



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



Copyright © 2016
by the Foundation for Ichthyosis
& Related Skin Types, Inc.®

Ichthyosis Focus is published quarterly
by the Foundation for Ichthyosis &
Related Skin Types, Inc.®

Requests to reprint information
contained in the *Ichthyosis Focus*
should be directed to the editor.

The Foundation for Ichthyosis
& Related Skin Types, Inc.®
2616 N. Broad Street
Colmar, PA 18915

Phone: 215.997.9400
Toll-free: 800.545.3286
Fax: 215.997.9403

Email: info@firstskinfoundation.org
Web: www.firstskinfoundation.org

Chief Executive Officer
Jean Pickford

Editor
Maureen Neville

Medical Editor
Amy Paller, MD

Editorial Assistant
Kimberly Cole

*The Foundation for Ichthyosis &
Related Skin Types, Inc.® is a 501(c)3
charitable organization supported by
public and private donations. All
contributions to the Foundation are tax
deductible to the full extent of the law.*

*The editor invites your correspondence.
We welcome your comments,
observations and suggestions. Please
send your letters to *Ichthyosis Focus*
at the address listed above.*

*Ichthyosis Focus is provided as a
service to members of the Foundation
as a medium for the free exchange of
information. Neither the Foundation for
Ichthyosis & Related Skin Types, Inc.®
its Board of Directors, its Medical
Advisory Board nor the Focus Editors
endorse any treatments or products in
Ichthyosis Focus. Views and opinions
expressed in this publication do not
necessarily reflect the views of the
Foundation or Foundation officials.*

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.



NEW & IMPROVED!

**30% Urea
Moisturizer**
for FIRST Members

Hundreds of FIRST members use Dermal Therapy's odor free, non-greasy moisturizers to improve skin and scalp instead of expensive prescription products.

MONEY BACK GUARANTEE

Ask for FIRST Members SPECIAL DISCOUNT!

30% Urea Moisturizer 4 oz. (30% Urea, 10% Alpha Hydroxy) \$15.99	10% Urea Moisturizer 16 oz. (10% Urea, 10% Alpha Hydroxy) \$20.99
---	--

minimum order is 3 products

To order call: 1 (800) 668-8000 or visit
www.dermaltherapy.com

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



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

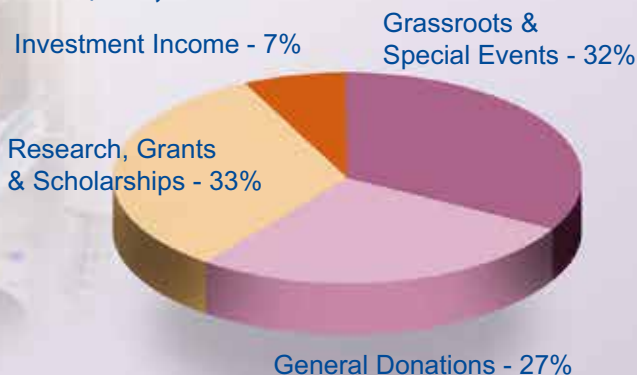
Research - Leverage FIRST's resources to help connect researchers and other organizations to benefit our members

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

FINANCIALS

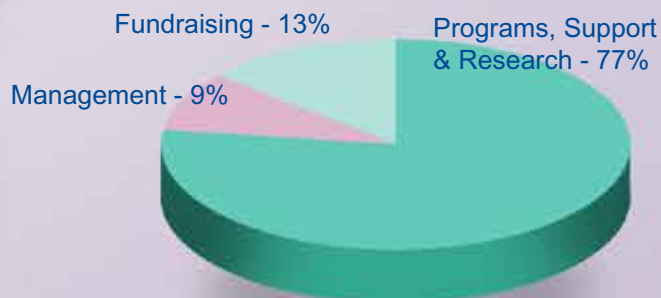
Fiscal Year 2015 - Revenue

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***

2015 Board of Directors

JEFF HOERLE **PRESIDENT**

LARRY SILVERMAN **CFO**

MOISE LEVY, MD
VICE PRESIDENT

DENISE BENEDETTO
SECRETARY

KEITH CHOATE, MD, PHD

KIMBERLY COLE

JONATHAN DYER, MD

GREG LICALZI, JR.

TRACIE PRETAK

GABRIELE RICHARD, MD

WILLIAM B. RIZZO, MD

ERIC SCHWEIGHOFFER

RACHEL SEE

ROBERT SILVERMAN

DANIEL J. SIEGEL, ESQ.
GENERAL COUNSEL

Board Members Emeriti

PHILIP FLECKMAN, MD

LEONARD M. MILSTONE, MD

AMY PALLER, MD

DAVID SCHOLL, PHD

MARY L. WILLIAMS, MD



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

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. Gumersindo Aguila Jr.
Ms. Margareth Alonzo
Altered Images Color Salon & Day Spa
Ms. Kathy Alvarenga
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 Ashkeboussi
Auto Magician
Mr. and Mrs. Douglas Auw
Ms. Jacquelyn Bach
Ms. Rebecca Ann Bach
Mr. and Mrs. Thomas Bachand
Ms. Eileen Baltazar
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 Bernard
Ms. Norma Bertuzzi
Mr. and Mrs. Robert Bialer
Mr. Sander Bieber & Ms. Linda E. Rosenzweig
Mrs. Mardel Bierwagen
Ms. Shawn Bittner & Mr. Stephen Olsthoom
Ms. Diane Blackstone

Branislav 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 Bosita
Mr. and Mrs. Robert Bowie Jr.
Ms. Sharon Boyle
Mr. and Mrs. Michael Bradley
Mr. and Mrs. Travis Bricker
Ms. Tresea 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 Buccella
Dr. and Mrs. Patrick Burkhardt
Mr. and Mrs. William Burns
Mr. Christopher Burns & Ms. Cristina Crimauoda
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 Ceconi
Mr. and Mrs. John Cerminara
Ms. B. J. Chandler
Mr. and Mrs. Alexander Cheek
Chevron Humankind
Mr. Vincent Chirico & Ms. Angela DiGiglio

Ms. Hugh Choy
Ms. Judith Cichowicz
Mr. and Mrs. Sean Cina
Mr. and Mrs. David Cina
Ms. Elizabeth Cipoletta
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
Mrs. Kimberly Cole
Mr. John Conlee
Mr. Paul Connolly
Mr. and Mrs. Kenneth Cornwell
Mr. and Mrs. Michael Cosgrove
County Municipal Employees' Supervisors' and Foremens' Union
Ms. Patricia E Crockett
Mr. Ralph Curton Jr.
Ms. Erica Daniell
Bobbie Danino
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 Dettman
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 Dugoni
Mr. Frank Duncan & Ms. Karen E. Shine
Ms. Anne Dunipace

Ms. Julie Dunipace
Mr. Kevin Dunipace
Harry and Jeni Durant
Mrs. Cynthia Early
Mr. Steven Eccher
Mr. and Mrs. Thomas Egan Jr.
Ms. Teri Ehrlich
Mr. Ralph Ekonen
Mr. and Mrs. Mark Ekonen
Mrs. Betty Ellen
Mr. and Mrs. Donald Enting
Mr. and Mrs. George Estes
Ms. Diane Esty
Mr. and Mrs. Andrew Evan
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 Finn
First Equity Mortgage
First Savings Bank
Mr. Lamar Fletcher
Mr. Steven Flury
Mr. Craig Foreman
Ms. Carol Fox
Ms. Rebecca Frankwicz
Joe and Janice Franz
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. Reggie Gassman

Mr. and Mrs. Gregory Gathy
Gathy Home Repair Service, Inc.
Mr. and Mrs. Gary Gelormino
Mr. Andrew George
Mrs. Linda George
Ms. Mary Jo Gerland
Mr. Mohammad Haroon Ghalib
Ms. Nagham Ghandour
Ms. Kimberly Ghane
Ms. Cynthia Gibbons
Mr. and Mrs. Richard Gibson
Ms. Kathryn Gifford
Mr. and Mrs. Ferdiand Gigl
Mr. and Mrs. Brett Gilbreath
Mr. Ernest Gilchrist
Mr. Jeff Gleason
Mr. Theodore Glowacki & Ms. Ann Pokalsky
Mr. and Mrs. Donald Gober
Ms. Andrea Gold
Mr. James Gomez
GoodSearch/GoodShop
Dr. and Mrs. John Goodsell
Goshen Center School
Mr. and Mrs. David Gosselin
Mr. and Mrs. William Grady
Mr. and Mrs. Charles Greene
Mr. Carl Greenfeld & Dr. Rachel Brandt-Greenfeld
Ms. Susan Griess
Mr. and Mrs. Jack Groom
Ms. Mary Gross
Ms. Beverly Groves
Dr. Diane Haggis & Mr. Douglas Haggis
Mr. and Mrs. Gary Hahn
Mrs. Nancy Hamill
Mr. Dan Hamilton
Mr. and Mrs. Darren Hamilton
Ms. Carolina Hane
Tyler and Renee Haning
Mr. Scott Hanks
Mr. and Mrs. Dan Hanson
Ms. Ann Harley
Mr. and Mrs. Timothy Harper
Dan and Kathy Harper
Mr. and Mrs. Adam Hartman
Mr. and Mrs. James Harvey
Mr. and Mrs. Mark Hawn Sr.
Mr. and Mrs. Frank Hazel
Ms. Cora Hefley
Ms. Jennifer Heinemann
Mr. and Mrs. John Hemmer
Ms. Thelma Henry
Ms. Susan Hentz
Mr. and Mrs. Rodney Hennis
Mr. Sean Hickey
Hidden Talent Art Studio
Mr. and Mrs. Scott Hirz
Mr. and Mrs. Thomas Hislop
Mr. William Hoerle
Mr. and Mrs. Kurt Hoffman
Ms. Laura Hogan
Mr. Peter Holm
Mr. and Mrs. Tom Holmes
Dr. Kristen Hook
Mr. Adam Hopkins
Mr. Larry Hornback
Ms. Jeanne Hotchkiss
Kelly Hubbard
Mr. Christopher Hussey
Ms. Sarah Hutchinson
Ms. Patricia Jacklitch
Steve and Nancy Jackson
Mr. and Mrs. Jerome Jacobsmeyer
Mr. and Mrs. David Jansa
Jay Hereford and Margaret Winsor Charitable Fund
Ms. Lisa Jewett
Patrik Johansson
Corey Johnson
Mrs. Sharon Johnston
Mr. Andrew Joncich
Mr. and Mrs. James Jones
Mr. and Mrs. James Joyner
Mr. and Mrs. Hilel Kagan
Ms. Maria Kahn
Mr. Edward Kaier
Ms. Tejal Kamdar & Mr. Jason Snyder
Ms. Grace Kataoka
Ms. Marianne Katz
Mr. Steve Kealey
Mr. Michael Kenny
Mr. Eric Kim
Kimco Consulting, Inc.
Mr. Jim Kingsbury
Mrs. Linda Kister
Jan Kjellberg
Mr. and Mrs. Raymond Kleinert, III
Mrs. Gail Kleintop
Ms. Margot Kiima
Ms. Kellie Kline
Mrs. Susan Klopp

Ms. Stephanie Knauss
Mr. and Mrs. Frederick Kober
Kocher Farm and Tack
Dr. and Mrs. W. R. Konneker
Mr. William Kraybill
Ms. Linda Kroeger
Rev. Kermit Krueger
Mr. and Mrs. Paul Kuhns
KVC Solutions, LLC
Olof Lönroth
Ms. Heather Laberinto
Laborers Int'l. Union of North America
Mr. and Mrs. Andre Landry III
Frank & Darlene Lange
Mr. and Mrs. Gary Lauters
Ms. Nancy Le
Mr. Bob Lebda
Ms. Ann Ledezma
Ms. Jenny Lefkowsky
Mr. and Mrs. Jason Legate
Ms. Nancy Lemer
Ms. Kate Lenaway Undercoffer
Mr. and Mrs. Lance Leshner
Ms. Carol Lesiak
Mr. and Mrs. Kenneth Levitan
Mr. and Mrs. Edward Leyba & Mr. John Paul Leyba
Mr. and Mrs. Gregory LiCalzi Sr.
Mrs. Ethel Lindberg
Lodge Martha Washington #38 AMLA
Loiseau Construction, Inc.
Ms. Carol Losey
Mr. Steven Lower
Mr. Wayne Lucas
Mr. and Mrs. Harold Lustgarten
Ms. Erin Luther
Mr. and Mrs. Fred Lyford
Mr. and Mrs. James Lynch
Ms. Ashley Mack
Ms. Sherri Madonia
Mrs. Anita Maemone
Ms. Gloria Maffettone
Mahomed Sales & Warehousing, Inc.
Mrs. Clara Makowski
Mr. and Mrs. Joseph Malfara
Ms. Debora Mallouk
Yamini Manickam
Ms. Paige Mansell
Mr. and Mrs. Peter Marchiano
Mr. Kenneth Markley
Mr. Fernando Marques
Ms. Nicole Marshall
Mr. Timothy Marszalek
Mr. Christopher Martin
Ms. Kathy Martin
Ms. Donna Martineau
Mr. and Mrs. Roberto Martinez
Mr. Thomas Marty
Mr. and Mrs. Guy Mason
Mr. and Mrs. J. David Mast
Mr. and Mrs. Richard Maurer
Ms. Rosemary Maye
Mr. and Mrs. Mark Mayone
Mr. and Mrs. Richard McArdle
Mr. and Mrs. Robert McCabe
Ms. Kimberly McCormick
Ms. Doris McCue & Mr. George V.W. Ball
Mr. and Mrs. James McGovern
P. J. & Lisa McGuigan
Ms. Caroline McGuigan
Ms. Christina McHale
Ms. Claire McHugh
Mr. Matt McLane
Mr. John McTaggart & Ms. Kristine Bernhardt
Mr. James Meier
Ms. Teresa Mendiola
Merck Partnership for Giving
Mr. Gary Metz
Mr. David Metzker
Mr. and Mrs. Charles Michael II
Ms. Jill Micsky
Mrs. Laila Migally
Mr. and Mrs. James Miller III
Mr. Michael Miller
Mr. and Mrs. Gary Miller
Mr. Alan Milstone
Ms. Regina Miozzi
Mr. and Mrs. Matt Molchan
Mr. Josh Molsbee
Mr. and Mrs. Dominick Mond
Mr. and Mrs. Nicholas Mond
Mrs. Patricia Mond
Moody National Bank
Ms. Elizabeth Mooney
Mr. and Mrs. L. Kristopher Moore
Ms. Lisa Moran
Ms. Kassie Morgan
Mr. Daniel Morris
Ms. Virginia Morsman
Mr. and Mrs. Frank Mosunic

Mr. Kevin Mulcahy
Mr. Thomas Mullins
Mr. and Mrs. Matthew Mulqueen
Ms. Isbel Munoz
Mr. Rick Muroski
Mr. and Mrs. George Murphy
Mr. Richard Murphy
Ms. Hollie Murrin
Mr. and Mrs. Frank Musso
Mr. and Mrs. Gerald Myers
Ms. Michelle Myers & Mr. Ashley Hogg
Robert and Virginia Myers
Mr. Eric Nagareda
Matt & Candace Nelson
Mr. and Mrs. Gerald Nerone
Mr. and Mrs. Matthew Newman
Ms. Angela Ng
Mr. and Mrs. Ernest Nightingale
Ms. Deborah Nobriga
Mrs. Dawn Nolet
Dr. and Mrs. David Norris
Mr. Jon Nussbaum
Nutrition Depot
Ms. Sharon O'Brien
Mr. Edward O'Connor
Mr. and Mrs. Kevin O'Boyle
Ms. Sonja Och Kajsa
Ms. Antonina Odindo
Emil Og & Felix Lexberg
Ms. Ellen Olivier
Magnus Olsson
Ms. Michelle Omalley
Mr. Alan Orme
Mr. and Mrs. George Orso
Mr. and Mrs. Frank Osowski
Ms. Victoria Ovelgonne
Ms. Heidi Overton
Mr. and Mrs. Allen Overway
Ms. Julie Oxford-Sommers
Mr. and Mrs. Paul Pacheco
Mr. Mikael Palmer & Ms. Lisa Andersson Palmer
Mr. and Mrs. John Papp
Mr. and Mrs. Patrick Paris
Ms. Monique Parsons
Ms. Holly Pastor
Mr. and Mrs. Steven Pateuk
Mr. Dhiren Patra
Mr. Stephen Patrick
Mr. Nick Payne
Ms. Jeanne Penney
Ms. Elizabeth Pennington
Mr. Nicholas Perez
Ms. Stacy Peters
Mr. and Mrs. Jeffrey Peterson
Mr. and Mrs. Donald Peterson
Mr. Johan Petersson
Mrs. Patricia Pfeiffer
PG&E Corporation Foundation
Mr. and Mrs. Jim Phillips
Mr. Bradley Phillips
Ms. Virginia Pickles
Pilates Studio of Friendswood
Mr. and Mrs. Marlon Poole
Mr. Jay Poole
Mr. and Mrs. Robert Pratt
Ms. Priscilla Alta Pratt
Ms. Judith Prichard
Mr. Alan Prince
Progressive Casualty Insurance Co.
Ms. Kathleen Quinn
Ben Raimor MD & Sharon Smith Raimor MD
Kalpana Raina
Mr. and Mrs. John Reardon
Mr. and Mrs. Larry Reeves
Ms. Cathy Register
Mr. and Mrs. James Register
Ms. Jaime Resendes
Mr. and Mrs. John Retondo
Vin and Lucia Ricci
Ms. Carol Richardson
Ms. Pauline Ridenour
Mr. and Mrs. Mark Rieger
Ms. Paula Rivers & Mr. Steven R. McConnell
Mr. and Mrs. William Robbins
Mr. and Mrs. Joseph Roberts
Mr. and Mrs. Kyle Robinson
Ms. Alice Rodkey
Ms. Shirley Rogers
Ms. Martha Rogers
Ms. Lauren Roland
Mr. and Mrs. John Ross
Mr. and Mrs. Joseph Ruggiano
Rushton & Company
Mr. and Mrs. Michael Ryan
Ms. Jessica Sadelund
Sabux, Inc.
Ms. Loretta Sahoo
Mr. Lester Salamon
Mr. and Mrs. Peter Salit

Mr. Joel Sanderi
Mr. and Mrs. Gordon Sanders
Ms. Barbara Sanders
Mr. Stuart Sanders
John and Becky Sandifer
Mr. and Mrs. Mark Santoro
Dr. and Mrs. H. G. Sawyer
Ms. Stephanie Sawyer-Ames
Mr. and Mrs. David Saxon
Mr. and Mrs. Shawn Saylor
Mr. and Mrs. Charles Scheidt
Mr. and Mrs. Ronald Schiff
Mr. James Schlachter
Mrs. Arden Schlegel
Ms. Faye Schmit
Mr. and Mrs. Eric Schneider
Mrs. Norma Scholl
Mr. and Mrs. Bill Scholl
Ms. Kathy Schroeder
Mrs. Ada Laverne Schwartz
Dr. and Mrs. Joseph Scirica
Mr. and Mrs. Michael Scirica
Mr. and Mrs. William Scully
Mehervan Sethi
Ms. Rosanna Sforza
Mr. Thomas Shaer & Lisa Shelnitz
Mr. Brian Shea
Mr. F. Kevin Shea
Shell Oil Company Foundation HERO Matching
Gifts Program
Ms. Patricia Shiffner
Ms. Amy Shook
Mr. Christopher Short
Asa Silfverberg
Mr. and Mrs. Robert Simmons
Mr. and Mrs. Kenneth Simpson
Dr. Maura Simpson
Ms. Margaret Sinclair
Petra Sintorn
Mr. and Mrs. John Sipe Jr.
Mr. Jesse Sipper
Dr. and Mrs. Michael Sisack
Ms. Lisa Sligh
Mr. and Mrs. Lloyd Smith
Ms. Jeanne Marie Smith
Mr. and Mrs. John Snyder
Softerware, Inc.
Mr. and Mrs. Dennis Sopher
Mrs. Caroline Spayde
Dr. Mary Spraker
Mr. and Mrs. Curtis Sproull
Mr. and Mrs. Brian St. Louis
St. Mark's United Methodist Church
Stanley High School
Mr. and Mrs. Peter Stano
Mr. and Mrs. Larry Staton
Mr. Christopher Stefanos
Mr. and Mrs. Kurt Stenn
Mr. and Mrs. Lauren Stephens II
Mark Stepovich DDS
Mr. William Stern
Ms. Janese Stimmel
Mr. and Mrs. Ronen Strassburg
Mr. and Mrs. Harry Stultz
Ms. Jennifer Suarez
Mr. and Mrs. Joseph Suffield
Virginia Sybert MD
Mr. George Sycip
Tanglewood Group
Mr. Mark Tanner
Mr. and Mrs. Donald Tasser
Technology Marketing Corp.
Mr. and Mrs. Mel Teetz
Ms. Maria Tessinari
Mr. Marcus Thell
Douglas Thomas MD
Mr. and Mrs. Scott Thompson
Ms. Heather Thompson
Ms. Kathryn Thompson
Reine Thoren
Mr. and Mrs. James Thorn
Titan HK Inc.
Tom Sheridan Insurance Agency, Inc.
The Towers Victorian Inn
Ms. Shelley Trojanowski
Joe and Melinda Trojanowski
Tropic Supply, Inc./The DelVecchio Family
Mr. and Mrs. Roland Unruh
Mr. and Mrs. Jason Ura
Mr. and Mrs. Dietmar Urbat
Ms. Libe Valdez
Mr. John Valdez
Mr. and Mrs. Zachary Van der Meer
Ms. Fulvia Veronese & Mr. Marino DeMarzo
Mr. and Mrs. Mark Verratti
Mr. Matthew Vilim
Mr. Keith Vitale
Mr. and Mrs. Thomas Voll
Mr. and Mrs. Charles Wagner

Mr. and Mrs. John Allen Waldrop III
Mr. and Mrs. Ron Wallace
Mr. John Walls
Mr. and Mrs. Samuel Walters
Mr. and Mrs. John Wandalowski
Ms. Donna Warg
Mr. and Mrs. Deshdeep Wasu
Ms. Judith Watts
Mr. and Mrs. Thomas Watts
Mr. and Mrs. Donovan Weger
Mr. David Weglarz
Mr. Nicholas Weinand
Kris Weinberg
Mr. and Mrs. Michael Weinert
Mr. and Mrs. Bill Westlake
Mr. and Mrs. Richard Wiese
Mr. and Mrs. Dennis Wiklund
Mr. Michael Wilburn
Wilcox Sportsmen's Club
Mr. and Mrs. Robert Willcox
Ms. Barbara Williams
Mr. and Mrs. Peter Williams
Mr. Thomas Wilson
Ms. Ann Winters
Ms. Elizabeth Wirstrom
Ms. Debra Witmer
Ms. Amy Wittman
Mr. David Wohlfarth
Mr. David Wright
Mr. and Mrs. James Wu
Albert Yan MD
Genet Yonis
Mr. Kevin Young
Mr. and Mrs. Mike Young
Mr. and Mrs. Edward Zawacki
Mr. Eric Zugeran

Ms. Anne Harriman
Ms. Judith Hartmann
Ms. Barbara Hawke
Mr. Mark Hawn
Mr. and Mrs. Timothy Heslin II
Ms. Jill Hirschfeld
Mr. Alexander Hoerle
Mrs. Brenda Hood
Ms. Katherine Huggins
Ms. Carole Jahnke
Ms. Ann Johnston
Meera and Bharat Kamdar
Mr. and Mrs. Richard Kass
Mr. and Mrs. Richard Keathley
Kelly Mill Elementary School
Ms. Anna Kennedy
Ms. Marsha Kent
Mr. John Kilmer
Dr. Samira Kirmiz
Ms. Carmen Klaffer
Mr. Matt Kozinski
Mr. and Mrs. James Kuzik
Laborers Int'l. Union of North America
Laborers' Local 225
Mr. Harry Lancaster III & Ms. Jane G. Henderson
Dr. Leslie Potter Lawley &
Mr. Thomas J. Lawley, Jr.
Ms. Kelley Linn
Mr. James R. Lowe
Mr. Thomas Lyons
Mr. and Mrs. Rick Malatesta
Mrs. Margaret Manning
Mr. and Mrs. Omar Marrero
Mr. and Mrs. Harold Mason
Dr. Erin Mathes
Mr. and Mrs. Simon Morris
Mr. Glenn Neurohr
Mr. and Mrs. Kenneth Nichols
Ms. Kristine Norton & Mr. William W. Wall
Mr. Timothy Ohlweiler
Ms. Lavanya Palakshreddy
Ms. Patricia Patoch
Pearland Pediatrics, P.A.
Ms. Claudia Penas
Ms. Esther Pinto
Mr. and Mrs. Anthony Poselenzny
Ms. Kim Price
Ms. Marguerite Pullen
Mike and Glenda Queen
Mamal Rahimi
Ms. Ella Rajnys
Mr. Max Ramirez
Rare Kids, Inc.
Mr. John Richardson Jr.
Mr. and Mrs. Angelo Sampona
Scelba Enterprises LLC dba The Learning -
Experience of Roseland
Ms. Mary Schafer
Mr. and Mrs. David Schell
Mr. Stephen Schweighoffer
Mr. Armando Sciullo
Mr. and Mrs. Frank Selvaggio
Terry and Rusty Sharkey
Mr. and Mrs. Elliot Shulman
Mr. and Mrs. Daniel Siegel
Mr. Jeffrey Simon
Rama Shankar Singh PhD
Dr. John Smaha
Ms. Betty Sparaco
Sarah Spencer Foundation
Mr. and Mrs. David Spruill
Mr. and Mrs. Larry Spruill
Mr. and Mrs. Eric Stafford
Mr. and Mrs. David Stevenson
Mr. and Mrs. Mike Tobey
Mr. and Mrs. Sam Unruh Jr.
Reverend and Mrs. Franklin Vilas
Mr. and Mrs. Richard Weinert
Mr. and Mrs. Alfred Westlake
Mr. and Mrs. Brian Wetzel
Mr. and Mrs. Bud Wheeler
Mr. Christopher Williams
Mr. and Mrs. Sammy Williams
Mr. David Witt
Wrinkle, Gardner & Co., P.C.
Mrs. Sherry Zailer
Mr. and Mrs. Brian Zavitz

\$500 - \$999

Ms. Laura Alessio
Rex Amonette MD & Johnnie Dacus Amonette
Anonymous (5)
Kjartan Armann MD
Mr. John Armstrong
Ms. Kim Auer
Azteca America
Ms. Claudia Barry

Ms. Jane Barry
Mrs. Isabell Blanton
Ms. Regina Bower
Mr. and Mrs. William Broekman
Mr. and Mrs. Bert Broekstra
Mr. Jovita Carranza
Mr. and Mrs. Doug Chaney
Mr. and Mrs. Rodney Chapin
Mr. and Mrs. Salvatore Corbo
CustomInk Campaigns LLC
Mr. Steve Day
Dell Employee Engagement Fund
Russell and Carla Dietz
Mr. and Mrs. Mark Evans
Ms. Carly Findlay
The Fred R. Fernandez - Irma R. Rodriguez
Foundation
Mr. and Mrs. Carlos Godby
Ms. Sue Green
Mr. and Mrs. Mike Hall
Mr. and Mrs. John Havrilla
Mr. and Mrs. Leo Hecke
Mr. Stephen Henry
Mr. and Mrs. Marty Hollingsworth Jr.
Mr. William Horton Jr.
Mr. and Mrs. Robert Hutchinson
Industrial Packaging Systems
The Isidro J. Gonzalez Living Trust
The Karlssons
Mr. and Mrs. Thomas Kennedy
Mr. and Mrs. Stephen Klaffer
Laborers Int'l. Union of North America
Ms. Lynn Langford
Mr. and Mrs. Paul Licursi
Kyle and Deann Look
Mr. and Mrs. Bruce Lynch
Mr. and Mrs. Jeffrey Lyngaas
Ms. Nancy Mantel
Ms. Dorothy Martin
Mr. and Mrs. John McCoy
Ms. Amy McKee
Mr. and Mrs. Andrew McNelly
Mr. and Mrs. Robert Melton
Drs. Leonard and Ellen Milstone
MMG Renovations
Mr. Joseph Morsman III
Mr. and Mrs. David Murray
Ms. Meghan Nesselroade
Mr. and Mrs. Warren O'Brien Jr.
Ormco Corporation
Mr. and Mrs. Juha Paakinaho
Mr. and Mrs. Richard Pedtke Charitable Foundation
Peterson Commercial LLC
Mr. and Mrs. Brent Pfeiffer
Mr. Peter Phillips
Pitney Bowes
Mr. and Mrs. Robert Ponzo
Mr. and Mrs. Roger Pretak
Mr. and Mrs. David Purcell
Ms. Suzanne Ragg
Mr. and Mrs. Victor Rice
Lee and Ken Roberts
Rock Roofing and Construction, LLC
Mr. and Mrs. Mark Saylor
Mr. and Mrs. Bryan Schell
Matthias Schmuht MD
Mr. Harold Schoendorf
Mr. and Mrs. Gregory Shea
Mrs. Janet Showers-Patterson &
Mr. Day Lewis Patterson
South Troy Timing Association
SR Lotion
Mr. and Mrs. Harry Sundik
Ms. Katie Swenson
Texas Gauge & Controls, Inc.
TWWC, Inc. D/B/A Tony Walker & Co.
Volume Salon
Ms. Mary Anne Wegmet
Mary Williams MD & Peter Elias MD
Ms. Edna Wong
Mr. and Mrs. Thomas Wornom
Jeanette Ziemek DDS

\$1,000 - \$4,999

Dr. Mark Ajlouni & Dr. Connie Ajlouni
Anonymous (4)
Mr. and Mrs. James Babcock
Sherri Bale PhD
BeAed
Ms. Gioia Bianchi-Williams
Mr. Brian Brager
John Browning MD
Dr. Brian Cheng
Keith Choate MD, PhD
Dr. and Mrs. Jason Cohen
Mrs. Marie Cox
Dr. and Mrs. Clifford Daugherty

Ms. Sarah Davie
DBG Services, LP
Mr. and Mrs. David Denman
Deutsche Bank Americas Foundation
Dona Wood Family Fund
Edwards Lifesciences Foundation
Mark Fagan DDS
Wen Fan DMD, MD
Dr. and Mrs. Phil Fleckman
Ms. Bobbi Florian
The Gaffney Foundation
GE Foundation
Mr. and Mrs. Ken Gendotti
Matt & Cristina Goebel
Mr. James Griffin Jr.
Hacienda Gardens
Mr. and Mrs. David Heyson
Mr. and Mrs. Robert Hoerle
Mr. and Mrs. Scott Hollenbeck
Mr. and Mrs. Joseph Hugenberg
Robert Hyde DDS
Mr. and Mrs. John Jessiman
JK Painting and Decorating
Mr. Kevin Kelly
Mr. and Mrs. Mark Klaffer
Mr. and Mrs. Wolfgang Knabe
Mr. Robert Kraybill & Ms. Durreen Shahnaz
Songbae Lee
Joseph McMurray DMD
Mr. and Mrs. Michael Miller
Ms. Debbie Montana
Mr. & Mrs. Todd Mooney
Ms. Edie Nordlund & Mr. Bob Nordlund
Mr. David Norris
Ms. Marcia Ohlweiler
Amy Paller MD & Etahn M. Cohen
Mr. and Mrs. James Pate
Mr. and Mrs. Thomas Petelin
Mr. and Mrs. James Phillips
Mr. and Mrs. Michael Potack
Mr. and Mrs. Joseph Proscia
Mr. and Mrs. Jeff Ricci
Gabriele Richard MD, FACMG
William Rizzo MD
Mr. and Mrs. Craig Saylor
Mr. and Mrs. Charles Schaffer
Mr. Eric Schweighoffer
Ms. Jennifer See & Rachel See
Drs. Pedro and Lucy See
Mr. and Mrs. Vincent Sellecchia
Sewer & Tunnel Miners Union
Mr. Joseph Shank & Ms. Patricia Pairman
Ms. Nomi Silverman
Mr. and Mrs. Lawrence Silverman
Dr. and Mrs. Robert Silverman
Mr. and Mrs. Ronald Swenson
Ms. Janie Thompson
Mr. and Mrs. John Tierney
Toyota Motor Sales, USA
Mrs. Margaret Vernet
Vestal Central Schools
Mr. and Mrs. Andy Wohlgang
Ms. Denise Yong
Ms. Nancy Yu
Dr. and Mrs. Ruey Yu PhD, OMD

\$5,000 - \$9,999

Allergan Foundation
Mr. and Mrs. Michael Briggs
Mr. Tim Dang
Flint Center
Chris & Laura Phillips
Mr. John Schoendorf
Select Equity Group Foundation
Mr. Martin Shkreli
Tang Fund
Dr. Eugene Van Scott

\$10,000 - \$99,999

Ace in the Hole Foundation, Inc.
The Ambrose Monell Foundation
Galderma International S.A.S.
Mr. Jeff Hoerle & Ms. Allison Draper
Mr. George Loening
Dr. and Mrs. David Scholl

\$100,000 +

Lennox Foundation



JUNE 13 - JULY 31, 2016

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!

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.

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.

MicrodermaMitt

FAST – EASY – NATURAL

Removes dry skin cells and scaling instantly using only water!



Before

After one use

Discounts available by contacting FIRST @ 800.545.3286
To Order: 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."

LAST CALL! 19th Biennial National Conference - San Diego, June 24-26



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

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



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.

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?

	First Name	Last Name	Date of Birth	Age	Affected with ichthyosis or a related skin type?	Relationship to person affected? (mom, brother, uncle, friend, etc.)	Participating in Kid-a-Palooza?	Participating in FIRST's Got Talent Show?	T-Shirt Size
1)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	<i>Provide address if different than above</i>								
2)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	<i>Provide address if different than above</i>								
3)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	<i>Provide address if different than above</i>								
4)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	<i>Provide address if different than above</i>								
5)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	<i>Provide address if different than above</i>								
6)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	<i>Provide address if different than above</i>								

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



Clinical Appointments & Ichthyosis Registry at Yale

All appointments will be scheduled for Saturday, June 25

This unique opportunity is offered to any affected member(s) and families to meet with expert dermatologists and researchers from Yale University. Please check which option you are interested in:

- 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

Registrant	Number	Fee Per Person	Total
Adult (ages 13+)	x	\$200 per person	= \$
Child (ages 5 to 12)	x	\$100 per person	= \$
Preschool (ages 2 to 4)	x	\$25 per person	= \$
Infant/Toddler	x	No Charge	= \$
Optional Add-Ons			
Kid-a-Palooza (ages 1 to completed fifth grade)	x	\$10 per child	= \$
Friday Night Pizza & Trolley Tour			
Adult: Ages 13+	x	\$35 per person	= \$
Child: Ages 4 to 12	x	\$21 per person	= \$
Toddler: Ages 3 and under	x	\$3 per person	= \$
 Celebrate FIRST's 35th anniversary with a \$35 gift to support the Conference Scholarship Fund - helping those who need it most...			\$
Grand Total			\$

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

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



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

WONDER by R.J. Palacios. New York: Alfred A. Knopf, 2012, ISBN: 978-0-375-86902-0

"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.





Foundation for Ichthyosis & Related Skin Types®

Educate • Inspire • Connect

2616 N. Broad Street • Colmar, PA 18915

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



2016 National
Conference
San Diego!
June 24 - 26, 2016



**Registration
Forms
Inside!
Pages 13 & 14**

Use #FIRSTNC16
for Conference
Updates!

SAVE the DATE!

September 10, 2016
1:30pm-4:30pm
Ichthyosis Picnic At
Northwestern University,
Evanston, Illinois

Join Dr. Amy Paller and other affected families for a fun and informative event!
More info at www.firstskinfoundation.org