COMMUNITY IMPACT REPORT 2025

20 Years of Connecting and Empowering the Global Fabry Community

"Together, we create impact".

FIN
Fabry International Network

OPENING

For Twenty Years, FIN Has Been Creating These Moments

> ***"When I attended my first FIN meeting, I realised for the first time that our organisation wasn't facing these challenges alone."***
>
> — Member of the FIN community

This report celebrates those moments, the people behind them and twenty years of connecting the global Fabry community.

A MESSAGE FROM OUR PRESIDENT

Celebrating 20 Years of Connection, Collaboration and Community

As we reflect on 2025, we do so with immense pride and gratitude. This year marks a truly special milestone for the Fabry International Network as we celebrate 20 years of connecting and empowering the global Fabry community.

Twenty years ago, FIN was founded on a simple but powerful belief: that by working together, patient organisations could achieve more than any one organisation could alone. What began as a small international network has grown into a vibrant global community of 62 member organisations across 59 countries, united by a shared commitment to improving the lives of people affected by Fabry disease.

Throughout these two decades, our community has demonstrated the extraordinary impact of collaboration. Together, we have shared knowledge, strengthened patient organisations, raised awareness, supported research and, most importantly, ensured that the voices of people living with Fabry disease are heard.

This report celebrates the achievements of 2025, but it is also a celebration of the people behind those achievements. Every volunteer who gives their time, every patient organisation that supports its community, every healthcare professional who listens, every researcher seeking better answers and every partner who shares our vision has contributed to the story of FIN.

One of the highlights of this anniversary year was our annual Expert Meeting in Lisbon. Bringing together patient leaders, healthcare professionals and partners from around the world reminded us of the power of connection. It reinforced that while our healthcare systems, cultures and experiences may differ, our commitment to improving the lives of people affected by Fabry disease unites us.Throughout the year, we also continued investing in the future of our community. Our Young Adults programme has gone from strength to strength, creating opportunities for young people living with Fabry disease to connect, learn and support one another. We expanded educational opportunities through webinars and resources, strengthened collaboration across our international network and continued working to ensure that patient perspectives remain central to research, healthcare and advocacy.

As we celebrate twenty years of progress, we also recognise that our journey is far from over. Challenges remain, from achieving earlier diagnosis and equitable access to care to ensuring that every person affected by Fabry disease has the support they need to live the fullest life possible. These challenges remind us why FIN exists and why our work continues to matter.

> ***"For twenty years, our greatest strength has never been the organisation itself — it has been the people who make up our global community."***
>
> — Mary Pavlou, President, Fabry International Network

Looking ahead, I am filled with optimism. I see a global community that continues to grow stronger through collaboration, generosity and shared purpose. I see passionate patient leaders supporting one another across borders. I see young adults stepping forward as the next generation of advocates. And I see partners who recognise that meaningful progress is only possible when we work together.

On behalf of the FIN Board, I would like to extend my heartfelt thanks to our member organisations, volunteers, healthcare professionals, researchers, industry partners and everyone living with Fabry disease who places their trust in our community. Your dedication, resilience and willingness to support one another are what make FIN truly special.

As we celebrate our twentieth anniversary, let us also look confidently towards the future. Together, we will continue building a stronger, more connected and more empowered global Fabry community.

Thank you for being part of this journey.

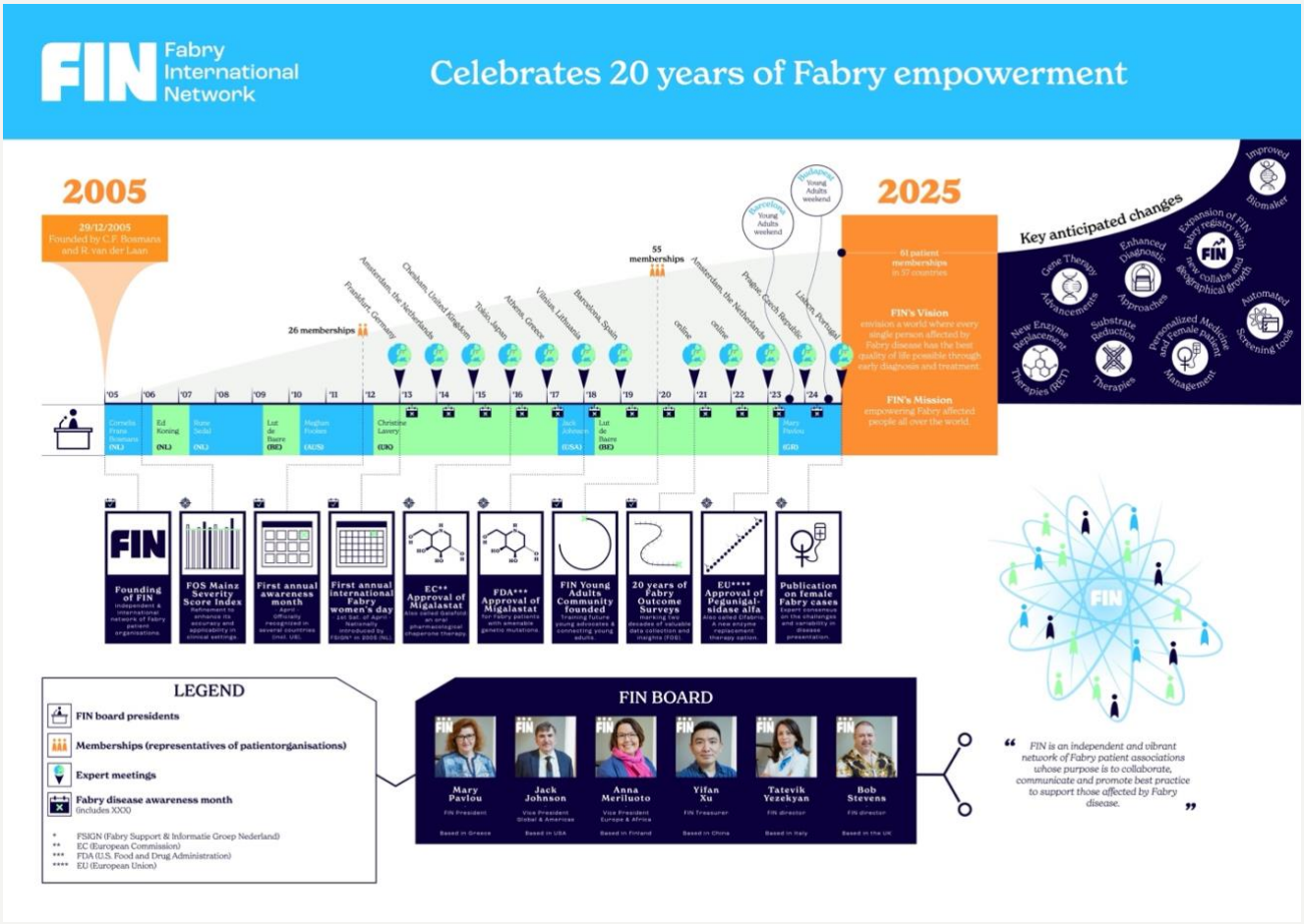
Mary Pavlou

President, Fabry International Network

OUR JOURNEY

Twenty Years of Connection and Collaboration

Every milestone in this report represents more than an achievement. It represents people coming together to learn, support one another and improve the lives of those affected by Fabry disease. As we celebrate our twentieth anniversary, we invite you to look back on the journey that has shaped FIN — and to look ahead to the future we will continue building together.



ABOUT FIN

Connecting People. Sharing Knowledge. Creating Impact.

About the Fabry International Network

For twenty years, the Fabry International Network (FIN) has been bringing people together with one shared purpose: improving the lives of everyone affected by Fabry disease.

Founded in 2005, FIN is the international umbrella organisation for Fabry patient organisations worldwide. What began as a small network of dedicated advocates has grown into a vibrant global community connecting 62 member organisations across 59 countries.

At the heart of FIN is a simple belief: we are stronger together.

Many patient organisations work with limited resources, often facing similar challenges in isolation. By creating opportunities to connect, collaborate and learn from one another, FIN helps strengthen organisations around the world and empowers them to better support people living with Fabry disease.

Today, FIN serves as a trusted platform where patient leaders, healthcare professionals, researchers and industry partners come together to exchange knowledge, share experiences and drive meaningful change. Through education, advocacy, international collaboration and patient engagement, FIN works to ensure that the voices of people living with Fabry disease remain central to improving care, advancing research and shaping the future.

While every member organisation serves its own local community, together we form a truly global network, one that believes collaboration creates stronger organisations, better-informed patients and improved outcomes for people living with Fabry disease worldwide.

Our Vision

A world where every person affected by Fabry disease has access to timely diagnosis, appropriate treatment, comprehensive care and the opportunity to live a full and meaningful life.

Our Mission

To connect and empower the global Fabry community by strengthening patient organisations, facilitating international collaboration, sharing knowledge and ensuring that the patient voice is represented in research, healthcare and policy.

What We Do

FIN's work focuses on five key areas that strengthen the global Fabry community.

Connecting the Global Community

We bring together patient organisations from around the world to exchange ideas, share experiences and learn from one another through international meetings, networking opportunities and collaboration.

Sharing Knowledge

FIN provides trusted educational opportunities through expert meetings, webinars, publications and resources that help patients, families and patient organisations stay informed.

Empowering Patient Organisations

By facilitating the exchange of best practices, practical tools and innovative ideas, FIN supports organisations in strengthening their advocacy, governance and sustainability.

Amplifying the Patient Voice

FIN works to ensure that patient perspectives are included in discussions around research, healthcare, policy and the development of new treatments.

Building Partnerships

FIN works alongside healthcare professionals, researchers, industry partners and other rare disease organisations to improve care, advance research and create opportunities that benefit the community.

FIN BY THE NUMBERS

62 MEMBER ORGANISATIONS	**59** COUNTRIES REPRESENTED	**20 yrs** SUPPORTING THE GLOBAL COMMUNITY	**5** INDUSTRY PARTNERS

Why International Collaboration Matters

Fabry disease is rare, and many patient organisations work with small teams and limited resources. Bringing organisations together allows knowledge, experience and practical solutions to be shared across borders.

An awareness campaign developed in one country can inspire another. A successful advocacy initiative can become a model elsewhere. Lessons learned from one healthcare system can help improve another.

By creating opportunities for collaboration, FIN helps ensure that no organisation has to face these challenges alone. For twenty years, this spirit of collaboration has remained at the heart of everything we do.

> ***"Alone we support our communities. Together we strengthen the global Fabry community."***

2025 AT A GLANCE

A Year of Connection, Collaboration and Community

2025 was a landmark year for the Fabry International Network. As we celebrated 20 years of FIN, we continued to strengthen the global Fabry community by connecting patient organisations, expanding educational opportunities, empowering young adults and ensuring that the patient voice remained at the centre of everything we do.

Together with our members, volunteers, healthcare professionals and partners, we continued building a stronger and more connected international community where knowledge is shared, experiences are valued and no one faces Fabry disease alone.

OUR COMMUNITY

62 MEMBER ORGANISATIONS	**59** COUNTRIES REPRESENTED	**20 yrs** CONNECTING THE GLOBAL COMMUNITY	**5** INDUSTRY PARTNERS

CONNECTING OUR COMMUNITY

64 PARTICIPANTS AT THE FIN EXPERT MEETING	**26** COUNTRIES REPRESENTED IN LISBON	**23** PATIENT ORGANISATIONS PARTICIPATING	**3** INTERACTIVE WORKSHOPS

SHARING KNOWLEDGE

2 FABRY MOMENTS MATTER WEBINARS	**50+** REGISTRANTS — FABRY FEMALES WEBINAR	**46** PARTICIPANTS — WORLD SYMPOSIUM HIGHLIGHTS	**4** GLOBAL NEWSLETTERS PUBLISHED

EMPOWER — INVESTING IN THE NEXT GENERATION

47 YOUNG ADULTS	**19** COUNTRIES REPRESENTED	**17** ONLINE COMMUNITY MEETINGS	**3** FACE-TO-FACE MEETINGS

Collaboration in Action

Throughout 2025, FIN worked closely with healthcare professionals, researchers, patient organisations and industry partners to strengthen education, improve patient engagement and ensure that the voices of people living with Fabry disease continued to shape research, care and advocacy.

Together with our partners, we delivered educational programmes, supported international collaboration and created opportunities that would not be possible for organisations working independently.

Every webinar delivered, every meeting organised and every connection made contributes to a stronger global Fabry community. By bringing together people with different experiences, expertise and perspectives, FIN creates opportunities for learning, collaboration and advocacy that extend far beyond individual events. This collective approach is what makes FIN unique.

CONNECT

Bringing the Global Fabry Community Together

FIN Fabry Expert Meeting 2025

CELEBRATING 20 YEARS OF COLLABORATION

For two decades, the Fabry International Network has brought together patient organisations from around the world to learn from one another, share experiences and strengthen the global Fabry community.

In April 2025, this mission came to life once again as FIN welcomed members, healthcare professionals, researchers and industry partners to Lisbon, Portugal, for the annual FIN Fabry Expert Meeting.

The meeting was particularly significant as it marked FIN's 20th anniversary — a milestone celebrating two decades of international collaboration, patient leadership and shared commitment to improving the lives of people affected by Fabry disease.

Over two inspiring days, 64 participants representing 26 countries came together to exchange knowledge, build relationships and explore new ways of supporting people living with Fabry disease.

WHY IT MATTERS

Patient organisations play a vital role in supporting people living with Fabry disease. Yet many organisations operate with limited resources, small teams and unique healthcare systems. FIN's annual Expert Meeting creates something that cannot be achieved through online communication alone — a dedicated space where patient leaders can learn from one another, openly discuss challenges, celebrate successes and develop practical solutions together.

BUILDING STRONGER PATIENT ORGANISATIONS

The first day of the meeting was dedicated to strengthening patient organisations. Members from across the FIN network shared successful initiatives, advocacy campaigns, awareness activities and organisational experiences, creating an open environment where ideas could be exchanged freely.

Participants discussed common challenges, including organisational sustainability, volunteer engagement, communication strategies and supporting increasingly diverse patient communities.

PREPARING FOR THE FUTURE

Two keynote sessions provided practical tools to help organisations continue growing and adapting in an increasingly digital and challenging environment.

Digital Strategy — André Correia

Communications specialist André Correia explored how patient organisations can use digital tools strategically to build stronger communities, improve communication and increase visibility.

Sustainable Organisations — Vanessa Ferreira

Vanessa Ferreira, from Humanized Solutions, focused on one of the greatest challenges facing patient organisations worldwide: long-term sustainability.




ADVANCING KNOWLEDGE TOGETHER

The second day focused on scientific education and patient-centred care. International experts presented the latest developments in Fabry disease while encouraging open discussion between clinicians and patient advocates. Topics included:

- Understanding cardiovascular health in Fabry disease
- (Peri)menopause and women's health
- Healthy ageing with Fabry disease
- Building stronger communication between patients and healthcare professionals

LEARNING THROUGH CONVERSATION

One of the defining characteristics of FIN meetings is their interactive nature. Participants took part in three practical workshops designed to encourage discussion, reflection and peer learning.

Fabry & Women

A dedicated workshop exploring the experiences, challenges and unmet needs of women living with Fabry disease.

Fabry & Men

A safe and supportive environment where participants explored the medical, emotional and social aspects of living with Fabry disease as a man.

Talking to Your Doctor

A practical workshop helping participants develop confidence in preparing for appointments and becoming active partners in their own healthcare.

EXPERT MEETING AT A GLANCE

64 PARTICIPANTS	**26** COUNTRIES	**23** PATIENT ORGANISATIONS
2 DAYS OF LEARNING	**3** INTERACTIVE WORKSHOPS	**20 yrs** CELEBRATING FIN

COMMUNITY VOICES

> ***"I'm still taking it in that there are more people like me, it's a big deal for me."***
>
> — FIN Expert Meeting participant

> ***"Meeting people from different countries reminded me that although our healthcare systems are different, many of our challenges are shared."***
>
> — Patient organisation representative

THE IMPACT

The FIN Fabry Expert Meeting is much more than an annual conference. It is where new collaborations begin, where patient leaders find inspiration from one another, and where ideas developed in one country become initiatives in another. Most importantly, it reminds everyone in the room that no organisation, and no person living with Fabry disease, is alone.

IMPACT HIGHLIGHTS

✓ Connected 64 participants from 26 countries

✓ Strengthened collaboration between 23 patient organisations

✓ Shared practical strategies to support stronger, more sustainable patient organisations

✓ Expanded knowledge through expert-led education and interactive workshops

✓ Fostered international relationships that continue to support people living with Fabry disease beyond the meeting itself

EMPOWER

Investing in the Next Generation

FIN Young Adults Community

> ***"Building confidence, connection and community for the next generation of Fabry advocates."***

WHY IT MATTERS

Growing up with Fabry disease presents unique challenges. Young adults are often navigating education, employment, relationships and increasing independence while also learning to manage a lifelong rare disease. Many have never met another young person living with Fabry disease.

Creating opportunities for connection, shared learning and peer support helps reduce isolation and empowers young adults to become informed advocates for themselves and their communities.

BUILDING A GLOBAL COMMUNITY

Throughout 2025, FIN continued to invest in its growing Young Adults Community, bringing together young people from around the world through regular online meetings and face-to-face events.

By the end of the year, the community had grown to representing 26 countries, creating one of the largest international networks of young adults living with Fabry disease.

During the year, participants connected through 17 online meetings and three face-to-face gatherings in Barcelona, Budapest and Antwerp.

These meetings created safe spaces to discuss topics that are often difficult to talk about including mental wellbeing, relationships, careers, independence, family planning and living confidently with Fabry disease. More importantly, they helped young adults realise that they are not alone

YOUNG ADULTS AT A GLANCE

47 YOUNG ADULTS	**26** COUNTRIES REPRESENTED	**17** ONLINE MEETINGS	**3** FACE-TO-FACE MEETINGS

FUTURE IMPACT

FIN has recognised that today's young adults will become tomorrow's patient advocates, board members and community leaders. By investing in young people today, FIN is helping ensure a strong, connected and sustainable future for the global Fabry community.

> ***"For the first time, I met people my own age who truly understood what living with Fabry is like."***

SHARE

Empowering Through Education

Knowledge is one of the most powerful tools available to people living with Fabry disease. Throughout 2025, FIN continued to make expert knowledge accessible through webinars, educational resources, newsletters and international discussions.

These initiatives ensured that patients, families and patient organisations had access to trusted, practical and up-to-date information regardless of where they live. Education not only improves understanding of Fabry disease, it empowers people to ask questions, make informed decisions and become active partners in their healthcare.

2025 EDUCATIONAL HIGHLIGHTS

- Fabry Moments Matter webinar series
- Fabry Females webinar with Dr Dawn Laney
- World Symposium Highlights webinar
- Online Membership Meeting
- Four global newsletters
- Global Fabry Females Survey

EDUCATION AT A GLANCE

2 FABRY MOMENTS MATTER WEBINARS	**50+** FABRY FEMALES Webinars	**46** WORLD SYMPOSIUM PARTICIPANTS	**80+** GLOBAL SURVEY RESPONSES

Reliable information empowers people to make informed decisions about their health and strengthens patient organisations in supporting their communities. By creating opportunities for learning and dialogue, FIN helps ensure that knowledge reaches people wherever they live.

BUILDING NEW COMMUNITIES

A Historic Milestone in Iceland

The First-Ever Fabry Patient Meeting in Iceland

Some milestones are measured in numbers. Others are measured in the lives they change.

On 7 June 2025, the Fabry International Network proudly partnered with the Fabry team at Landspítali University Hospital and industry partners to organise the first-ever Fabry Patient Meeting in Iceland. More than an educational event, the meeting marked the beginning of a new chapter for the Icelandic Fabry community.

Held in Reykjavík, the event brought together 34 participants from across the country. For many, it was the first opportunity to meet another person living with Fabry disease, transforming years of isolation into a shared sense of understanding, support and belonging.

WHY IT MATTERS

For people living with a rare disease, meeting someone who truly understands their experiences can be life changing. In smaller countries, opportunities to connect with others affected by Fabry disease are often limited. The Reykjavik meeting demonstrated that even a single day can become the catalyst for a stronger, more connected community.

SHARING KNOWLEDGE, BUILDING CONFIDENCE

The programme combined expert presentations with interactive workshops and open discussion, creating a balance between scientific education and peer support. Participants explored topics including:

- Fabry & Females — recognising the unique experiences and healthcare challenges faced by women living with Fabry disease.
- Fabry & Pain — improving understanding of chronic pain and practical approaches to managing its impact on daily life.
- Mental Health and Communication Workshops — creating a safe and supportive environment to discuss emotional wellbeing and effective communication

For FIN, this represented far more than the creation of a new member organisation. It reflected the power of collaboration and demonstrated how bringing people together can inspire lasting change.

ICELAND AT A GLANCE

34 PARTICIPANTS	**1** NEW PATIENT ORGANISATION FOUNDED	**7 JUN** 2025	**Reykjavík** ICELAND

"For many participants, this was the first time they had met another person living with Fabry disease."

The first Fabry Patient Meeting in Iceland demonstrated the lasting impact that collaboration can have on a rare disease community, leading to the establishment of Iceland's first Fabry patient organisation, ensuring people living with Fabry disease in Iceland will continue to have a collective voice for years to come.

DRIVING CHANGE TOGETHER

Raising Awareness — Celebrating Fabry Heroes

Awareness begins with stories. During Fabry Awareness Month 2025, FIN celebrated the healthcare professionals who have transformed the lives of people living with Fabry disease through compassion, dedication and clinical excellence.

The Fabry Heroes campaign recognised the vital partnership between patients and healthcare professionals and celebrated those who continue to make a lasting difference every day. The campaign encouraged members around the world to share stories of gratitude, creating a powerful reminder that meaningful healthcare is built on trust, collaboration and human connection.

WHY IT MATTERS

Every story shared increases awareness. Every conversation started creates understanding. Every person reached brings us one step closer to earlier diagnosis, better care and stronger communities.

Influence — Amplifying the Patient Voice

People living with Fabry disease bring invaluable expertise through their lived experience. Throughout 2025, FIN continued ensuring that these voices informed education, research, healthcare and industry collaboration.

Patient perspectives were gathered through surveys, shared during advisory activities and integrated into educational initiatives, helping ensure that future developments reflect the real needs of the community. FIN believes that the best decisions are made when patients are recognised as equal partners.

> ***"For twenty years, FIN has worked to ensure that people living with Fabry disease are not passive recipients of healthcare but active partners in shaping research, education and advocacy."***

SUSTAIN

Building the Future Together

No organisation can create lasting change alone. FIN's strength lies in collaboration. Together with member organisations, healthcare professionals, researchers and industry partners, FIN continues to create opportunities that benefit the entire global Fabry community.

OUR PARTNERS

Amicus Therapeutics

Chiesi global rare diseases

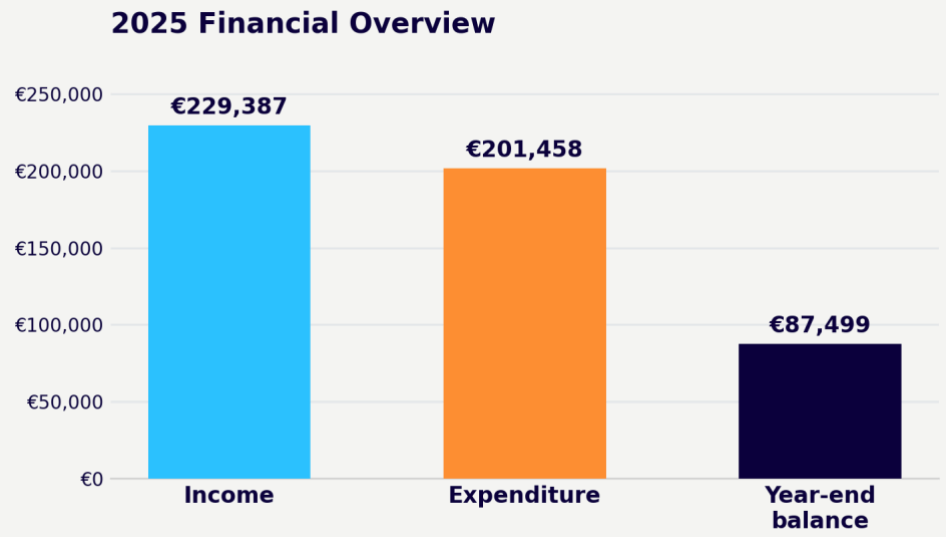
Takeda

sanofi

uniQure

INVESTING IN OUR COMMUNITY

2025 demonstrated FIN's continued commitment to investing in programmes that directly benefit the global Fabry community. Rather than measuring success solely in financial terms, FIN measures its impact through stronger patient organisations, better informed communities, meaningful international collaboration and empowered people living with Fabry disease.



Financial Contributions from our Industry Partners

- Sanofi: 21.80%
- Amicus: 19.62%
- Chiesi: 10.90%
- Takeda: 7.69%
- UniQure: 6.44%

Percentages are calculated against FIN's total organisational income for 2025 (€229,387), including project grants, honoraria, webinar funding, and other income.

LOOKING AHEAD

Building on Twenty Years of Impact

As FIN enters its third decade, we remain committed to strengthening the global Fabry community through collaboration, education and advocacy. In 2026 we look forward to:

- Continuing to grow the Young Adults Community
- Launching new educational resources
- Strengthening international collaboration
- Supporting member organisations
- Amplifying the patient voice
- Hosting the FIN Expert Meeting in Taiwan

Together, we will continue building a future where every person affected by Fabry disease feels informed, supported and connected.

Twenty years ago, a small group of patient organisations came together with one shared belief: that by working together, they could achieve more than any organisation could alone.

Today, that belief connects 62 member organisations across 59 countries, creating a global community united by knowledge, collaboration and hope. Every connection made. Every conversation shared. Every educational resource created. Every partnership formed. Every patient voice amplified. Together, these moments become something far greater than individual activities, they become stronger organisations, empowered communities and lasting impact.

As we celebrate twenty years of the Fabry International Network, we also look to the future with optimism. There is still much to achieve: earlier diagnosis, equitable access to care, stronger patient organisations, a louder patient voice and, ultimately, better lives for everyone affected by Fabry disease.

But one thing has remained constant throughout the past twenty years and will continue to guide us into the future:

"Together, we are stronger. Together, we create impact."

COMMUNITY IMPACT REPORT 2025

Empowering people living with Fabry

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