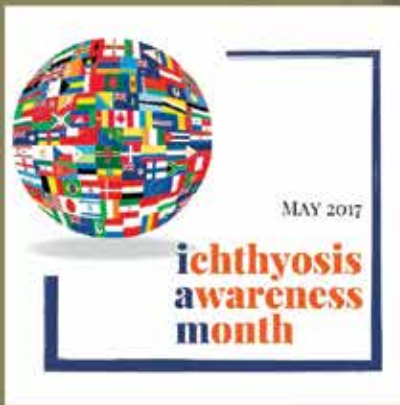


# Your Year in Review

## 2016 Annual Report



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## A Letter from Jean Pickford, CEO



You, our members, are at the heart of FIRST and what inspires me to embrace everything I do with compassion and determination. Looking back at this past year, if 2016 showed us anything, it's that FIRST is, without a doubt, resolute. The world, in so many ways, continues to rapidly change, and FIRST is poised, energized, and determined to continue to offer the most beneficial programs and services, in the most effective way possible....for you.

So what's new? With the continual challenge of a shifting and broadening terrain of healthcare technology and communications, FIRST must answer the challenge and invite members directly into our conversation to answer a singular question: How can we help to better serve you? In this issue, you'll discover a sampling of our new integrated approach to our programs like the FIRST-hosted Live WebEx Series with ichthyosis medical experts and product developers; a patient-driven upgrade to our Life Series modules - a library addressing the care and consideration for various stages of living with ichthyosis (new parents, teens, seniors); a new product sampling program and an international Ichthyosis Awareness Month (IAM) collaboration with our partners around the globe, for the very first time.

We pride ourselves in staying forward-thinking to assure that FIRST remains relevant and impactful. If you are interested in joining the conversation, please participate in one of our upcoming calls, events, or social media groups. Perhaps you are compelled to support or plan a fundraiser? There are plenty of ways to join our special family. Reach out and let me know what's on your mind, what do you need, and how can we help?

All the best,

Jean Pickford

## A Letter from Jeff A. Hoerle, President, FIRST Board of Directors



**Dear FIRST Members and Friends,**

FIRST enjoyed an exciting 2016, highlighted by our National Conference in San Diego, which saw a record 473 attendees connect with each other, with medical professionals, and with FIRST staff. I was privileged to be able to speak with many of you—a father and son from Australia, a long-time member from Texas, a family with two affected daughters from New Jersey—hear your stories, and learn from your experience. We are all partners in our community and we are stronger through our shared engagement. During 2016, FIRST reaffirmed its commitment to engage with members and to reach as many current and new members as possible. We will do this again in 2017 with a record-breaking 13 patient

support forums! Connecting provides solace and solutions; we learn best—about tips for daily treatment or advances in science—when we interact with each other.

Whenever possible, I speak with individual members and their families to improve my understanding of how FIRST can make a difference in people's lives. It is conversations with members—including my affected 10-year-old daughter Sasha—that help me get past the board strategy discussions and monthly update reviews. In one recent conversation, a FIRST member of nearly 20 years emphasized the importance of sharing insights and being able to trust the information that comes from FIRST. We aspire to meet this need through events like the *FIRST to Know* calls and a revamped website. Our goal is to provide as many opportunities as possible for members to connect and learn from each other. We are all experts in our own ways.



## Letter from Jeff A. Hoerle, continued...

This year, we have 11 *FIRST to Know* calls planned; perhaps you will have an idea for adding number 12! We care about your thoughts and can't do it without you! Additionally, during 2016, we created a vastly improved mobile version of the *FIRST* website—no mean feat for a small non-profit organization. We are adding new sections and developing an upgrade to our lifecycle materials. We continually enhance our content and utilize the professional expertise of our esteemed advisors on our Medical and Scientific Advisory Board (MSAB). I thank all *FIRST* staff and the MSAB for your ongoing dedication and passion for the foundation.

*FIRST* continues to focus on scientific advances and to work with leading researchers. We are playing a major role in the building of a new ichthyosis registry. Through this, the research community has access to information of which we could have only dreamed five years ago. Genetic understanding will lead to real breakthroughs and *FIRST* has a front row seat at the table. We also know that you want better treatments today. We have redoubled our efforts to explore new therapies and approaches that can make a difference. We learn from sharing with you, and the "Tools and Tips for Living with Ichthyosis" section on our website continues to grow—please engage with us if you have suggestions!

*FIRST*'s mission is to educate, inspire, and connect with YOU. The more I see the committed work of our staff, the volunteers, the board of directors, and the MSAB, the more I recognize that real human connection is what matters and drives progress. We are lucky to have so many talented groups of individuals working together in a variety of nurturing and ground-breaking ways. I urge you to please join with us and engage!

My best regards to you,



**Jeff A. Hoerle, President, Board of Directors**

# MicrodermaMitt

## FAST – EASY – NATURAL

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



Discounts available by contacting **FIRST @ 800.545.3286**  
To Order: [www.MicrodermaMitt.com](http://www.MicrodermaMitt.com)

"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."

# A Letter from Larry Silverman, CFO



**Dear Fellow Members, Donors, and Friends of FIRST,**

Congratulations to all of the staff and volunteers on another great year for FIRST, highlighted by the National Conference in San Diego. The reach and success of our organization continues to make a significant imprint on the ichthyosis community. I want to once again recognize Jean, Moureen, Lisa, Maureen and Madeline, our professional staff, for their continued commitment to excellence and their enthusiastic support to all. Our President, Jeff Hoerle, has worked tirelessly to improve the quality, stability, and support services of the organization. He, along with all my fellow board members are truly dedicated to fostering the very best results for the FIRST family.

Now, to the state of financial affairs. The year has produced a great number of challenges.

We saw a significant decrease in contributions over prior years and a reduction in investment income with the challenges of low interest rates. In spite of these financial hurdles, the overall health of FIRST has remained. The staff and board have made changes in order to reduce various expense areas while maintaining a high level of support for member services. We will continue to keep a careful watch on ways to keep our financial health strong as we move into the future. For the period ending September 30, 2016, net assets were down approximately \$125,000 primarily caused from a decrease in contributions and investment income. Despite these constraints, we were still able to provide over \$180,000 in research funding this last fiscal year. Once again, the lion's share of contributions are spent on FIRST's programs and services. Our Investment Committee continues to closely monitor all aspects of our progress and performance with our reserves and asset managers. Overall our financial health is strong and we have made adjustments to balance the budget for this next fiscal year.

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**

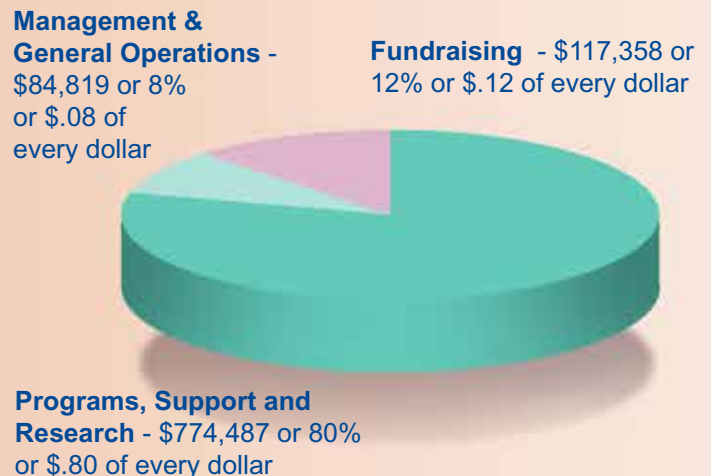
## Financials FY 2016

**FY16 – October 1, 2015 – September 30, 2016**

**Revenue \$702,017**



**Expenses \$976,664**



# Your Year in Review



OCTOBER 2015

NOVEMBER 2015

DECEMBER 2015

JANUARY 2016

FEBRUARY 2016

MARCH 2016

- Release the Butterfly Tour Stop #2! The second stop of the Release the Butterfly Tour brought Tracie & Bailey Pretak to Lancaster, Pennsylvania, the home town of the Stern family. Fox43 and WGAL-Lancaster, featured the event on the evening news.

- FIRST celebrates nine years of our in-house Research Grant Program, awarding medical investigators grants for their work in the field of ichthyosis or related skin types.
- Staff and board members collaborate together in Philadelphia to review, evaluate, and discuss future planning at FIRST Board of Directors Retreat.

- Another Ichthyosis Clinic opens its doors at Massachusetts General Hospital in Boston.
- Reaching another milestone...over 80 cases have been evaluated through FIRST's Tele-ichthyosis Program.

- Celebrating 35 Years! An historic achievement celebrated by the production of The History of FIRST video, which debuted at our National Conference, San Diego in June of 2016.
- Committed members Denise Eiser and Mark Evans join the Board of Directors.
- Dr. Christopher Bunick receives a \$50,000 Research Grant Award for his work in microscopic crystallography of keratins 1 and 10.

- The Jane and Henry Bukaty Skin Care Fund has awarded \$19,190 dollars since its inception in 2000.
- FIRST YouTube channel reaches 300,000 views!

- Drs. Sherri Bale, John Compton & Gabriele Richard are honored at FIRST's 2016 Testimonial Dinner at the City Club of Washington in Washington, DC.
- A record-breaking 19 affected students receive funding from the UFIRST Scholarship Program to support their post-secondary education.
- FIRST is awarded \$100,000 grant from the Lennox Foundation to support strategies for member connection and engagement.







APRIL 2016

- An exclusive TV series on TLC, "Two in a Million," features Ken Krips and Bobbi Green, two FIRST members living with ichthyosis.

MAY 2016

- The National Registry for Ichthyosis & Related Skin Disorders combines with the former Registry at University of Washington and goes live! Over 700 individuals are registered to date and nearly 650 have received genetic diagnoses.
- Number of members in FIRST Facebook Groups breaks 1,000!

JUNE 2016

- Our signature event, the three-day National Conference for individuals and families in San Diego celebrates a record-breaking number of attendees, reaching 473!
- The 2nd annual nationwide online fundraiser, RAISE, is featured at the National Conference.
- Dr. Amy Paller and her colleagues from Northwestern University enroll participants in a study to understand the cause of skin redness in ichthyosis, and Dr. Keith Choate and the team from Yale University host the Gene Discovery Clinic at the National Conference. Both studies are ongoing.
- The Pretak & Kocher families are crowned Volunteers of the Year.

JULY 2016

- The first FIRST to Know support conference call for grandparents is held!
- Dr. Britt Craiglow, in collaboration with FIRST's MSAB and PeDRA, is awarded funding for a research project studying newborns and children with ichthyosis.

AUGUST 2016

- Longtime member Anne Kaier's story, *Finding Refuge with the Skin I'm In*, is published online by The New York Times and FIRST's website visitor traffic spikes with 4,425 views in a single day.
- FIRST promotes the Sjögren-Larsson Syndrome (SLS) study, which was followed by Aldeyra Therapeutics announcing positive results from a randomized, double-blind, vehicle-controlled clinical trial of topical dermatologic NS2 in patients with Sjögren-Larsson Syndrome. Study is currently ongoing.
- Hooray for the first FIRST Champions! Marc, Denise, Marc and Eric Benedetto are honored in New York surrounded by family and friends.
- FIRST member database reaches 20,000 and Facebook fans hits 4,000!

SEPTEMBER 2016

- ¿Habla español? Educational booklets and resource sheets are translated into Spanish and a new Spanish section of the website is developed.
- The 2nd Annual Chicago Area Picnic, hosted by Dr. Amy Paller and her team at Northwestern University, brings more than 75 individuals together in one region for discussions and fun (next one is Sept 23, 2017).
- FIRST goes mobile! A redesigned website launches, improving access from mobile devices.
- 52 fantastic members wrap up RAISE, the nationwide fundraiser with a grand total of \$33,549 to support FIRST.
- An automated physician finder service goes live on the website, helping connect members to knowledgeable dermatologists across the country. To date, over 500 patients have accessed the new online service.



**In Memoriam**

Our deepest sorrow and heartfelt condolences recognize the family of FIRST member Stephanie Turner, who passed away on March 3. Stephanie, who was affected with harlequin ichthyosis, lived in Wynne, Arkansas, with her husband Curtis and two beautiful young children. She and her family have been members of FIRST since 1993. Stephanie was a positive spirit, an enthusiastic advocate for ichthyosis awareness, and an inspiration to all who knew her both in person and through our online community. We know how many people she touched and her joyous nature will forever live in our hearts. *Rest in peace.*

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 Cal Safe  
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 Mr. Joe Crouse  
 The De Leon - Khanna Charitable Fund  
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 Dell Employee Engagement Fund / Silicon Valley  
 Community Foundation  
 District Doughnut LLC  
 The Fred R. Fernandez - Irma R. Rodriguez  
 Foundation  
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 Mr. and Mrs. Carlos Godby  
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 Mr. and Mrs. Michael Hall  
 Mr. Edward Hartman  
 The Haunted Game Café  
 Mr. and Mrs. John Havrilla  
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 Mr. Eric Schweighoffer  
 Drs. Pedro and Lucy See  
 Jennifer and Rachel See  
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 Mr. Day Lewis Patterson  
 Siemens Caring Hand Foundation  
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# Meet members Rog, Tina and Mui Thomas



We are delighted to introduce Rog, Tina and Mui Thomas, an extraordinary family from Hong Kong who are challenging attitudes, raising awareness, and inspiring women and men the world over. Their book, *The Girl Behind the Face*, written by Rog from Tina's perspective, is a story of how three people became a family, the obstacles they overcame and the choices that had to be made along the way. It champions Mui's resilience and strength while living with harlequin ichthyosis, all while empowering others along the way. In the words of Tina Thomas, "It is what love is."

**(Paragraph below is an excerpt from *The Girl Behind the Face* by Rog Thomas)**

*Sai Kung in the eastern New Territories of Hong Kong is a surprise, a breath of fresh air, a relaxation, a break, a quality of life; Sai Kung is coffeehouses, bars, little bakeries, eclectic eateries, seafood restaurants and al fresco dining; and beyond the town itself, Sai Kung is rugged beauty: rolling hills, uninhabited islands and white sand beaches; wild monkeys, barking deer and feral pigs, and cows that wander through the streets. Sai Kung is a world away from the picture postcard*

*images of Hong Kong: the hustle and bustle and towering glass skyscrapers of downtown Central; the "girlie" bars of Wan Chai made famous by Richard Mason's *The World of Suzie Wong*; and the madding crowds of densely populated Mong Kok.*

**(Excerpt below is an adaptation from *The Girl Behind the Face* by Rog Thomas)**

*SAI KUNG is also where my wife Tina and I raised our daughter, Mui. We became Mui's parents quite by chance.*

It was summer and Tina suggested we volunteer for a couple of weeks with young children. It sounded fun. We were introduced to Mui, an abandoned one-and-a-half year old Hong Kong Chinese girl with a rare deforming and life threatening skin disorder called harlequin ichthyosis. We looked forward to having Mui visit us in Sai Kung.

But each time we visited Mui in the hospital where she lived, she screamed and turned away, and ripped off her skin and tore out clumps of hair until she was a bloody mess. For Tina, winning Mui's trust quickly became a stubborn battle of wills. And each time Mui would finally calm down, she was inseparable from Tina, like a baby kangaroo in her mother's pouch.

It wasn't until the beginning of the following year that this battle was won and Mui finally came to visit.

Twenty years ago, caring for a child who looked as different as Mui did in Hong Kong was a constant challenge: people in wheelchairs were stared at. Taking Mui outside meant walking the gauntlet of staring and occasional cruelty: sometimes people shouting insults at us, sometimes people screaming at Mui. Once, someone spat in Tina's face.

But Sai Kung has always had a strong sense of community – although connecting with the warmth and kindness of the local Chinese population meant making a bit of an effort. It began with our first ever walk through Sai Kung.

In the market curious Chinese women, men and children clustered round us. Tina smiled and said jo san – good morning – to the different faces in the crowd and told Mui to say hello, too. An old lady pushed forward and demanded to know what had happened to Mui. Tina told her it was a skin disorder and added, Mui's Heung Gong yan – a Hong Kong person. The woman smiled and gave Mui sweets. Tina told Mui to say thank you and give the woman a hug, and with a hefty nudge of encouragement from Tina, Mui hugged the woman, who smiled, and the cluster of people was soon smiling, too.

When we left the market Tina told Mui to wave and blow a fei man – a 'flying kiss' – and everyone smiled and waved and blew kisses back.

In the street, some people stopped stiffly, some stared silently, some screwed up their faces. Some people recoiled or jerked their heads back like they'd been scalded. We walked

on and smiled at them, said hello, made eye contact and sometimes held their stare, or chose not to see them.

Treating Mui as an ordinary child seemed to put the people we bumped into in Sai Kung at ease. As she has grown up, folks in Sai Kung have tended to embrace her and regard her as a sweet and confident girl.

How we came to adopt this courageous little girl, how our daughter grew up to inspire ordinary men and women across Hong Kong, how she won over a British prime minister, billionaires and royalty with her dynamism and spirit, and how cyber bullies drove her to the brink of suicide – that is our Hong Kong story. We've shared it in a book: *The Girl Behind the Face* and we have now signed with a US literary agent in Dallas, Texas. Our aim is to challenge attitudes, empower others and raise awareness of commitment, cyberbullying and visible differences.

(This article was first published in: the Cathay Pacific Airways inflight magazine.) Find out more about their book, *The Girl Behind the Face*, and their motivational speaking engagements.

<http://thegirlbehindtheface.weebly.com>

## *Why I Fundraise for FIRST*

**By Kimberly Cole, Member of FIRST Board of Directors  
Assistant Editor *Ichthyosis Focus***

**Recently we sat down with one of our loyal and enthusiastic supporters, Kimberly Cole, to find out what compels her to continually support and fundraise for FIRST, and how she might encourage others to do the same. Here's what she had to say:**

"We recognized the value of everything we were receiving from FIRST and felt a duty to give back so families that came after us could benefit from the same support. While I know every dollar counts, we couldn't afford to contribute at a level we felt was adequate. (A new baby is expensive, and one with a medical condition can be really expensive!) A fundraiser let us draw on the support of our friends and family – so many of whom were eager for a meaningful way to support us – to collectively raise a larger donation amount.

My favorite fundraisers have been in partnership with friends who work in direct sales and donated their profits from a certain period. I am so thankful for their generosity! I hosted a "party" at my house for product demos and shopping -- and to share information about ichthyosis and FIRST -- and was also able to share information online for family and friends that live away. Everyone enjoyed shopping for jewelry, beauty products or cleaning supplies – in many cases, they were items they were buying anyway, now with the benefit of supporting a good cause.

My advice is to make it personal, don't be afraid and say thanks. Before asking people for money, I had to get comfortable with sharing our story. I am typically a very private person and, as a result, a lot of people around me didn't realize how extensively ichthyosis affects our family, or how much FIRST has supported us. Opening up about this wasn't always easy, but I was so overwhelmed by the response I received. We are truly grateful for every donation we've brought in – whether \$5 or \$500 – and I always make an effort to let donors know how much we appreciate them." - **Kimberly Cole**

