



Foundation for  
Ichthyosis & Related  
Skin Types®

# FY2022 Annual Report





Foundation for  
Ichthyosis & Related  
Skin Types

## 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 Darriers. 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](http://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 Francisco, CA - ***Emeriti***

# 2022 By the Numbers

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.



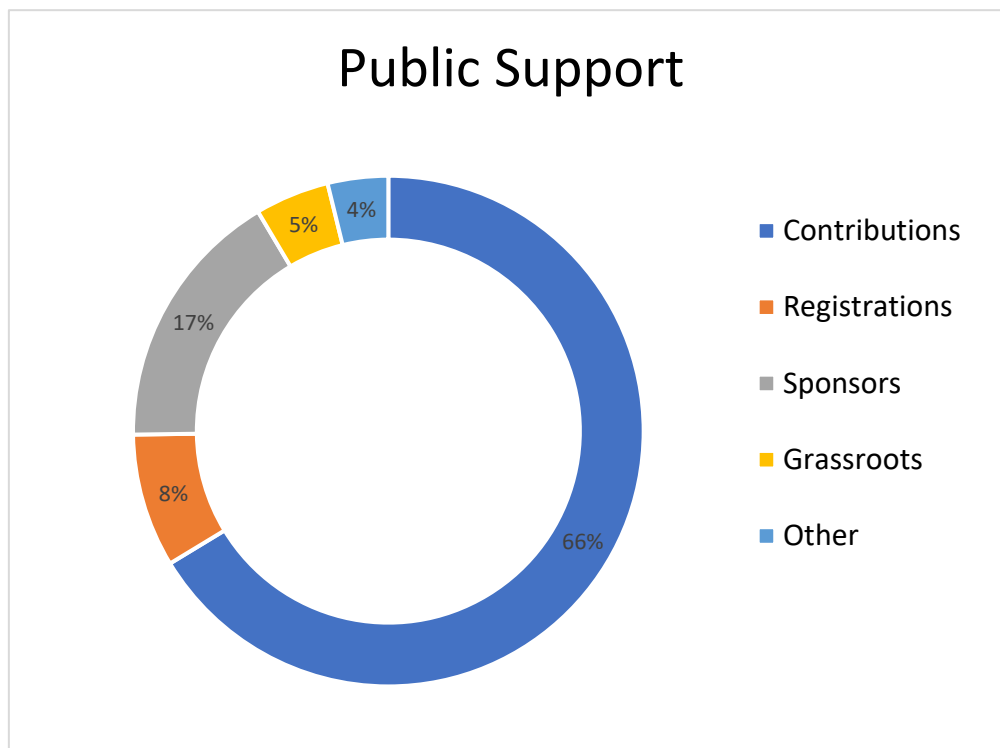
Foundation for  
Ichthyosis & Related  
Skin Types

# 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:			
			FY '21 - '22
Contributions			\$410,841
Registrations			\$52,396
Sponsors			\$103,380
Grassroots			\$29,109
Other			\$23,721
<b>Total Support</b>			<b>\$619,447</b>



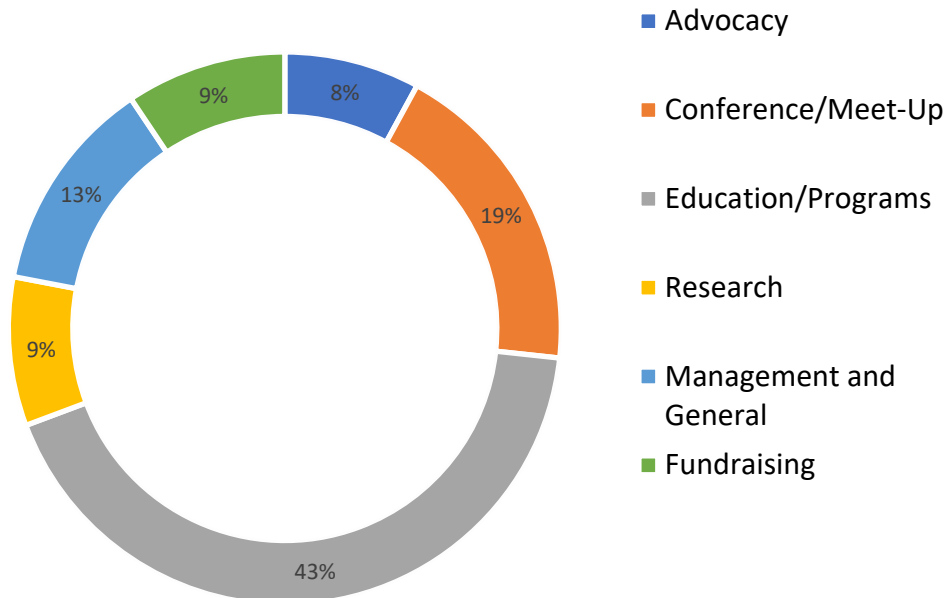
# The Impact of your Donations

## Expense Allocation

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

	<u>FY '21-'22</u>
Advocacy	\$70,960
Conference/Meet-Up	\$167,733
Education/Programs	\$380,620
Research	<u>\$77,807</u>
<b>Total Mission Program Services</b>	<b>\$697,120</b>
Management and General	\$112,637
Fundraising	<u>\$83,924</u>
<b>Total Mission Support Services</b>	<b><u>\$196,561</u></b>
<b>Total Mission Program and Support Services</b>	<b><u>\$893,681</u></b>

## Your Impact



# 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 Egan  
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 Leshner  
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 Mauldin  
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

Marilyn and Allen Overway  
Connie Palmer  
Ken Parkin  
Kathy Patterson  
Leslie and Don Patterson  
Nancy Pelton  
Gail and Donald Peterson  
Jenny and Steve Phelan  
Carol and Jim Phillips  
Madison Piceno  
Paige and Michael Pinnisi  
Paula and John Pinto  
Mr. and Mrs. Keshav Pitani  
Ann Pokalsky and Ted Glowacky  
Sylvia and Rodney Pollan  
Mary Alice and Robert Ponzo  
Alan Prince  
Marguerite Pullen  
Muhit Rahman  
Kara Ramsey  
Laurie and Jerry Raz-Astrakhan  
Lucy and James Register  
Marcia Richmond  
Freida and Ronnie Ridings  
Julie and Matt Rienzo  
Robert Half  
Kelly and Kyle Robinson  
Sharon Robinson  
Loren Rodwin  
Ana Rosa-Cortes  
Ellen and Corwin Roscoe  
Alli Rose  
Mary and Rodney Runestad  
Allison Sanford  
Barbara Sawyer  
Michelle and Allan Schell

Amy and Peter Schemm  
Suzanne and Tristan Schlomann  
George Seiz  
Rosanna Sforza  
Pamela Shea  
Shell Oil Company Foundation  
Karen and Richard Sherman  
Pat Shiffner  
Phyllis and Elliot Shulman  
Carol and Bob Simmons  
Margaret Sinclair  
Gabriela and John Sipe  
Bob Sipper  
Linda and Michael Sisack  
Candy Skedel  
Betsy and Larry Spruill  
Richard Staiman  
Joely and Peter Stano  
Lisa and Lauren Stephens  
Julia and Brian Stern  
Janese Stimmel  
Anga Strine  
Mary Swope  
Virginia Sybert  
Jasmyn and Matthew Tanner  
Jenifer Taylor  
Joyce Teng  
TIAA  
Lori Townsend  
Natalie Turton  
Kaarin Van Ausdal  
Sue and Garrett Van Essen  
Eugene Van Scott  
Shannon VanderSwaagh  
Nancy Variano  
Varada and Lee Vaughan

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  
Clauda Ephrem  
Carol Estes  
Evergreen Fund  
Lynn and Dave Fasanella  
Bobbi Florian  
Angela and Carlos Godby  
Patrick Grunloh  
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 Lefkowski  
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 Zuger

## **\$500 - \$999**

Cindy Ashton  
Mr. and Mrs. Robert Bialer  
Sabina Blackwell

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

Rachel Rizzuto  
Matthias Schmutz  
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

### **\$1,000 - \$4,999**

AmazonSmile  
William Aughenbaugh  
Jackie Barrett  
Latanya Benjamin  
Gioia Bianchi-Williams  
Ryan Bibler  
Betsy Blackford  
Patricia Brennan  
Jamie and Jack Casey  
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

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

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