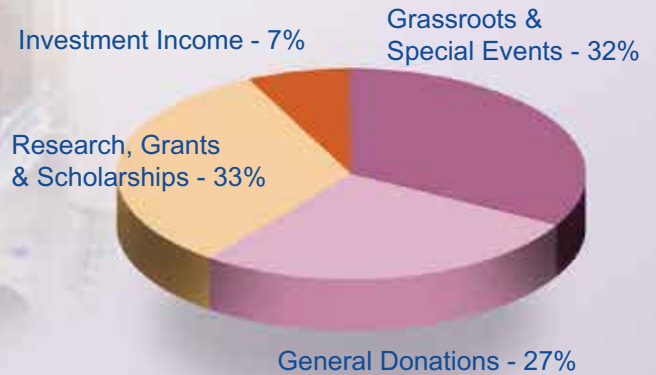
**Research** - Leverage FIRST's resources to help connect researchers and other organizations to benefit our members

**Revenue** - Achieve annual fundraising goal greater than \$1 million

## FINANCIALS

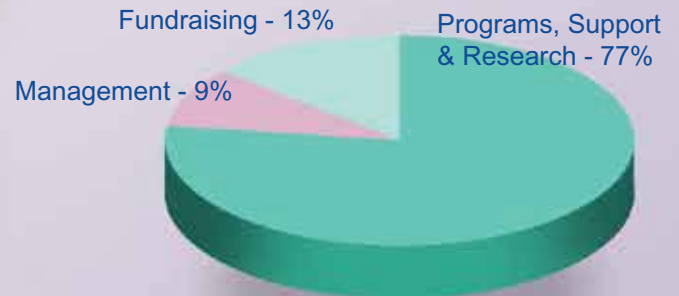
Fiscal Year 2015 - Revenue

Total \$789,461



Fiscal Year 2015 - Expense

Total \$822,3051



# A Dedicated Doctor Takes on a New Role in the FIRST Family

*Join us in welcoming Moise Levy, MD, as the new President of FIRST's Medical and Scientific Advisory Board*



Dr. Moise Levy, physician-in-chief and chief of pediatric dermatology at Dell Children's Medical Center has served on FIRST's Medical Advisory Board of Directors for the past eight years. Dr. Levy is a steadfast supporter of the mission of FIRST as well as a beloved participant in many of FIRST's support meetings and conferences. We are delighted to embrace Dr. Levy's vision and enthusiasm for FIRST's evolving role in the landscape of patient advocacy and ichthyosis research. We are inspired by his deep compassion for those living with ichthyosis, or a related skin type, and his never ending quest for better treatments to help them live the best quality of life possible. Please join us in welcoming Dr. Levy to his exciting new role as president of the Medical and Scientific Advisory Board at FIRST.

*"From my early affiliation with FIRST through the MSAB... with Mary Williams and (most recently) with Len Milstone... the intent of the MSAB has been to provide sound medical advice to our patients and families and to provide mentoring to our younger colleagues. While I cannot predict how our roles will evolve over the next few years, fundamentally our responsibilities are to our patients and families. We will continue to work in a collaborative fashion with them through advocacy, medical assistance, mentoring, and research, and to help our excellent staff to make this happen."*

**- Dr. Moise Levy**

# Why FIRST Matters to Me

By FIRST's President of the Board of Directors, Jeff Hoerle



## Dear FIRST Members and Friends,

I offer a warm hello to all of you in my first letter as President of FIRST. The past year has seen great change and growth at the foundation—we now have almost 5,000 affected members!—and our staff, board of directors, and board of medical and scientific advisors have all made significant additional investment of time and resources to ensure FIRST remains at the forefront in meeting the complex needs of the ichthyosis community. In both the social media landscape and in genetic understanding and technology, the world is evolving rapidly. FIRST continues to refine its organization and priorities to keep pace with this dynamic change. On



behalf of all the constituencies committed to FIRST's mission to educate, inspire, and connect, I pledge that FIRST will meet the coming challenges with passion and a commitment to success.

Allow me to provide some context for my involvement and devotion to the Foundation. FIRST connected

my family with the medical researchers who changed my daughter's life. In 2009, Sasha, then nearly three, suffered from an undiagnosed and untreatable condition. My wife Allison and I endured years of conflicting opinions and questionable and risky recommendations. We lost faith that the healthcare profession could help. Then, at FIRST's Patient Support Forum in Mystic, Connecticut, we encountered the warmth, compassion, and knowledge of Jean Pickford and Moureen Wenik. They received our daughter not as a medical puzzle, but as a human being in need of support and answers. They connected us with Dr. Keith Choate, who said, "I know what this is, and we can

help." This distills the crucial importance of FIRST.

Ichthyosis is a rare condition with which many physicians have no experience; the connections FIRST provides can be life changing. Through Dr. Leonard Milstone and Dr. Choate—both leaders at FIRST—we obtained genetic confirmation that Sasha has CHILD syndrome, a rare form of ichthyosis. This knowledge created the starting point from which we are now developing effective treatments. We are forever grateful for this personal miracle and are determined to help FIRST continue to change the lives of families like ours. It is a privilege to be on this journey and we have considerable ambitions for FIRST's growing impact, but if my time as president helps even one family as much as FIRST helped mine, I will count it a great success. I invite you to learn about some highlights from the past year; why I believe FIRST makes a crucial difference; and what FIRST hopes to accomplish in the future.

In becoming President of the Board of FIRST, I follow in some illustrious footsteps. I've had the privilege of working closely with two former Presidents, Mike Briggs and Dave Scholl, and am excited to build upon their more than ten years of leadership! During the past year, through an impressive collaboration among FIRST members, FIRST staff, and the board, we have developed a new four-year strategic plan to support FIRST's updated mission statement: "To improve lives and seek cures for those affected by ichthyosis and related skin types." The astute financial management of our current and former chief financial officers, Larry Silverman and John Schoendorf, has enabled FIRST to invest in additional staff time. This facilitates greater outreach; optimizes printed and digital communication programs, as well as our use of social media; and keeps us abreast of cutting-edge medical technology. We are the primary source of insight for ichthyosis-related issues, and we intend to maintain our presence as the locus that brings all of the ichthyosis communities together.

One of FIRST's deepest missions is to help members share and solve the daily problems of managing their condition. We all understand the need for better daily skin treatments—right now! FIRST's upgraded infrastructure enables more interaction among members—via calls, blogs, emails, etc.—

and more insight from the experts on FIRST's Medical and Scientific Advisory Board (MSAB). Great treatment insights can come from any member and the more we reach out, the more we learn. Our "No Child Left Unknown" program strives to contact every one of the roughly 300 babies born annually with moderate to severe ichthyosis. We reach more families every year; our vision is to reach every family. The more connections we make, the more lives we can change. I met personally with several new families at the Miami patient forum last August and witnessed how sharing stories brings hope. My own email correspondence with FIRST members galvanizes my dedication to the foundation. Every single person has something important to say; FIRST strives to combine these voices into a powerful force for advocacy.

FIRST is very fortunate to have on its board and the MSAB, the worldwide leading medical experts in ichthyosis and related skin types. We are unique in how we connect these individuals and their institutions. This enhanced discourse among experts, the current genetic revolution, and the advent of pathogenesis-based personalized medicine, provides a high-powered (and singular!) recipe for medical and scientific breakthroughs. We intend to harness FIRST's relationships with these leaders and their powerful organizations to pull the future closer, sooner! A major first step has been to deepen FIRST's relationship with the Ichthyosis Registry at Yale (IRAY). This will provide decisive answers about specific gene mutations to affected individuals; it will also offer a comprehensive pool of information to global researchers. The cumulative result of this is better data, which, over time, equals better insights—

which increase the chance of breakthrough concepts and treatments. Genetic research is here and FIRST is playing an important role. Stay tuned for more to come on this project in 2016!

FIRST has accomplished a great deal in thirty-five years. We are now at a major inflection point where the support we've offered and the data we've gathered can dovetail with the needs and visions of high-level research. It is time to accelerate our process. We want to reach more families faster and encourage greater genetic understanding sooner. This requires your support. Support comes in many forms. We need volunteers to assist new families as they adapt to a world that includes ichthyosis; we need members to host informal events to increase ichthyosis awareness in local schools and communities; and, as always, we need donations. FIRST has a long history as a successful, change-driving, and beloved organization; all of this is due to the power and commitment of you, FIRST's individual members. Please join with us to help FIRST provide the support and leadership necessary to change the lives of those affected around the world by ichthyosis and related skin types.

***On behalf of FIRST's staff, board of directors, and MSAB, I thank you for your commitment to FIRST, and I very much look forward to seeing as many of you as possible at our National Conference in San Diego this summer!***

My best regards

***Jeff Hoerle -  
President, Board of Directors***

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What a wonderful year for FIRST. The reach and success of our organization has been growing at a terrific clip. Our financial stability has remained intact despite the additional demands and significant research contributions that have been made. We give great thanks to Jean and her professional staff for their continued commitment to excellence and their enthusiastic support to all. Jeff Hoerle has stepped in as our new president with great passion, enthusiasm, and leadership. He has helped take this group to even greater heights and continues to enhance our greater good. Thanks for all you do, Jeff, and your tireless energy and efforts.

Now to the state of financial affairs. We had a strong year for the period ending September 30, 2015. Based on our audited financial statements, net assets were slightly down by \$104,294.

This was totally expected due to research grants paid for the fiscal year. We granted over \$150,000 in research this last fiscal year. We were actually close to \$110,000 in net income over and above our original budgeted numbers, mostly due to a very favorable expense control that was well under the budget. Overall, our income was almost \$33,000 more than the projected budget. 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.

***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 contentment.***

Warmest regards,

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

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Ms. Elizabeth Pennington  
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Mr. and Mrs. Jeffrey Peterson  
Mr. and Mrs. Donald Peterson  
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Reine Thoren  
Mr. and Mrs. James Thorn  
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Tom Sheridan Insurance Agency, Inc.  
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Wilcox Sportsmen's Club  
Mr. and Mrs. Robert Willcox  
Ms. Barbara Williams  
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Ms. Ann Winters  
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Capitol Dance Company  
Caravan Beads, Inc.  
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## **\$100,000 +**

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