IMPACT REPORT 2025

10th FSIG ANNIVERSARY

Fabry Support & Information Group
30 Years of Rare. 30 Years of Resilience.

Our Commitment to the Community

What we do

The Fabry Support & Information Group (FSIG) is dedicated to supporting, educating, and empowering individuals and families affected by Fabry disease. Through trusted resources, meaningful programs, and a strong sense of community, FSIG works to ensure that no one navigates this rare disease alone. By providing access to accurate information and opportunities for connection, FSIG helps individuals feel informed, supported, and understood at every stage of their journey.

At the heart of FSIG's mission is a commitment to building connections and advancing awareness. By bringing together patients, caregivers, healthcare professionals, and industry partners, FSIG fosters collaboration that leads to better outcomes and stronger support systems. As the organization continues to grow, it remains focused on expanding its reach, increasing access to education and support, and improving the lives of those impacted by Fabry disease.

Our Mission

It is the mission of the Fabry Support & Information Group to provide the Fabry community and the general public with information, advocacy, education, and compassionate support to improve the quality of life and the quality of care for Fabry patients and family members.

9

Patient Meetings

Facilitated 9 patient meetings and a national conference, strengthening connection, education, and support across the community.

8

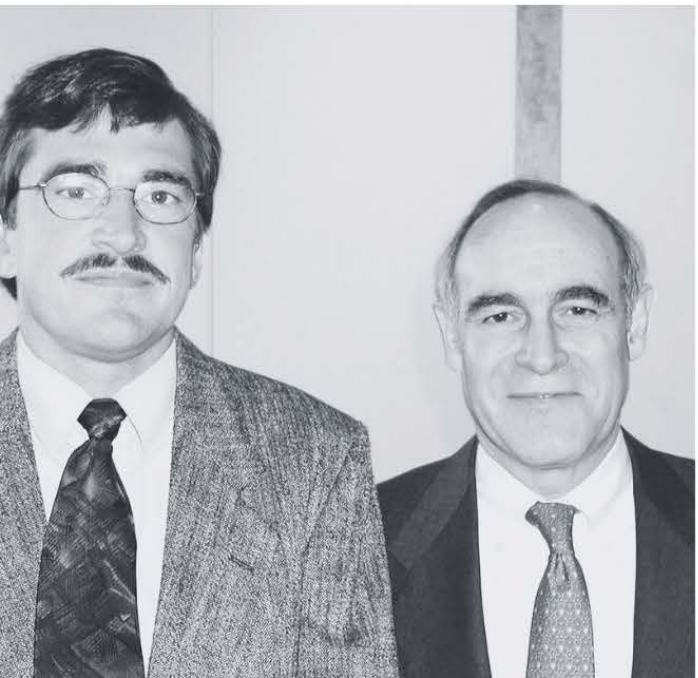
Newborn Screening

Expanded engagement with states nationwide to advance and support newborn screening efforts, increasing early detection and impact for affected families.

11

Policy

Advanced policy and legislative efforts through strategic collaborations, strengthening advocacy and driving meaningful progress for the community.



FROM KITCHEN TABLE TO GLOBAL ADVOCATE

CELEBRATING 30 YEARS

Fabry Support & Information Group (FSIG) began with a simple but powerful mission: make sure no one faces Fabry disease alone. Three decades later, that promise still guides everything we do. How We Got Started When Jack, Debra, and Kathy Johnson first gathered to create FSIG—encouraged by Dr. Robert Desnick— they knew the Fabry community needed a voice. In 1997, we published our very first newsletter (just 100 copies!) and launched the first website dedicated to Fabry patients. Those modest beginnings planted seeds that would grow into a worldwide network of support, education, and advocacy. The early 2000s brought major milestones. Along with you we wrote letters to the FDA, attended meetings, and helped influence the approval of enzyme replacement therapy in 2003. By 2005, we participated in the formation of Fabry International Network, connecting patients and advocates across the globe. Every step forward was guided by one question: What does our community need? Changing the Conversation One of our proudest achievements has been advocating for women and girls with Fabry disease. For too long, females were told their symptoms weren't from Fabry or didn't need treatment. We refused to accept that. By partnering with researchers, clinicians, and industry leaders, we've helped change the medical conversation. Today, more women are being diagnosed, validated and treated with the care they deserve. We've also been champions for the youngest members of our community. By partnering with "Testing for Tots" and our ongoing push for newborn screening, we're working to ensure babies get diagnosed early—sparing families years of uncertainty and giving children the best possible start.

Jack & Connie 20 Year celebration cake

Jack receiving the PAL Award

Support That Shows Up

FSIG isn't just about advocacy—we're here in practical ways too. Since 2011, our Fabry Assist program has provided over 750 financial awards to families who needed help. Whether it's covering travel to appointments or easing other burdens, we show up when it matters most. We've also earned a seat at important tables. From the National Kidney Foundation to international medical conferences, FSIG represents your voice in conversations about research, treatment, and policy. We've advocated on Capitol Hill, collaborated on patient-focused reports, and joined coalitions to amplify the rare disease community.

What's Next

As we look ahead, our focus remains clear: expand newborn screening so more babies are identified early, support newly diagnosed families from day one, and keep fighting for care that honors every person's Fabry experience—regardless of age, gender, race, or how the disease shows up for them. We're grateful to be part of this incredible community and the broader rare disease family. Being surrounded by partners who listen, collaborate and truly put patients first reminds us that real progress happens when we move forward together. From those first 100 newsletters to a global network of support, FSIG's story is really your story. Thank you for letting us walk alongside you, today and always.

Jack visiting North Dakota Senator Kevin Cramer's office in 2019

Jack always showing "our colors" for the Fabry Awareness Walk

30 Years of Community

Fabry Support & Information Group

30 Years of Rare. 30 Years of Resilience.

384k+

in assistance awarded to more than

1,025

eligible Fabry patients

Community & Events

- Annual conference
- Walk of Hope / Faces of Strength
- Regional meetups
- Awareness events
- Women's Summit
- Young adult roundtables

Education & Core Programs

- Weekly emails & mailings
- Webinars / expert sessions
- Newsletter
- Resource library
- Newly diagnosed support
- Partnerships with HCPs/pharma
- Policy or outreach work
- Mentor program (when launched)

Patient Support & Assistance

- Cooling vest program
- Travel scholarships
- Financial assistance
- Care packages

Impact

For years, the Fabry Support & Information Group has recognized the critical need for financial assistance within the Fabry community. In 2011, Fabry Assist (formerly RAFT) was established to help individuals and families facing overwhelming financial burdens. Through this program, FSIG provides support for Fabry-related expenses that are often not covered by other resources, ensuring that patients can access the care and services they need. Assistance is available to individuals in the United States who demonstrate extraordinary financial hardship.

Since its inception, Fabry Assist has supported hundreds of requests, helping individuals attend patient meetings, travel to see Fabry specialists, and bridge gaps left by other assistance programs. This impact is made possible through the generosity of our community. Every dollar distributed through Fabry Assist is raised through individual donors, grassroots fundraising efforts, and community support—not through pharmaceutical grants or sponsorships—making it a true reflection of the community helping one another.

FSIG remains deeply committed to sustaining and growing this support. As the need continues, so does our reliance on the generosity of those who believe in this mission. Together, we are making a meaningful difference in the lives of individuals and families affected by Fabry disease.

SCAN ME

FSIG

making AN IMPACT

Our Vision

A world where no one is impacted by Fabry disease, and every individual and family has access to the care, support, and resources needed to live a full and healthy life.

Our Strategy

Improved Patient Lives

Bringing patients together while providing trusted information, support programs, and resources for newly diagnosed families.

Expanded Access to Early Diagnosis

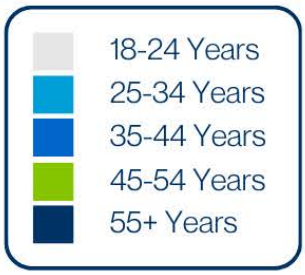
Increased Awareness and Understanding

Empowered Patient Advocacy

Collaboration and Research Support

Social Impact

This report provides an overview of our social media audience, including key demographics, interests, and engagement trends on Facebook, Instagram and now TikTok throughout the 2025 calendar. By analyzing these insights, we can better connect with the Fabry community, expand awareness, and improve our outreach efforts. From 2024 to 2025, we saw a dramatic increase in community interactions.



Followers by Age

TikTok, Instagram, Facebook Total Followers

1000%

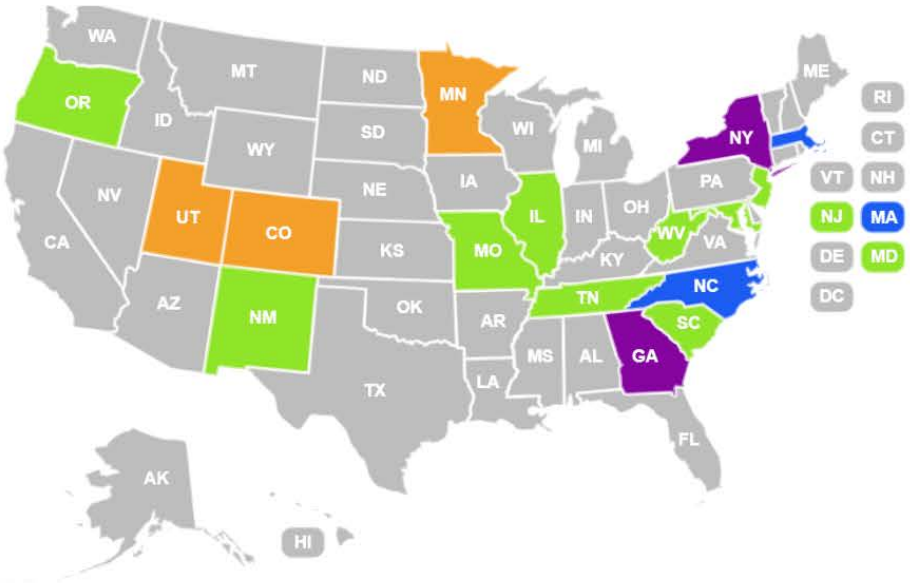
Growth over 2024

111,562

Social Interactions

NEWBORN SCREENING FOR FABRY

WHERE DOES YOUR STATE STAND?



- States currently screening
- Actively Under Consideration
- Bill in progress
- Screening in Pilot Study

Why NBS

Newborn screening is a life-saving tool for undiagnosed families, effectively identifying Fabry disease in infants. On average, one newborn diagnosis leads to five additional family members receiving a correct diagnosis, enabling informed treatment and care decisions.

T4T Mission

We envision a Fabry disease community empowered to improve quality of life through early diagnosis.

T4T Impact

- Expanding access to newborn screening for Fabry disease
- Supporting state-level screening initiatives
- Enabling earlier diagnosis and intervention
- Reducing diagnostic delays for families
- Driving awareness and progress nationwide

You can be a part of history.
Help advocate for Fabry newborn screening in your state
Find out more about our Testing for Tots Program.

SCAN ME

2024 FINANCIALS

Total Revenue

$645,226

Total Expenses

$608,196

Products Sold

Net Surplus

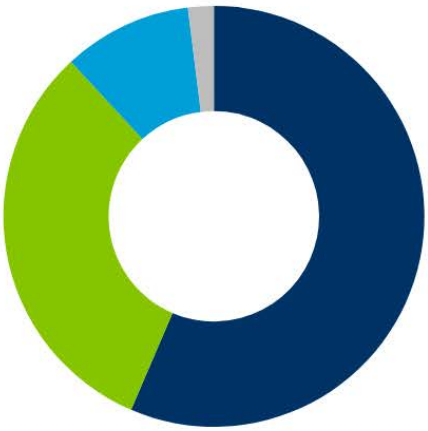
$37,030

75% of every dollar goes directly to programs

Program Efficiency

75%

Revenue Breakdown



- 56.4% Donations & Grants
- 31.7% Program Service
- 9.9% Other Revenue
- 2% Investment Income

Expense Breakdown

In 2024, FSIG generated $645K in revenue—primarily through donor and partner support—and invested 75% directly into programs serving the Fabry community. With over $458K dedicated to patient meetings, education, and conferences, FSIG continues to expand access to critical resources while maintaining strong financial health.