





## About Us

### OUR MISSION STATEMENT

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

### OUR LEADERSHIP

The Foundation for Ichthyosis and Related Skin Types (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.

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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 lives and seek cures for those affected by ichthyosis and related skin types.”

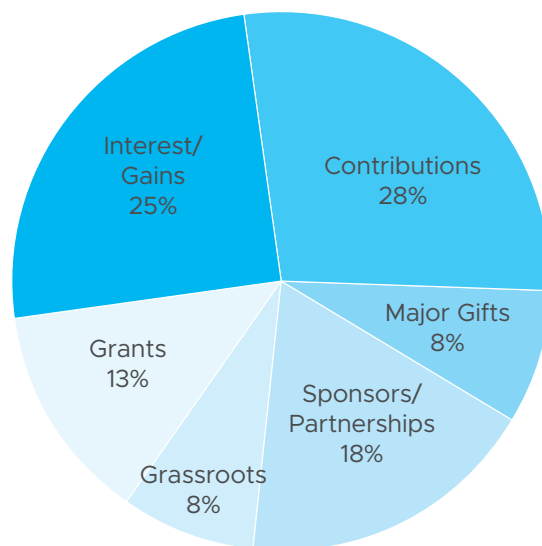
The following pages contain information from our audited financial statements to show how we raised and stewarded donor dollars in fiscal year 2022-23 to empower affected individuals and their families.

### REVENUE

Total revenue, gains and other support for the year ended September 30, 2023

	FY '22-'23
Contributions	\$248,148
Major Gifts	\$66,443
Sponsors/Partnerships	\$163,102
Grassroots	\$72,213
Grants	\$117,500
Other	\$217,013
<b>Total Support</b>	<b>\$884,419</b>

### TOTAL SUPPORT



## 2023 Reach and Results



FIRST hosted member meet-ups in St. Louis, Tampa and Seattle that were attended by **62** individuals and families.

# 177,918

unique visitors found their way to [firstskinfoundation.org](https://firstskinfoundation.org) for help and information.

# 310

new families reached out to FIRST for information, resources and to become a part of this nurturing community.

# 281

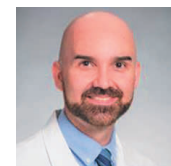
people inquired about ichthyosis experts through our Physician Referral program.

**TWO** researchers were awarded a total of **\$100,000** to further their research.

- Dr. Benjamin Nanes from the University of Texas Southwestern Medical Center looked at keratin isoform switching during epidermal differentiation.
- Dr. Cory Simpson's grant studies pathogenic mechanisms and evaluates new treatment approaches for Darier disease.



Dr. Benjamin Nanes



Dr. Cory Simpson

# 25

members of our community received over **\$15,000** in financial support for the purchase of creams and lotions and UFIRST scholarships for college.

FIRST worked with **six** pharmaceutical companies to create patient-focused clinical trials and marketed those trials to our membership to accelerate the development of new therapies.



## Member Stories - Hope for Patients



Genetic testing through the Ichthyosis Registry revealed Camillia's rare ichthyosis-associated heart complication, allowing her to receive prompt treatment. Read Camillia's story at [firstskinfoundation.org/camellia-2024](https://firstskinfoundation.org/camellia-2024).



Thanks to a dedicated team at Northwestern Hospital in Chicago focused on researching Darier's disease, Genevieve believes effective treatment – and an ultimate cure – is closer than ever. Read Genevieve's story at [firstskinfoundation.org/genevieve-2025](https://firstskinfoundation.org/genevieve-2025).

## MSAB Drives Progress on Many Fronts

The Medical and Scientific Advisory Board is swinging into action to move forward the many advances related to ichthyosis. Long an advisory group to FIRST, the MSAB has approximately 25 members, all physician experts on ichthyosis. The goals of the MSAB are to guide FIRST in discovering content for education, partner in helping patients with concerns, promote research that leads to better understanding of ichthyosis and new therapies, and provide information about international and national activities in the field. The MSAB includes some younger physicians who are interested in ichthyosis and thus serves as a way to mentor future leaders in the field.

At the every-other-year FIRST National Conference, MSAB members have been central in giving talks, networking with affected individuals and families, conducting research, and providing one-on-one guidance about diagnoses. They are also a network for physician referral to make the diagnosis of ichthyosis subtypes and provide cutting-edge recommendations. MSAB members have been central to growing the Ichthyosis Registry.

The MSAB meets at least quarterly and presents to the Board of Directors of FIRST on a regular basis. At MSAB meetings, members share information about activities. For example, at the most recent meeting, there was discussion about new guidelines for treatment of ichthyosis that are being published in 2025, a new consortium of sites for research that has been formed and is hoping for funding from

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the National Institutes of Health to forge new paths towards treatment, and a proposed re-classification of ichthyosis and related skin types.

The latter has grouped ichthyosis subtypes and all of these “related skin types” in what is now called “epidermal differentiation disorders”, simplified to EDDs. For translation, “epidermal” refers to the outer layer of skin where all the action is in ichthyosis and “differentiation” refers to the healthy maturation of skin to form the skin barrier, which is impaired in ichthyosis.

The MSAB is also supporting the development of guidelines through the Pediatric Dermatology Research Alliance for neonatologists, dermatologists, and other specialists to educate and standardize best care for newborns with ichthyosis.

Other actions to look forward to in the next year or two from the MSAB are:

- Creating an inventory of MSAB-approved letters that affected individuals can use (for example, for taking emollients onboard when traveling)

- Annotating the list of dermatologist members to help identify areas of expertise and developing a roster of national subspecialists (beyond dermatologists) who have expertise
- Advising about the new FIRST “Research Roadmap”
- Generating data-based informational short videos for posting on social media about ichthyosis
- Continuing the EDVYCE tool online to answer questions about ichthyosis
- Sharing updates through the website, newsletter, and social media about new guidelines, classification, and therapies
- Being present in full-force at the June 2026 conference in Minneapolis to meet with participants and drive forward education and research

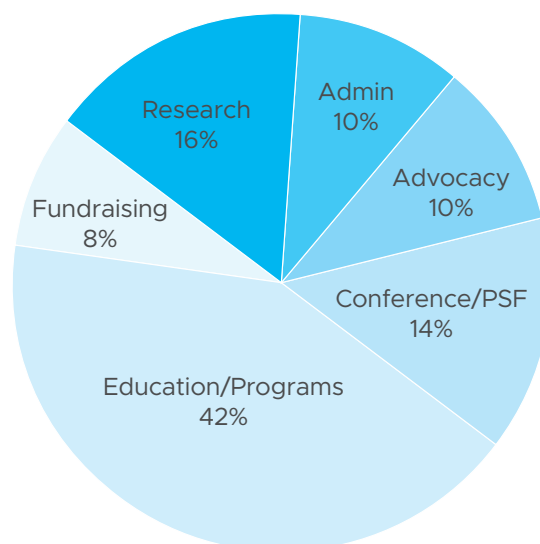
## The Impact of Your Donations

### EXPENSE ALLOCATION

Total mission program and support expenses for the year ended September 30, 2023, were as follows:

	FY '22-'23
Advocacy	\$76,713
Conference/Meet-Up	\$105,003
Education/Programs	\$321,556
Research	\$117,517
<b>Total Mission Program Services</b>	<b>\$620,789</b>
Management and General	\$73,153
Fundraising	\$62,147
<b>Total Support Services</b>	<b>\$135,300</b>
<b>Total Mission and Support Services</b>	<b>\$756,089</b>

### YOUR IMPACT



## 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.

### NET ASSETS

2023

	Without Donor Restrictions	Temporarily Restricted	Permanently Restricted	2023 Totals	2022 Totals
<b>Support and operating revenue</b>					
Contributions	\$566,871	\$32,222	\$77,338	\$676,431	\$619,447
Net assets released from restrictions	\$110,171	-\$110,171	\$0	\$0	\$0
<b>Total support and revenue</b>	<b>\$677,042</b>	<b>-\$77,949</b>	<b>\$77,338</b>	<b>\$676,431</b>	<b>\$619,447</b>
<b>Operating expenses</b>					
Program services	\$620,790	\$0	\$0	\$620,790	\$695,120
Management and general support	\$73,153	\$0	\$0	\$73,153	\$112,637
Fundraising support	\$62,147	\$0	\$0	\$62,147	\$83,924
<b>Total operating expenses</b>	<b>\$756,091</b>	<b>\$0</b>	<b>\$0</b>	<b>\$756,091</b>	<b>\$891,681</b>
Changes in net assets before non-operating revenues and expenses	-\$79,049	-\$77,949	\$77,338	-\$79,660	-\$272,234
<b>Non-operating revenues and expenses</b>					
Investment income (loss)	\$207,988	\$0	\$0	\$207,988	-\$387,094
<b>Change in net assets</b>	<b>\$128,939</b>	<b>-\$77,949</b>	<b>\$77,338</b>	<b>\$128,328</b>	<b>-\$659,328</b>
<b>Net assets, beginning of year</b>	<b>\$1,043,955</b>	<b>\$721,864</b>	<b>\$160,512</b>	<b>\$1,926,331</b>	<b>\$2,585,659</b>
<b>Net assets, end of year</b>	<b>\$1,172,894</b>	<b>\$643,915</b>	<b>\$237,850</b>	<b>\$2,054,659</b>	<b>\$1,926,331</b>

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