The Year in Review
2015 Annual Report
Last Chance, National Conference June 24-26!

The Kocher family, recipients of the 2015 Volunteer of Year Award

Inside This Issue:
FIRST Annual Report 3
RAISE 11
Conference Registration Form 13 & 14
Living Well with Ichthyosis 15
FIRST Advocates 15
Correspondence Corner

Dear FIRST Foundation,

“FIRST has had such a positive effect on my life. Just reading FIRST’s Ichthyosis Focus makes me feel like I am not the only one suffering from ichthyosis. That is a true gift!”

Rich Graham

“The day my daughter was born, I found your website on my phone while in absolute despair. I was so grateful to read stories of people living full lives with ichthyosis. It made me feel a lot more relaxed. When we left the NICU our doctors literally just printed pages from FIRST’s website for us because it is absolutely the best information available.”

Janet Holt

“The foundation is doing a great job of keeping everyone connected and up-to-date on all the newest solutions and findings. We pray that our son still continues to get better as he gets older.”

Blake Harrington

Have you been receiving emails from FIRST?
If not, contact Lisa Breuning at lbreuning@firstskinfoundation.org to have your current email address added to our lists.
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 expeditiously 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
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

### 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.
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

FINANCIALS

<table>
<thead>
<tr>
<th>Fiscal Year 2015 - Revenue</th>
<th>Total $789,461</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investment Income - 7%</td>
<td>Grassroots &amp; Special Events - 32%</td>
</tr>
<tr>
<td>Research, Grants &amp; Scholarships - 33%</td>
<td>General Donations - 27%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Fiscal Year 2015 - Expense</th>
<th>Total $822,3051</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fundraising - 13%</td>
<td>Programs, Support &amp; Research - 77%</td>
</tr>
<tr>
<td>Management - 9%</td>
<td>------------------</td>
</tr>
<tr>
<td>Revenue - Achieve annual fundraising goal greater than $1 million</td>
<td></td>
</tr>
</tbody>
</table>

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 |

LOOKING AHEAD TO 2016 - 2018

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

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

“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

www.firstskinfoundation.org
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
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 major 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

---

Donor Listing  (This listing includes all donations made during the 2015 calendar year)

**$100 - $249**

- 007 Pest Control, Inc.
- 58-74 Grand Avenue Tire Corp.
- Mr. Scott Aaronson
- Mr. and Mrs. Robert Adamo
- Dr. and Mrs. Harvey Adams
- Adaptive Driving Access, Inc.
- Rolena Adorno PhD
- Mr. and Mrs. Gumesindo Aguila Jr.
- Ms. Margareth Alonzo
- Altered Images Color Salon & Day Spa
- Ms. Kathy Alvaranga
- Mr. Harold Ames
- Mr. Clement Amore
- Mr. David Anderson
- Magnus and Anna Anderson
- Okey Anderson
- In Memory of Shirley & Carl Anderson
- Anonymous (19)
- Mr. and Mrs. Gerald Arendt
- Mr. and Mrs. Tom Armstrong
- Mr. and Mrs. Robert Ash
- Mr. and Mrs. Mohsen Ashkiebousi
- Auto Magician
- Mr. and Mrs. Douglas Awu
- Ms. Jacquelin Bach
- Ms. Rebecca Ann Bach
- Ms. Eileen Ballard
- Mr. and Mrs. Thomas Bachand
- Ms. Eileen Ballazar
- Hooman Bamdad
- Mr. Randy Barr
- Mr. and Mrs. Richard Barry
- Susan Bayliss MD
- Mr. and Mrs. Brian Beck
- Mr. Joseph Benincasa
- Ms. Barbara Berger
- Mr. Lynn Bernard
- Mrs. Shirley Bernhard
- Ms. Norma Bertuzzi
- Mr. and Mrs. Robert Bialer
- Mr. Sander Bieber & Ms. Linda E. Rosenzewig
- Mrs. Mardel Bienwagen
- Ms. Shawn Blitner & Mr. Stephen Olsztoom
- Ms. Diane Blackstone

---

**$250 - $499**

- Bransislav Blagoyevitch Vaga LLC
- Bloom Real Estate Group LLC
- Mr. Jeffrey Bonjo
- Mr. Artem Borchakovski
- Mr. and Mrs. James Borden
- Mr. and Mrs. Jack Borland
- Drs. Renato and Juliet Bostia
- Mr. and Mrs. Robert Bowie Jr.
- Ms. Sharon Boyle
- Mr. and Mrs. Michael Bradley
- Mr. and Mrs. Travis Brinker
- Mrs. Tressa Briggs
- Mr. William Britton
- Ms. Nellie Brooks
- Mr. Mark Broude
- Mr. and Mrs. Jerry Brown
- Ms. Amy Brown
- Mr. and Mrs. Ernest Brown
- Ewan Brown-Wight
- Mr. and Mrs. Brad Bryant
- Magnus Brynestam
- Ms. Jennifer Bube
- Mr. and Mrs. James Bucchella
- Dr. and Mrs. Patrick Burkhardt
- Mr. and Mrs. William Burns
- Mr. Christopher Burns & Ms. Cristina Crimando
- Mr. John Burton
- Mr. and Mrs. John Butler
- Mr. and Mrs. Richard Butler
- Ms. Christine Butler
- Mr. and Mrs. Robert Caligan
- Mr. and Mrs. Noll Campbell
- Ms. Florence Campbell
- Mr. and Mrs. Paul Cantwell
- Mr. and Mrs. George Cardinal
- Carey Mac’s Salon
- Mr. and Mrs. Robert Carney
- Ms. Sarah Carroll
- Mr. and Mrs. Rodolfo Castillo
- Dr. and Mrs. Daniel Cencetti
- Mr. and Mrs. John Cermirana
- Ms. B.J. Chandler
- Mr. and Mrs. Alexander Cheek
- Chevron Humankind
- Mr. Vincent Chirico & Ms. Angela DiGiglio

---

**$500 - $999**

- Ms. Hugh Choy
- Ms. Judith Cichowicz
- Mr. and Mrs. Sean Cina
- Mr. and Mrs. David Cina
- Ms. Elizabeth Cipollita
- Mrs. Mary Clair
- Clairwood #40 AMLA
- Mr. and Mrs. David Clapp
- Mrs. Donna Clare
- Ms. Patricia Clavin
- Cleveland Indians Baseball Company
- CNB Bank
- Ms. Lisa Coakley
- Mr. Adam Cole
- Ms. Kimberly Cole
- Mr. John Conlee
- Mr. Paul Connolly
- Mr. and Mrs. Kenneth Cornell
- Mr. and Mrs. Michael Cosgrove
- County Municipal Employees’ Supervisors’ and Foremen’s Union
- Ms. Patricia E Cockett
- Mr. Ralph Curton Jr.
- Ms. Erica Daniell
- Bobbie Darino
- Ms. Rosemary Davis
- Mrs. Rhonda Davis
- Mr. and Mrs. James Dawson
- Jessie Deely Esq.
- DelGrande & Montefusco, Inc.
- Dell Employee Engagement Fund
- Mr. and Mrs. Richard DeLoughary
- Mr. and Mrs. Steven DePoy
- Ms. Serena Dittman
- Ms. Courtney Devin
- Mr. Steve Dickson
- Ms. Giulia DiMarzo
- Mr. and Mrs. James Dolan
- Mrs. Joyce Dombrowski
- Mr. Greg Donahue
- Ms. Cathy Donnelly
- Mr. and Mrs. Emil Drain
- Mrs. Marianne Dunlop
- Mr. Frank Duncan & Ms. Karen E. Shine
- Ms. Anne Dunipase
- Ms. Julie Dunipase
- Mr. Kevin Dunipase
- Harry and Jendi Durant
- Mrs. Cynthia Early
- Mr. Steven Ecker
- Mr. and Mrs. Thomas Egan Jr.
- Ms. Teri Ehrlich
- Mr. Ralph Ekorn
- Mr. and Mrs. Mark Ekornen
- Mrs. Betty Ellen
- Mr. and Mrs. Donald Erling
- Mr. and Mrs. George Estes
- Ms. Diane Esty
- Mr. and Mrs. Andrew Evans
- Mr. Don Evans
- Mr. and Mrs. Ray Evans
- Mr. and Mrs. Troy Evans
- Mrs. Audrey Evans
- Mr. and Mrs. Richard Fasciano
- Ms. Laura Fash
- Mr. and Mrs. Bob Feldman
- John Ferguson MD
- Ms. Marcia Ferguson
- Mr. Gary Fernet
- Ms. Holly Feree
- First Equity Mortgage
- First Savings Bank
- Mr. Lamar Fletcher
- Mr. Steven Flury
- Mr. Craig Foreman
- Ms. Carol Fox
- Ms. Rebecca Frankwicz
- Joe and Janice Fransz
- Ms. Edythe Free
- Mr. and Mrs. Charles Friddle
- Ms. Jackie Friedman
- Mr. and Mrs. Roger Fugman
- The Funky Monkey
- Ms. Frances Gabaldon
- Mr. and Mrs. James Gaffney
- Mrs. Linda Galloway
- Captain Joseph Galluccio
- Ms. Debbie Gamble
- Mr. Mark Garvin
- Mr. and Mrs. Regina Gassman
What’s RAISE?
In its second year, RAISE is FIRST’s international fundraising campaign which enlists the support of members, family and friends around the world to work together and raise awareness, funding and hope for all those affected with ichthyosis.

How can I help?
Each RAISE partner will receive their own personal RAISE page and step-by-step instructions on how to easily customize your RAISE web page. You can set your fundraising goal, share your story, upload a picture – make the website all about YOU and why FIRST is important to YOU!

Where Do the Funds Go? This year as a result of your 2015 donations to FIRST operations…

- 30 more families will be able to attend the 2016 National Conference in June, some meeting others with ichthyosis for the very first time.
- 12 new FIRST to Know calls have been scheduled, ranging from guidance for grandparents of those affected, to understanding occupational therapy, to how to navigate your way through health insurance.
- 4 patient support meetings were held where nearly 150 members across the country could speak with medical experts, make new friends, and find new information regarding caring for their condition.

In 2016, we hope to increase these opportunities for support and connection so that no one will ever feel that they are coping with a rare and complex skin condition, all alone.

For more information, or to sign up for RAISE, email Madeline Bergman at mbergman@firstskinfoundation.org or call FIRST at 215.997.9400.

Once your donation web page is ready, take action and tell the world! E-mail your RAISE page to friends, neighbors, family... anyone! Be sure to share your messages on social media, too!

Join a Group of Advocates
Throughout the fundraising campaign, FIRST will work with all RAISE Partners to help achieve your goal, whether it’s helping you build your RAISE fundraising page, providing you with a prompt to email your friends or just to give you a high five for your fundraising efforts! You can also network with other RAISE partners to learn tips and share stories on how they meet their fundraising goal.

“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

“Before” and “After one use” pictures are shown with text indicating the Mitt’s effectiveness.

www.firstskinfoundation.org
What Should I Expect?
The conference is an amazing, worthwhile, and moving event for the entire family. There will be an early bird registration and welcome room reception on Thursday night. Official registration begins early Friday morning. The workshops will end by 4:30 pm, so attendees are on their own for Friday night activities, including the optional pizza and trolley ride. Workshops will continue Saturday throughout the day until 5:00 pm. The dinner/dance party begins at 6:30 pm and features a live DJ, party games, and a raffle. Sunday workshops will end at 12:30 pm, which will be followed by a closing session and farewell lunch. Friendships are made that are life-changing.

What’s on the Agenda?
In addition to the exclusive opportunity to participate in a clinical screening appointment or research visit with the Yale Ichthyosis Research Project team, the agenda focuses on many different aspects related to living with ichthyosis. Disease and age appropriate discussions for adults and teens, genetics, research updates, group networking, specific care, skin management, and communications workshops are all featured. For the complete agenda, visit our website at www.firstskinfoundation.org.

Registration
Registration for the conference can be completed using the registration form in this newsletter or registering online at www.firstskinfoundation.org by June 8. Registrations without a completed form and payment will not be considered complete. Cancellations received prior to June 8 will be refunded less a $25 per person administrative fee. No refunds issued after June 8. Please note: Registration does not include your hotel room. Please go to www.firstskinfoundation.org for updates on room availability at the Marriott Mission Valley and alternate lodging.

Kid-A-Palooza
Social programs for all affected children and their siblings, ages 1 to 12, are an integral part of the conference. Participants will enjoy activities, entertainment, educational programs, and refreshments. A licensed childcare company will provide this service; a nominal fee is charged to confirm your participation.

Clinical Screening and/or Research Visits – Be a Participant!
Conference attendees will have several options for visits with ichthyosis medical experts and participating in clinical research.

Friday, June 24 - Dr. Amy Paller and her colleagues from Northwestern University have discovered what may cause the red skin of many forms of ichthyosis and will be starting a new medication trial this summer based on the results. On Friday only, all affected conference attendees will have the opportunity to participate by having their blood drawn and a biopsy done for personal analysis of what drives inflammation. If you are interested in participating in this clinical trial at the conference, or at Northwestern University, please contact Thy Huynh at thy.huynh@northwestern.edu or 312.227.6486 for more details.

Saturday, June 25 – Dr. Keith Choate and his team from Yale University will be conducting genetic research and clinical visits. Participants can choose one of three options: 1) a 15-minute appointment to discuss any questions or concerns you may have with expert physicians; 2) a one-hour, more in-depth appointment to enroll in the Ichthyosis Registry at Yale (IRAY) for research studies and a 15-minute appointment with expert physicians. For new enrollees, this option will involve providing a saliva sample, photographs, and completing a questionnaire, or; 3) for those already enrolled in the Ichthyosis Registry at Yale (IRAY), you are encouraged to still sign up, as there will be an opportunity to update information and ask any questions.

Join the New GENERation
Have you received a genetic diagnosis? Now is the time to GET DIAGNOSED and play an important role in ichthyosis research. FIRST is playing their part by supporting a transformational scientific endeavor with the world’s leading institution in ichthyosis research, Yale University. The Ichthyosis Registry at Yale (IRAY), available to investigators worldwide, will be the largest host of ichthyosis patient information – critical data that holds the key to better, more targeted treatments, and eventual cures. The Ichthyosis Registry at Yale (IRAY), sponsored by FIRST, is the next evolution of ichthyosis research.

PLEASE SEE OUR ONLINE CONFERENCE PROGRAM FOR INFORMATION REGARDING HOTEL AND TRANSPORTATION, MEALS, AND LOCAL ATTRACTIONS. www.firstskinfoundation.org
Registration can be submitted by completing this form or registering online at www.firstskinfoundation.org/conferences. All registrations must be received by June 8th. Registrations with missing information or payment will not be considered. Cancellations received prior to June 8th will be refunded, less a $25 per person administrative fee. No refunds issued after June 8th.

Surf’s Up! for the 2016 National Conference
Registration Form

Family Registration, Contact Info, and Permissions

Family Last Name: __________________________ Contact Person:__________________________

Address: ___________________________________________________________________________

City/Town :______________________State/Province: ________ Zip/Postal Code:______________

Country: ____________________________ Home Phone:___________________________________

Cell: _______________________________ Email:__________________________________________

Type of Ichthyosis: ___________________________________________________________________

☐ I give FIRST permission to publish names, contact, and type of ichthyosis in the conference roster, which will be distributed to attendees, vendors & faculty attending the event.

☐ I give FIRST permission to use and distribute any photos or videos taken at the conference, in which I, or my family, may be a part, including but not limited to use in newsletters, appeals, social media, website and reports.

Who’s Attending?

<table>
<thead>
<tr>
<th>First Name</th>
<th>Last Name</th>
<th>Date of Birth</th>
<th>Age</th>
<th>Affected with Ichthyosis or a related skin type?</th>
<th>Relationship to person affected? (mom, brother, uncle, friend, etc.)</th>
<th>Participating in Kid-a-Palooza?</th>
<th>Participating in FIRST’s Got Talent Show?</th>
<th>T-Shirt Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>1)</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>YS YM YL</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>S M L XXL</td>
</tr>
<tr>
<td>2)</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>YS YM YL</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>S M L XXL</td>
</tr>
<tr>
<td>3)</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>YS YM YL</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>S M L XXL</td>
</tr>
<tr>
<td>4)</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>YS YM YL</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>S M L XXL</td>
</tr>
<tr>
<td>5)</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>YS YM YL</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>S M L XXL</td>
</tr>
<tr>
<td>6)</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>YS YM YL</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>S M L XXL</td>
</tr>
</tbody>
</table>
Celebrate FIRST’s 35th anniversary with a $35 gift to support the Conference Scholarship Fund - helping those who need it most.

Option 1 – A 15 minute appointment with experts in ichthyosis to discuss your/your child diagnosis. This option does not involve participation in any research studies.

Option 2 – An in-depth, longer appointment to enroll in the Ichthyosis Registry at Yale for research studies. This option also includes a 15 minute appointment with expert dermatologists as well. For new enrollees, the study will involve providing a saliva sample, photographs, and completing a questionnaire.

Option 3 – For those already enrolled in the Ichthyosis Registry at Yale, you are encouraged to still sign up, as there will be an opportunity to update information, ask any questions, and participate in continued Registry activities.

Name __________________ Age ______ Type ______

A packet will be mailed to you from Yale which will contain necessary paperwork and confirmation of your scheduled appointment time.

Registration & Payment

<table>
<thead>
<tr>
<th>Registrant</th>
<th>Number</th>
<th>Fee Per Person</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult (ages 13+)</td>
<td>x</td>
<td>$200 per person</td>
<td>$</td>
</tr>
<tr>
<td>Child (ages 5 to 12)</td>
<td>x</td>
<td>$100 per person</td>
<td>$</td>
</tr>
<tr>
<td>Preschool (ages 2 to 4)</td>
<td>x</td>
<td>$25 per person</td>
<td>$</td>
</tr>
<tr>
<td>Infant/Toddler</td>
<td>x</td>
<td>No Charge</td>
<td>$</td>
</tr>
</tbody>
</table>

Optional Add-Ons

| Kid-a-Palooza (ages 1 to completed fifth grade) | x | $10 per child | $     |

Friday Night Pizza & Trolley Tour

<table>
<thead>
<tr>
<th>Registrant</th>
<th>Number</th>
<th>Fee Per Person</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult: Ages 13+</td>
<td>x</td>
<td>$35 per person</td>
<td>$</td>
</tr>
<tr>
<td>Child: Ages 4 to 12</td>
<td>x</td>
<td>$21 per person</td>
<td>$</td>
</tr>
<tr>
<td>Toddler: Ages 3 and under</td>
<td>x</td>
<td>$3 per person</td>
<td>$</td>
</tr>
</tbody>
</table>

Celebrate FIRST’s 35th anniversary with a $35 gift to support the Conference Scholarship Fund - helping those who need it most... $

Grand Total $

Enclosed is a check in the amount of $_________, payable to FIRST, Inc.

Please charge my credit card for $_________(Visa, Mastercard, American Express, Discover)

Credit Card Number ______ Exp. Date ______

Signature ______ Date ______

Waiver

In consideration of the acceptance of this registration entry, I/we the undersigned, assume full responsibility for any injury or accident which may occur while I/we am/are attending this conference. I/we hereby release and hold harmless the sponsors, promoters, and all other persons and entities associated with this event from any and all personal injury or damage, whether it be caused by the negligence of the sponsors, promoters or other persons or entity. Applications for minors will be accepted only if signed by a parent or guardian.

Signature ______ Date ______
FIRST ADVOCATES  Get informed. Stay involved.

FIRST staff members Moureen Wenik and Christine Wassel headed to the Pennsylvania State Capitol in Harrisburg on March 16 to participate in Rare Disease Day PA 2016. The purpose of this event is to raise awareness at the state level for the 1 in 10 individuals living with a rare disease and the challenges they face. They met with State Representative Todd Stephens and Eric Pauley, Assistant to State Senator Stewart Greenleaf, to discuss the National Organization of Rare Diseases' topics concerning medical foods coverage, prescription cost sharing and newborn screening. Both contacts were extremely interested in the impact to those with rare disease. The best news of the day was that Pennsylvania has recently established a Rare Disease Caucus that will enable rare disease to have a voice at the Capitol. We even participated in the press conference for the caucus. Please contact Chris at cwassel@firstskinfoundation.org if you would like to see how you can affect change at the state level. Together we are strong!

Members Seized the Opportunities to Advocate on Rare Disease Day

“The event at California State on February 29 was very successful. I gave the FIRST brochure to Andrea Vergne, the California State NORD organizer, to include in the agenda as well in the State Bill SCR 108 introduced by both Senators and Assembly Members”. -Rama Shankar Singh, Ph.D.

Living Well With Ichthyosis

By FIRST MSAB member, Dr. John Browning


“I don’t usually review fictional novels but this one was just too good to pass up! I believe, Wonder, by R.J. Palacios, can serve as a tool of support for families and individuals with appearance differences.” - Dr. John Browning

Wonder is a story of a boy named August who has an incredibly rare facial deformity. In his own words he refers to it as “mandibulofacial dysostosis.” Like so many individuals with birthmarks or genetic conditions, Augie feels defined by his appearance. He feels the countless stares of strangers and hears gasps of surprise whenever he is out in public. Halloween is his favorite holiday because he can wear a mask and be “normal” for a day. Between Augie’s parents’ desires to protect him from others and his numerous surgeries (27 since birth), he is home schooled until the 5th grade.

Being an intelligent child he is able to matriculate at an academically selective private school in upper Manhattan where the head of school, Mr. Tushman, tries to make Augie’s transition less difficult. He does this by negotiating with three current students who are perceived by him to be the best and brightest. (Unfortunately this also reveals that children are often able to fool adults by acting one way while treating their peers completely differently). As it turns out one of these kids, who is very popular with his peers, quietly bullies Augie.

The book starts out from the perspective of Augie. We learn directly from him about what life is like having so many people stare at you all the time. He has few friends and his best friend recently moved away. His world revolves around Star Wars and XBOX. But just when we are feeling sorry for Augie, his sister, Via, begins to narrate her perspective. We often forget about how difficult it is to be a sibling of someone who is different.

Via does not get much time with her parents and has been forced to act like a little adult from a young age. We learn about her struggle of simultaneously loving and resenting her brother. We also learn about Via’s own struggle with trying to fit in and navigate the social dynamics of high school. A special character in the book is Summer. She narrates her experience in pursuing genuine friendship with Augie while being ostracized by others. We also hear from the perspective of Jack Will, one of Tushman’s three who originally befriends Augie.

Jack tries to live in two worlds - the world of being Augie’s friend and the world of being cool. He bad mouths Augie to Julian (the bully) and Augie overhears the comment. However, Jack begins his own journey of transformation as he learns about the value of other people and standing up for what is right, in spite of the consequences. At the end of the book Mr. Tushman addresses the middle school in a closing ceremony, reminding them, “If every single person in this room made it a rule that wherever you are, whenever you can, you will try to act a little kinder than is necessary –the world really would be a better place.” He then reminds us that the best way to measure growth is in “what you’ve done with your time, how you’ve chosen to spend your days, and whom you have touched this year. That to me is the greatest measure of success.”

This book is a great resource for those with ichthyosis, their friends, classmates, and their families.

Editor’s Note: If you don’t have time to read, consider downloading the book from Audible.com and listening in your car. The narrators do a great job with the different character voices.
Get to know the FIRST Community with FIRST to Know Calls!

FIRST to Know calls are a great way to meet other families and individuals. Each call is centered on a topic or subject, and lasts for one hour. You can decide which calls are interesting to you and phone in. You can be an active participant, or just listen to what others are saying. All calls are held at 8 pm Eastern Time. Contact Moureen Wenik, mwenik@firstskinfoundation.org, for more information.

May 22 - Understanding Occupational and Physical Therapy
June 19 – Erythrokeratoderma Variabilis (EKV): Sharing Information
July 24 – Grandparents: Helping Your Grandchild and Your Adult Children
August 28 – Sjögren-Larsson Syndrome: Sharing Information
September 25 – Bathing with Microbubble Technology
October 23 – Lamellar: Sharing Information
November 27 – How to Work with Your Insurance Company
December 18 - Palmoplantar Keratodermas (PPK): Sharing Information

Registration Forms Inside! Pages 13 & 14

Use #FIRSTNC16 for Conference Updates!