



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 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.

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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.



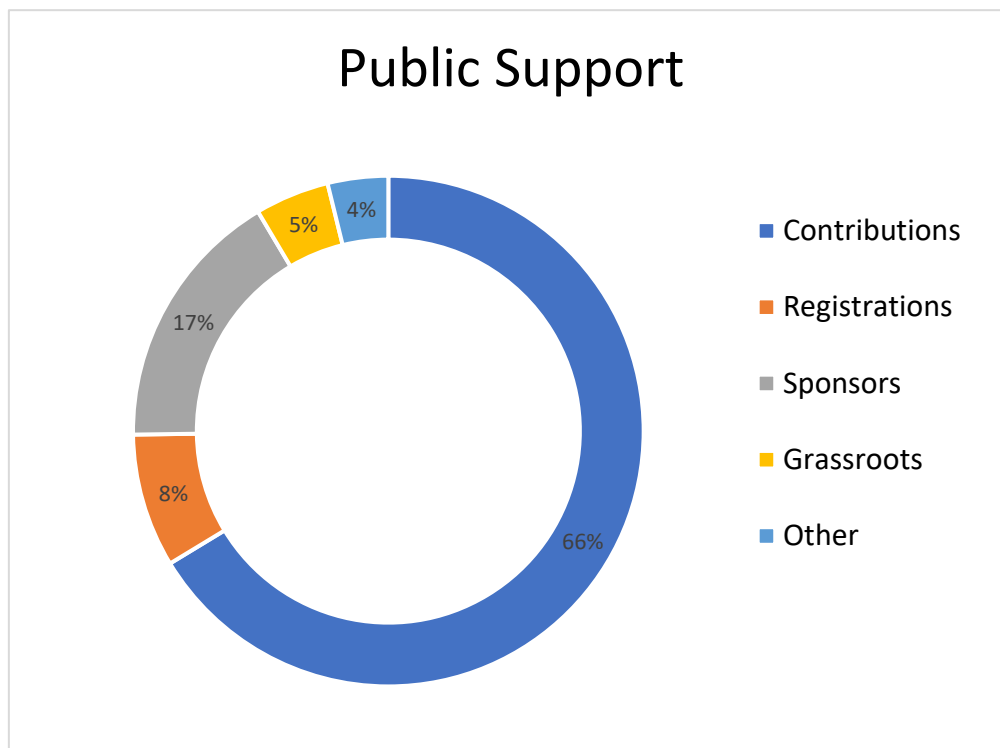
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How We Invest Your Money

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
Total Support			\$619,447



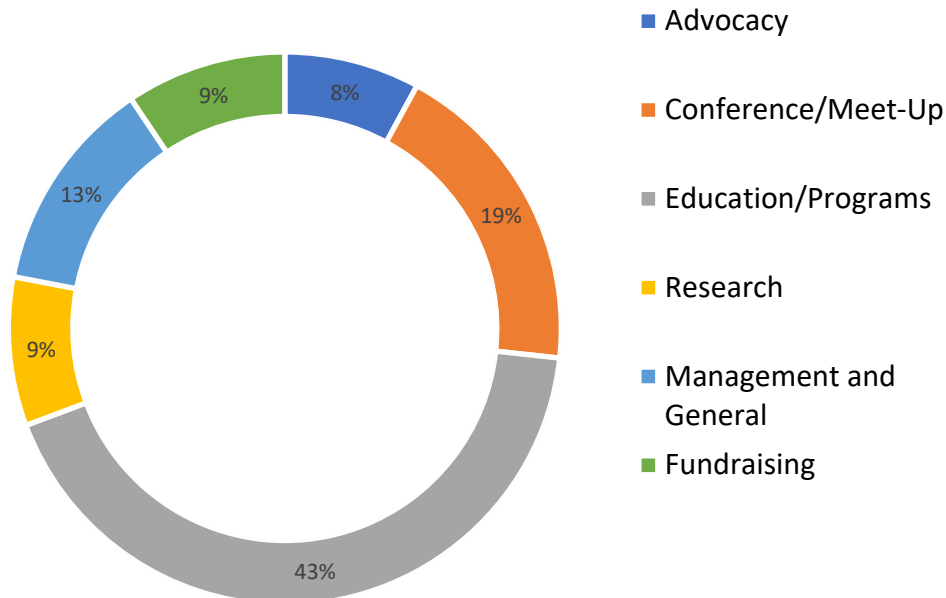
The Impact of your Donations

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	\$378,620
Research	<u>\$77,807</u>
Total Mission Program Services	\$695,120
Management and General	\$112,637
Fundraising	<u>\$83,924</u>
Total Mission Support Services	<u>\$196,561</u>
Total Mission Program and Support Services	<u>\$891,681</u>

Your Impact



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.

Net Assets

	2022				2021 Totals
	Without Donor Restrictions	Temporarily Restricted	Permanently Restricted	Total	
<u>Support and operating revenue</u>					
Contributions	\$455,775	\$113,173	\$50,499	\$619,447	\$602,335
Net assets released from restrictions	<u>\$120,668</u>	<u>-\$120,668</u>	<u>\$0</u>	<u>\$0</u>	<u>\$0</u>
Total support and revenue	<u>\$576,443</u>	<u>-\$7,495</u>	<u>\$50,499</u>	<u>\$619,447</u>	<u>\$602,335</u>
<u>Operating expenses</u>					
Program services	\$695,120	\$0	\$0	\$695,120	\$438,302
Supporting Services					
Management and general	\$112,637	\$0	\$0	\$112,637	\$116,705
Fundraising	<u>\$83,924</u>	<u>\$0</u>	<u>\$0</u>	<u>\$83,924</u>	<u>\$71,241</u>
Total operating expenses	<u>\$891,681</u>	<u>\$0</u>	<u>\$0</u>	<u>\$891,681</u>	<u>\$626,248</u>
Changes in net assets before non-operating revenues and expenses	<u>-\$315,238</u>	<u>-\$7,495</u>	<u>\$50,499</u>	<u>-\$272,234</u>	<u>-\$23,913</u>
<u>Non-operating activities</u>					
Investment income (loss)	-\$387,094	\$0	\$0	-\$387,094	\$329,306
PPP loan forgiveness income	<u>\$0</u>	<u>\$0</u>	<u>\$0</u>	<u>\$0</u>	<u>\$95,500</u>
Change in net assets	<u>-\$702,332</u>	<u>-\$7,495</u>	<u>\$50,499</u>	<u>-\$659,328</u>	<u>\$401,343</u>
Net assets, beginning of year	<u>\$1,746,287</u>	<u>\$729,359</u>	<u>\$110,013</u>	<u>\$2,585,659</u>	<u>\$2,184,316</u>
Net assets, end of year	<u>\$1,043,955</u>	<u>\$721,864</u>	<u>\$160,512</u>	<u>\$1,926,331</u>	<u>\$2,585,659</u>

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Donations made during the 2022 calendar year.

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