30 YEARS OF RARE. 30 YEARS OF RESILIENCE.

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CONTACT:
Sabina A. Kineen
Program Associate
Fabry Support & Information Group
SKineen@fabry.org
M: 610-733-8881 O: 660-463-1355

RARE DISEASE NONPROFIT CELEBRATES 30 YEARS

From humble start to global impact, FSIG marks three decades advancing community, research and innovation in Fabry disease

(Concordia, MO – August 1, 2026) – The Fabry Support & Information Group (FSIG) proudly marks its 30th anniversary in 2026, celebrating decades of unwavering commitment to individuals and families affected by Fabry disease — a rare enzyme deficiency disorder that was once a death sentence.

Founded in 1996 by Fabry patient Jack Johnson and his family, FSIG was born out of necessity at a time when there were no approved treatments, limited clinical understanding and few places for families to turn for reliable information or meaningful connection.

The Johnson family recognized that beyond the urgent need for scientific advancement, families impacted by Fabry disease needed something equally critical: community. Their vision laid the foundation for an organization that would become a trusted partner to patients, caregivers, clinicians, researchers and industry leaders alike.

A New Chapter of Leadership

As FSIG celebrates its 30th anniversary, the organization is also proud to announce an exciting transition in leadership that reflects both continuity and growth. After three decades of visionary leadership, founder Jack Johnson has transitioned into the role of Senior Advisor, where he will continue to provide strategic guidance while remaining an active advocate for the Fabry community.

Stepping into the role of Executive Director is Lisa Bacon, whose dedication to FSIG spans many years. Lisa first served as a passionate volunteer before joining the organization as Program Director in 2020. During her tenure, she has built trusted relationships across every corner of the Fabry community, working closely with patients, caregivers, clinicians, researchers, advocacy organizations, and industry partners. Her leadership has helped expand FSIG's educational programs, strengthen community engagement, and foster meaningful collaboration throughout the rare disease ecosystem.

"While our leadership is evolving, our mission remains unchanged," said Bacon. "FSIG will continue to serve as a trusted resource, advocate, and partner for everyone impacted by Fabry disease. We are committed to ensuring that every patient and family feels informed, supported, and connected while continuing to advance research and innovation that improves lives."

Together, Johnson and Bacon represent a seamless transition that honors the organization's remarkable history while positioning FSIG for continued growth and impact in the years ahead.

From Isolation to Innovation

Since its founding, FSIG has witnessed and contributed to extraordinary progress in the Fabry disease landscape. What began in an era of diagnostic uncertainty and limited therapeutic options has evolved into a dynamic field of enzyme replacement therapies, chaperone treatments, emerging gene therapies, and next-generation approaches.

Throughout these milestones, FSIG has served as a vital bridge, connecting patient experience with scientific advancement and industry innovation. The organization has consistently elevated the patient voice, helping inform research priorities, clinical trial design and treatment development.

Building a Community of ‘Warriors’

At its core, FSIG’s greatest achievement remains the community it has cultivated — a global network of resilient “Fabry warriors” who support one another through shared experience, advocacy, and hope.

FSIG provides year-round opportunities for families to learn, connect, and engage directly with leading experts in the field. These gatherings include national conferences, regional meetings, educational webinars and peer-to-peer connections, which foster meaningful dialogue between patients, clinicians. and industry partners. Each experience strengthens collaboration and accelerates progress.

Driving Earlier Diagnosis and Better Care

A key pillar of FSIG's mission is advancing earlier diagnosis and reducing disparities in care. Through partnership with "Testing for Tots," the organization's newborn screening advocacy program, FSIG jointly works to expand awareness of Fabry disease within state programs helping to identify affected children before irreversible organ damage occurs.

FSIG also partners closely with clinicians and researchers to identify gaps in care, particularly among women and underrecognized patient populations. By convening stakeholders across academia, biotechnology and pharmaceutical sectors, the organization ensures that lived patient experience informs ongoing clinical and therapeutic development.

Strong Partnerships Across the Ecosystem

Over three decades, FSIG has built enduring partnerships with academic institutions, biotechnology and pharmaceutical companies, advocacy organizations, and research consortia. These collaborations have supported educational initiatives, natural history research, patient registries and scientific exchange at national and international conferences.

As the Fabry therapeutic pipeline continues to evolve, including investment in gene therapy and novel treatment modalities, FSIG remains committed to fostering responsible innovation grounded in patient-centered outcomes.

Looking Ahead: The Next 30 Years

While the landscape of Fabry disease has transformed since 1996, FSIG's mission remains steadfast. Under the leadership of Executive Director **Lisa Bacon**, with founder **Jack Johnson** continuing to serve as Senior Advisor, the organization remains committed to supporting and educating families, advocating for timely diagnosis and equitable care, and fostering continued investment in groundbreaking research.

As the organization enters its fourth decade, priorities include:

- **Expanding** newborn screening advocacy through our program Testing for Tots

- **Strengthening** patient education and peer connection opportunities
- **Advancing** health equity and closing gaps in diagnosis and treatment
- **Encouraging** sustained industry investment in innovative therapies
- **Supporting** collaborative research initiatives that accelerate progress

Join Us in Advancing the Mission

FSIG invites biotechnology and pharmaceutical partners, academic institutions, and supporters to join in celebrating 30 years of impact and to help shape the next chapter of progress in Fabry disease.

Support opportunities include:

- **Sponsorship** of FSIG's National Expert Fabry Conference and/or Women's Summit
- **Partnership** in regional patient meetings and educational events
- **Corporate sponsorships** and research collaborations
- **Individual and philanthropic donations** to advance patient programs and newborn screening advocacy, one-time or recurring.

Together, we can continue transforming the Fabry journey from uncertainty to empowerment, from delayed diagnosis to early intervention, and from isolation to community.

For more information about partnership and sponsorship opportunities, or to support the mission of the Fabry Support & Information Group, please visit **fabry.org** or contact us at **info@fabry.org**.

About the Fabry Support & Information Group (FSIG)

Founded in 1996, the Fabry Support & Information Group is a patient-driven nonprofit organization dedicated to improving the lives of individuals and families affected by Fabry disease. Through education, advocacy, newborn screening initiatives, and collaborative partnerships across academia and industry, FSIG works to advance awareness, research, and equitable access to care worldwide.