Creating Connections for the Community

The 2021/22 fiscal year saw the waning months of the pandemic and the opportunity to get together in person once again. While virtual meet-ups and educational sessions continued as they had throughout the previous two years, all agree there is no substitute for gathering in person. FIRST will always strive to provide you with the resources and information you need, when you need it and where you can access it most conveniently.

FIRST tested the face-to-face waters with a Member Meet-up in Rehoboth, DE in November of 2021. New parents met with veteran parents to get reassurance and support. The group learned about the history of FIRST and the evolution of treatments from FIRST Board of Directors Emeritus Dr. Leonard Milstone.

In June, members gathered from across the nation and from several foreign countries in Providence, RI for our National Conference. Over fifty separate sessions included opportunities for parents to learn from each other, meet with experts in ichthyosis, participate in research and hear from inspirational speakers including our own Hunter Steinitz.

FIRST continued its support of the National Registry for Ichthyosis and Related Skin Disorders. The Registry is managed, sustained, and utilized to its fullest capability. FIRST resources support the principal investigator of The Registry, Dr. Keith Choate, and many of the functions in his laboratory at Yale University. FIRST also allocates resources to encourage our members to enroll in The Registry and receive a genetic diagnosis. FIRST supports outreach to research investigators and health organizations who specialize in ichthyosis and related skin types, to utilize The Registry’s many benefits.

Our mission is to “improve lives and seek cures” and we supported academic research as well as work with several pharmaceutical companies as they worked to develop new treatments for ARCI, Netherton’s, KID syndrome and Darier’s. The increase in the level of interest in ichthyosis from private industry over the last three years is very encouraging.

The FIRST website, www.firstskinfoundation.org is the front door to our organization for those seeking information and resources. Over 167,000 visitors entered that door and viewed over a quarter of a million pages. Through the pages 258 physician referrals were made.

Social media continues to grow as the preferred method to receive our information and to connect with each other. Facebook, LinkedIn, Instagram, Twitter and YouTube utilization all grew through the year. Consumption of FIRST YouTube videos grew substantially, and the primary way people took advantage of our virtual FIRST To Know sessions.

Many in our community took advantage of FIRST Aid, our program to provide financial assistance for the purchase of skin treatments. The UFIRST Scholarship program provided 11 students support for the growing costs of a college education.

I would like to thank all those who supported our mission through a financial contribution during the year. Our donors, quite literally, make our work possible. I would also like to thank our volunteers who gave of their time and energy, particularly our dedicated Board of Directors and Medical and Scientific Advisory Board.

Chris Boynton
Chief Executive Officer
About Us

Mission Statement
Our mission is to improve lives and seek cures for those affected by ichthyosis and related skin types.

Board of Directors
The Foundation for Ichthyosis and Related Skin Types, Inc (FIRST) is governed by a volunteer Board of Directors dedicated to supporting our mission with their time and talents. FIRST's Board members are active participants in the various activities of the Foundation and are representative of our diverse population locally and nationally.

Beth Hampshire, Fishers, Indiana, Board Chair
Jason Thogmartin, Carrollton, GA, Treasurer
Bailey Pretak, Beaver, PA, Secretary
Brian Stern, Lancaster, PA, Vice Chair
Sean McTernan, Lower Gwynedd, PA, Vice Chair
Sarah Asch, MD, North Oaks, MN
Jackie Barrett, Overland Park, KS
Jeff Blake, Novato, CA
Keith Choate, MD, PhD., Wallingford, CT
Jolie Cina, West Caldwell, NJ
Brittany Craiglow, MD, Fairfield, CT
Mark Evans, Hydes, MD
Tejal Kamdar, Oakland, CA
Jennie Wilklow-Riley, Highland, NY
Lowell Wright, McKeesport, PA

Leonard Milstone, MD, New Haven, CT – Emeriti
Amy Paller, MS, MD, Chicago, IL – Emeriti
Dave Scholl, PhD., Mason, OH – Emeriti
Mary L. Williams, MD, San Fransisco, CA - Emeriti
The Foundation for Ichthyosis and Related Skin Types or FIRST is a resource, a service, a hub, an advocacy organization, volunteer driven, and a community. The organization made a measurable impact on the lives of individuals and families we served in 2022. Here are some of the highlights:

**Research**—FIRST has funded more than $1,900,000 in research projects around the world from 2006 through 2022.

**Physician Referral**—Made 258 referrals to physicians who understand Ichthyosis.

**Resource Requests**—1,500 people reached out to FIRST for resources or help when they needed answers.

**Website Visits**—FIRST provided information to 166,552 unique visitors to our website.

**Financial Support**—provided grants for skincare or scholarships to 54 members, up 46% from last year.

**Social Media**—FIRST communicated through its six social media platforms to 10,377 followers and friends.

**National Conference**—Our twice postponed conference in Providence, RI drew 364 attendees. 111 came to their first conference.

**Workshops and Breakout Sessions**—48 different sessions held at the National Conference in Providence.
How We Invest Your Money

We believe our donors deserve full transparency on how their money is allocated in pursuit of our mission “To Improve the lives and seek cures for those affected by ichthyosis and related skin types.”

The following pages contain information from our audited financial statements to show how we raised and stewarded donor dollars in FY ‘21-’22 to empower affected individuals and their families.

### Revenue

Total revenue, gains and other support for the year ended September 30, 2022, were as follows:

<table>
<thead>
<tr>
<th>Source</th>
<th>FY ‘21-’22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>$410,841</td>
</tr>
<tr>
<td>Registrations</td>
<td>$52,396</td>
</tr>
<tr>
<td>Sponsors</td>
<td>$103,380</td>
</tr>
<tr>
<td>Grassroots</td>
<td>$29,109</td>
</tr>
<tr>
<td>Other</td>
<td>$23,721</td>
</tr>
<tr>
<td><strong>Total Support</strong></td>
<td><strong>$619,447</strong></td>
</tr>
</tbody>
</table>

### Public Support

- Contributions: 66%
- Registrations: 17%
- Sponsors: 8%
- Grassroots: 4%
- Other: 5%
Expense Allocation

Total Mission program and support services expenses for the year ended September 30, 2022, were as follows:

<table>
<thead>
<tr>
<th>FY '21-'22</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocacy</td>
<td>$70,960</td>
</tr>
<tr>
<td>Conference/Meet-Up</td>
<td>$167,733</td>
</tr>
<tr>
<td>Education/Programs</td>
<td>$378,620</td>
</tr>
<tr>
<td>Research</td>
<td>$77,807</td>
</tr>
<tr>
<td><strong>Total Mission Program Services</strong></td>
<td><strong>$695,120</strong></td>
</tr>
<tr>
<td>Management and General</td>
<td>$112,637</td>
</tr>
<tr>
<td>Fundraising</td>
<td>$83,924</td>
</tr>
<tr>
<td><strong>Total Mission Support Services</strong></td>
<td><strong>$196,561</strong></td>
</tr>
<tr>
<td><strong>Total Mission Program and Support Services</strong></td>
<td><strong>$891,681</strong></td>
</tr>
</tbody>
</table>
### Net Assets

<table>
<thead>
<tr>
<th>Without Donor Restrictions</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>Total</th>
<th>2021 Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Support and operating revenue</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions</td>
<td>$455,775</td>
<td>$113,173</td>
<td>$50,499</td>
<td>$619,447</td>
</tr>
<tr>
<td>Net assets released from restrictions</td>
<td>$120,668</td>
<td>-$120,668</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td><strong>Total support and revenue</strong></td>
<td>$576,443</td>
<td>-$7,495</td>
<td>$50,499</td>
<td>$619,447</td>
</tr>
<tr>
<td><strong>Operating expenses</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Program services</td>
<td>$695,120</td>
<td>$0</td>
<td>$0</td>
<td>$695,120</td>
</tr>
<tr>
<td>Supporting Services</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Management and general</td>
<td>$112,637</td>
<td>$0</td>
<td>$0</td>
<td>$112,637</td>
</tr>
<tr>
<td>Fundraising</td>
<td>$83,924</td>
<td>$0</td>
<td>$0</td>
<td>$83,924</td>
</tr>
<tr>
<td><strong>Total operating expenses</strong></td>
<td>$891,681</td>
<td>$0</td>
<td>$0</td>
<td>$891,681</td>
</tr>
</tbody>
</table>

Changes in net assets before non-operating revenues and expenses

<table>
<thead>
<tr>
<th></th>
<th>2022</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Without Donor Restrictions</td>
<td>Temporarily Restricted</td>
</tr>
<tr>
<td>Change in net assets</td>
<td>-$315,238</td>
<td>-$7,495</td>
</tr>
</tbody>
</table>

**Non-operating activities**

<table>
<thead>
<tr>
<th></th>
<th>2022</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Without Donor Restrictions</td>
<td>Temporarily Restricted</td>
</tr>
<tr>
<td>Investment income (loss)</td>
<td>-$387,094</td>
<td>$0</td>
</tr>
<tr>
<td>PPP loan forgiveness income</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td><strong>Change in net assets</strong></td>
<td>-$702,332</td>
<td>-$7,495</td>
</tr>
</tbody>
</table>

Net assets, beginning of year

<table>
<thead>
<tr>
<th></th>
<th>2022</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Without Donor Restrictions</td>
<td>Temporarily Restricted</td>
</tr>
<tr>
<td>$1,746,287</td>
<td>$729,359</td>
<td>$110,013</td>
</tr>
</tbody>
</table>

Net assets, end of year

<table>
<thead>
<tr>
<th></th>
<th>2022</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Without Donor Restrictions</td>
<td>Temporarily Restricted</td>
</tr>
<tr>
<td>$1,043,955</td>
<td>$721,864</td>
<td>$160,512</td>
</tr>
</tbody>
</table>

**Sustainability for our Future**

FIRST prudently invests reserves in a well-diversified portfolio to ensure consistent delivery of services regardless of the economy or investment environment. It is our goal to maintain one year of operating expenses in reserves.
2022 Donor Listing
Donations made during the 2022 calendar year.

$100 - $249
Suzanne Accardo
Adobe, Inc.
Susan and J.R. Aguila
Sarah and Kyle Alexander
Amanda Almaliah
Leanne and Cody Amdahl
Okey Anderson
Merritt Andrews
Margie Andrijasevich
Mary Arcidy
Sarah Arcoleo
Cheryl Ardis
Jeff Arenzana
Rayman Aryani
Jude Asphar
Sarah and Ben Aughenbaugh
Peter Ault
Amy and Doug Auw
Tamara Bailor
Sherri Bale
Linda and Glenn Balog
Juliana Bamrick
Barbara and Michael Barbaro
Cheryl Bayart
Susan Bayliss
Jennifer Beck
Ruthann and Joseph Beeler
Norma and Ted Berman
Charlotte and Larry Berry
Ketan Bhatia and Nikki Smith
Mardel Bierwagen

Renee Bizzell
BNY Mellon Corporation's Community Partnership
Beverly Bolin
Christine Booe
Linda and Jim Borden
Joan and Richard Borghi
Anne and Jack Borland
Peggy Boyle
Christopher Boynton
Margot Brandenburg
Karen and Barry Brandt
Rachel Brandt-Greenfeld
Chris Brewer
Nancy Brooks
Taina Bucci
Candace Cabonor
Tracie and Kevin Carey
Sarah Carroll and Kevin McPartland
Terry and Bill Carson
Tricia Carter
Thelma and Rodolfo Castillo
Chevron Humankind
Luksarah and John Choe
Mary and David Cina
Ellen and Tom Clemmer
Frederick Coates
Saul Cohen
Charles Conner
Corium, Inc.
Jennifer and Chris Covino
Cheryl and Alan Crouse
Jessie Deely
Rocco Defranco
Anthony Del Monte
Carol and Richard DeLoughary
Mirela Dibra
Deborah Donnell and Andrew Bruce
Drew Dornhecker
Aphrodite Doukas
Eugenia and Eugene Drum
Marianne Dugoni
Leslie Dummitt
East Rowan High School
Steven Eccher
George Eckles
Maura Eggan
Christy Ellman
Beth Elston
Sharon and Donald Enting
Bruce Evans
Ginny and Ray Evans
Erica and Anthony Farinella
Deborah Farley
Debra and Rick Fasciano
Sue Ferrell
Linette Finstad
Linde and Luke Fiore
Dani and Erik Fox
Marie and Michael Franco
Lisa Franklin-Daisey
Rebecca Frankwicz
Joe and Janice Franz
Regina Frazer
Linda Galloway
Joe Galluccio
Stacie and Chris Gann
Penny and Steve Garthe
Laura and Peter Gass
Sandra and Fred Gigl
Diana and James Gilbert
Laura and Ken Gillam
Tracy Giroux
Philip Gonzales
Chris and Juan Gonzales
Michelle Good
Google
Mary and Robert Graham
Rich Graham
Jennifer Grams
Grateful Fund at the Community Foundation of Greater Des Moines
Sue Green
Flora & Julio Gurman
Christine Haddad
Diane and Douglas Haggis
Barbara Hall
Maureen and Norman Hamel
Virginia and Paul Hammer
Patti and Dan Hanson
Cindy Harris
Sherry and John Havrilla
Jeanne and David Helmar
Sean and Kara Hickey
Melissa and Tim Hickey
Roylene and Victoria Hill
Elisabeth and Steven Hirtzinger
Sarah and Craig Hodgkinson
Jeremy Hoffman
Laura Hogan and George Drucker
Sandra Holland
Jacque and Marty Hollingsworth
Stephanie Hollis
Christine Horn
York Huang
Jan and Paul Hudson
Linda and Robert Hughes
Joyce Hutton
Premu Jasansky-Isaac
Thomas Johnson
Carol Jones
Joyce and Morris Judson
Hilel and Debbie Kagan
Edward Kaier
Akiko and Li Li Kawaguchi
Scott Keen
Eileen Keerdoja
Shawna Kehler
Amanda Kelly
Nafees Khundker
Kimberly Kim
Christine Kim
Linda Kister
Rita and Mike Klemm
Shelley Koch
Cynthia and John Kohl
Char and John Kopchick
Anna and Roman Kowalczyk
Sarah Laskey
Jennifer and Joseph Lecker
Cynthia and Lance Lesher
Jeff Levene
Father John Leyba
Carol and Gregory LiCalzi
Abby Liff
Sue and Joe Linaugh
Ethel Lindberg
Daneen and Alan Locascio
Jaclyn and Robert Lorenz
Leslie Love
William Love
Laura and Jeff Lucarelli
Marcy and Kevin Lundy
Gloria Maffettone
Peter Margittai
Betsy Marrero
Marian and Roberto Martinez
Elizabeth Maudlin
Kelly and Robert McAllister
Thomas McClune
Ingrid McConnell
Carol and Thomas McTernan
Diane and Roger Measel
Molly Mech
Lakshmi Menon
Thomas Messner
Jason Meyer
Jeanne Michels
Microsoft Matching Gifts Program
Jodi and Gary Milam
Allyson Miller
Lisa and Jim Mooney
Sandra Morison
John and Pamela Morley
Becky Morrell
Beth Mulpas
Mikela Murphy
Catherine Murphy
Christopher Murphy
Joan and Dennis Neaton
Carol and Kenneth Nichols
Douglas Nickerson
Gail Niesl
Dawn Nolet
Rosemary Norton
Erin O'Brien-Keefe
Ella O'Reilly-Warren
Albert Venegas
Joyce and Skip Vilas
Valerie and Phillip Vitali
Judy and Chuck Wagner
Kitty and Jimmy Wall
Margaret and Charles Wells
Sharon Wilklow
Carol and Paul Williams
Barbara Wilson
Angela and Kevin Wilson
Joanne Winter
Julie and Donald Wismar
Joanna and Chris YedreYESKI
Frank Yoder
Debra and Mark Yoder
Debbie and Mike Young
Sherry and George Zailer
Yuliana Zapata
Frank Ziede

$250 - $499
Ammar Al Ojaili
Harry Alexander
American Family Insurance Company
Patricia Arick
AT&T Foundation
Michelle Basnet
Siobhan and Jeffrey Blake
Jamie and Brandon Bond
Regina and Robert Bower
Anna Bruckner
Stephanie and Steve Budman
Jovita Carranza
Costco Wholesale Corporation
Dell Employee Engagement Fund
Christy and Mike Dennison
Andrew DeTerlizzi
Jed Emerson
Claudia Ephrem
Carol Estes
Evergreen Fund
Lynn and Dave Fasanella
Bobbi Florian
Angela and Carlos Godby
Patrick Grunloeh
Terri Guarriello
Hallton Church of Christ
Beth Hampshire
A Howland Hartley
Judy Hartmann
Marianne Heck
William and Flora Hewlett Foundation
Anne Kaier
Paul Kelley and Loretta Mitchell
Gail and Eric Kleintop
Charles Kohlbecker and Lynna Search
Jacqueline Koutsoukos
Harry Lancaster and Jane Henderson
Leslie and Thomas Lawley
Jennifer Lefkowska
Erin Mathes
Janet and John McCoy
Nicole McMillian
Margaret McTernan
Alan Mendelsohn
Tim Ohlwiler
John O'Neil
Melissa and Doug Osterloth
Kathryn and Matthew Pedicino
Irene Peltzer
Alisa and Nick Pettry
Hollie and Brent Pfeiffer
Kay Pinto
Emily Preston
Christopher Raschke
Kathy Rejcek
Darin and Ronald Saavedra
Sadaf and Athar Saeed
Jenny and Shawn Saylor
Beth and Craig Saylor
Nicole and Mark Saylor
Linda and David Schell
Jamie Schlather
Samantha and Adam Schlitt
Valerie and David Scholl
Securian Foundation
Jennifer and Rachel See
Lucy and Pedro See
Eileen and Dan Siegel
Steven Sobkowski
Dennis Sopher
Douglas Thomas
Tower Research Capital
UBS Employee Giving Program
Cyndi Vanslander
Fulvia Veronese and Marino DeMarzo
Laurie and John Wallace
Jorja and Greg Watts
David Weintraub
Connie and George Welborn
Denise Yong
Eric Zugerman

John Browning
Sharyn Brubaker
Jennifer and David Bryson
Mr. and Mrs. Steven Busch
Janet and Robert Caligan
Mike Carroll
Sara and David Clapp
Kimberly and Jason Cole
Jennifer and Michael Crudele
Kushal Dave and Emma Pelzner
Mary Kay and John Deering
Joseph Delgrande
Quinn Deloughary
Mary and Emerson Farley
Jody Fasnacht
Mary Elise Gianos
Stacey and Adam Hartman
Jeff Hoerle and Allison Draper
Jody and Scott Hollenbeck
Kristen Hook
Skip Horton
Frank Levinson
Joan and Moise Levy
DeAnn and Kyle Look
Olivia Lyngaas
David and Betty McMasters
Kathleen McTernan
Pauline and Mike McTernan
Patti and Adrian Metzger
Inna Nikolaeva
Eugene Nogi
Warren O'Brien
Sarah and Michael Pannacciulli
Mary Ann and Richard Pedtke Charitable Foundation
Melisa Ridenour

$500 - $999
Cindy Ashton
Mr. and Mrs. Robert Bialer
Sabina Blackwell
Rachel Rizzuto
Matthias Schmuth
John Schoendorf
Rama Singh
Brenda and Larry Staton
Donna and Ronen Strassburg
Beth and Fred Straub
Deborah Van Zaun
Tal Vander
Pat and John Veale
Vestal Central Schools
Paul Wopperer
Joseph Yurcik

H&R Block
Babs and Jerry Hajdusiewicz
Jan and Mike Hall
Carole Jahnke
Judith Jauch
Mary and John Jessiman
Susan and Harry Kaneshige
Lisa and Rich Kass
Heather and Wolf Knabe
Shelly and Paul Licursi
Linda Lucas
Kathleen McEnerney
Lisa and Lawrence McTernan
Carolyn and Sean McTernan
Steve Melhuish
Ellen and Len Milstone
Kathleen and Ray O’Loughlin
Amy Paller and Etahn Cohen
Patricia Patock
Liliana Perez-Rios
Elza and James Phillips
Laura Phillips and Chris Phillips
Mitch Poiset
Randi and Michael Potack
Tracie Pretak
Joanne and Joseph Proscia
Gabriele Richard
Bill Rizzo
Mary Roberts*
Eric Schweighoffer
Janet Showers-Patterson and Day Lewis Patterson
Ethel Sorgatz
Jennifer and Adam Stier
Jason Thogmartin
Catherine Tiemeyer

$1,000 - $4,999

AmazonSmile
William Aughenbaugh
Jackie Barrett
Latanya Benjamin
Gioia Bianchi-Williams
Ryan Bibler
Betsy Blackford
Patricia Brennan
Martina Cheung and Tracy Zukowski
Keith Choate
Jolie and Sean Cina
Laurence Conroy
Britt Craiglow
Deutsche Bank Americas Foundation
Disney VoluntEars Program
Page Elliott
Exelon
Star and Phil Fleckman
Jim Griffin
Victoria and Mark Trout
Volkswagen Group
Liz and Benjamin Waldshan
Courtney and Evan Westlake
Mary Williams and Peter Elias
Kim and Lowell Wright
Ho Chin and Ruey Yu

$5,000 - $9,999
Pat & David Denman
Gaffney Foundation
Billie Gaskill* Estate
Tejal Kamdar and Jason Snyder
Nancy Mantel*
Sasha and Ryan McTernan
Rachael and Todd Mooney

Anonymous
Tao Family Fund
Margaret Vernet

$10,000 and above
Rhayne and Mark Evans
Teri and David Heyson
Catherine and Robert Hutchinson
Terry and Robert Melton
Ryan Memorial Foundation
Brent Teeter

*deceased

Corporate Advertisers, Partners & Sponsors

Beiersdorf, Inc.
Dermal Therapy Research, Inc.
G16 Lotion
Genentech, Inc.
Quoin Pharmaceuticals
Timber Pharmaceuticals, LLC
Whitewater Co.
Young Pharmaceuticals