Fabry International Network
Annual Report 2024

FIN
Fabry International Network

2024 has been a remarkable year of growth, innovation, and connection for the Fabry International Network (FIN). As a vibrant, global umbrella organization, we continue to stand with those affected by Fabry disease, championing their voices, empowering communities, and connecting stakeholders across continents.

This year, we expanded our programs for youth, deepened strategic collaborations, and launched exciting new initiatives including our pilot Patient Registry and new tools for advocacy.

Our mission remains clear: to create a world where every person affected by Fabry disease can live a full and informed life.

Thank you to every member, partner, and advocate who walked with us this year. Together, we are stronger.

Mary Pavlou
FIN President

FIN
Fabry International Network

Our 2024 Strategic Priorities

FIN is a bold, global network of Fabry patient associations committed to collaboration, connection, and driving best practices in care and support. We work alongside 61 organizations across 57 countries, uniting patients, health professionals, and industry partners to improve lives.

Our mission comes to life through four key pillars:

Advocacy, empowerment, community-building, and raising awareness. These guide everything we do—from policy engagement to capacity-building initiatives—ensuring no one faces Fabry disease alone.

At FIN we aim to:

- Inspire Patients – Making knowledge accessible and empowering
- Empower Organizations – Supporting patient leaders and local advocacy
- Amplify Voices – Advocating globally for better care
- Connect Stakeholders – Fostering collaboration across patients, professionals, and industry

A Snapshot of Our Impact in 2024

Throughout 2024, FIN remained committed to its mission of empowering the global Fabry community. Our collaborative efforts, patient-focused initiatives, and educational outreach contributed to another strong year of progress and connection.

Here are some of our key milestones:

10+ Collaborative Projects with Industry Partners
We worked closely with our partners to co-create educational materials, participate in advisory boards, and gather community insights through joint initiatives.

Young Adults Community: 5 Gatherings, Growing Strong
The FIN Young Adults group met four times online and came together in person for a powerful weekend in Barcelona. These meetings offered peer connection, advocacy training, and health-focused discussions.

Membership Survey with Global Reach
We launched a comprehensive member survey that received responses from 24 countries—helping us better understand local needs, challenges, and aspirations.

Two Global Webinars for the Fabry Community
These well-attended sessions featured leading experts and tackled key topics such as Fabry in women and clinical guideline updates.

WORLDSymposium 2024
FIN was featured in a dedicated session focusing on arrhythmia in Fabry disease—raising awareness and amplifying patient perspectives in front of an international scientific audience.

Fabry Awareness Month Campaign: Global Reach
Our 2024 campaign “My Life with Fabry” celebrated patient stories from around the world, shared through an interactive global map and video testimonials.

Online Membership Meeting
We hosted an all-member virtual meeting, giving organizations the chance to share updates, voice concerns, and brainstorm future collaborations.

FIN Expert Meeting in Prague
We welcomed 73 participants from over 20 countries for two days of interactive sessions, workshops, and networking—strengthening the bond within our growing community.

FIN Fabry Young Adult Community

“The FIN Young Adults Community has flourished this year. We now count over 40 active members from 20+ countries.

2024 Highlights:

- Second in-person weekend in Budapest, co-designed by the group, featuring workshops on self-advocacy, relationships, and transitions to adulthood.
- Quarterly online meetups with themes including mental wellbeing, reproductive health, and patient rights

Young adults can still apply to be part of the group through the application form on the FIN website and we welcome new members!

Learning patient advocacy skills will allow you not to be limited by Fabry but to be empowered by a community of patient advocates

FIN Young Adults

FIN Fabry Expert Meeting 2024

Held in April in Prague, Czech Republic, our annual F2F meeting brought together 80 participants from 22 countries.

Key features:

- Thematic focus on reproductive health, female perspectives, and new treatments
- Introduction of advocacy workshops co-led by patients and experts
- Dedicated sessions for industry collaboration under CDA for honest exchange

Feedback showed 95% rated the event as “very useful” or “excellent.”

Expert meeting

FIN Fabry Expert Meeting 2024, a genuine reflection by our FIN Director, Tatevik Yezekyan

Finding inspiration often comes from those who face adversity. A rare disease may present challenges, but it also brings a unique perspective. There is a certain authenticity in the comfort found in understanding without needing to elaborate, in lightening the weight of thoughts, in finding answers to enduring questions. The value of care and empathy is sometimes missed in everyday life, yet it shines brightly in the lives of those dealing with a rare disease...

Discover the full article here

FIN Award

FIN awards a patient (association) led initiative that informs and educates the Fabry community and helps raise awareness with a financial grant. We want to encourage our members to organise activities and initiate projects by contributing financially and offering a platform to share with the wider community.

The Czech Fabry Organisation was awarded the 2024 FIN Fabry Award for their impactful annual patient meeting. The event promotes education and community building through expert talks on symptoms, diagnosis, treatment, and quality of life

Applications will be accepted again in November 2025.

Governance

FIN Board in 2024

- President: Mary Pavlou
- Vice President Americas & Global: Jack Johnson
- Vice President Europe & Africa : Anna Meriluoto
- Treasurer: Yifan Xu
- Director: Tatevik Yezekyan
- Director: Bob Stevens

The FIN Board have met online every month during 2024 to take forward the bu

Collaborations & partnerships

FIN is very pleased to have partnered with organisations over the course of 2024 and of course our industry partners for exciting projects such as roundtable meetings, podcasts, interviews, patient forums and questionnaires, advisory boards.

We are grateful for all the continuous support and the relationships we are building to serve the Fabry community best.

Website & Newsletter

We continue to send out our quarterly newsletters to an audience that has grown to over 1200 subscribers. In these newsletters we gather all the latest news on both the scientific findings on Fabry Disease and the news from within our organization.

Subscribe here

Learn all about Fabry and the latest news on our projects on the FIN website.

www.fabrynetwork.org

Fabry Findings

To inform the Fabry community about medical developments in Fabry disease, FIN initiated Fabry Findings, in these issues we 'translate' clinical information into lay language that can be digested and easily understood.

All issues are available on our website, as we wish to share these insights with as many people as possible. Moreover, we keep on motivating our members to translate them to their own languages.

Fabry Findings

Fabry Awareness Month


- Michelle, 21, The Netherlands

"She's a friend for life who knows exactly what I'm going through."

Michelle, 21, The Netherlands


- Gina, 33, Japan

"She always goes above and beyond to make me feel welcomed, heard and comfortable during my treatment."

Gina, 33, Japan


- Nick, 27, United States

"My visits to my therapist help me cope with setbacks and bad days, so let this also be a reminder that it's okay to seek help if you feel like you need it."

Nick, 27, United States


- Danielle, 52, Germany

"From the moment we met, he has been educating himself and learning more about Fabry every day."

Danielle, 52, Germany


- Woo, 17, South Korea

"They always did everything in their power so we could be living the best lives possible. Now that I'm a bit older I understand that must have been very stressful and hard on them too."

Woo, 17, South Korea


- Lily, 37, Canada

"I have no clue what my life would look like without a patient organization."

Lily, 37, Canada

In 2024 during Fabry Awareness Month, we celebrated the support system of those living with Fabry. They might not always be facing the disease themselves, but can also be true superheroes.

International Fabry Women's Day

In 2013, the Dutch patient organization FSIGN (Fabry Support & Information Group Netherlands) declared every first Saturday of April International Fabry Women's day. The International Fabry Women's day was established to raise awareness about women and girls affected by Fabry disease and how females with Fabry are not just 'carriers'. In 2024 we rallied together again – albeit in online environments – to honor all women living with Fabry.

Fabry Brochure

To be able to give newly diagnosed patients, caregivers and family members the information they're looking for, we've published the Fabry brochure. This brochure explains the different symptoms and complications of Fabry disease and contains an introduction to FIN. The English version is available on our websites, while the source file may be shared with our members to have it locally translated.

Topics addressed:

- What is Fabry
- Symptoms
- Inheritance
- Family planning
- Mental wellbeing
- GI Symptoms
- Why should you join a patient organization and how can an organization support you?

Fabry Brochure

Financial Report

The Fabry International Network is most grateful to Sanofi, Amicus, Takeda, Chiesi and Uniqure and Spark for the unrestricted educational grants and charitable contributions they have made to FIN in 2024.

The year ending 31 December 2024 accounts were audited by Stratevision Acountants.

- Closing balance: €96,419.28
- Total income: €190,631.50
- Total expenditure: €117,881.72
- Surplus: €72,749.78

Funds received in 2024

Funder	Percentage of overall income
Sanofi	23.00%
Amicus	16.79%
Chiesi	8.93%
Spark	7.87%
Takeda	7.22%
Uniqure	2.40%

Industry Partners

In 2024 FIN met with industry partners in online meetings in May with representatives from Sanofi, Takeda, Spark, Amicus, Chiesi and Uniqure.

These meetings were held under Company CDAs (Confidentiality Disclosure Agreements) to enable the FIN Directors and the company representatives to discuss matters not yet in the public domain.

We are grateful for their continuous support and value our collaborations!

Our members

Argentina - Alianza Lisosomal Argentina
Australia - Fabry Australia
Austria - Morbus Fabry Selbsthilfegruppe
Belarus - Белорусская организация больных мукополисахаридозом и другими редкими генетическими заболеваниями.
Belgium - Belgische Organisatie voor Kinderen en volwassenen met een Stofwisselingsziekte
Brazil - Associação Brasileira de Pacientes Portadores da Doença de Fabry e seus Familiares
Bulgaria - Fabry Bulgaria
Canada - Canadian Fabry Association
Chile - Fundación Chilena de Enfermedades Lisosomales Felch
China - Fabry China
Columbia - Asociación Colombiana de Pacientes con Enfermedades de Depósito Lisosomal
Croatia -Fabry Anderson Croatia
Cyprus - ΑΣΠΙΔΑ ΖΩΗΣ
Czech Republic - Sdružení META
Denmark - Fabry Patientforening Danmark
Ecuador - Fepel Dasha
Finland - Suomen Fabry Yhdistys
France - APMF
Germany - Morbus Fabry Selbsthilfegruppe
Greece - ΠΑΝΕΛΛΗΝΙΟΣ ΣΥΛΛΟΓΟΣ ΑΣΘΕΝΩΝ ΚΑΙ ΦΙΛΩΝ ΜΕ ΛΥΣΟΣΩΜΙΚΑ ΝΟΣΗΜΑΤΑ "Η ΑΛΛΗΛΕΓΓΥΗ
Guatamala - Asociación Nacional Guatemalteca para las enfermedades lisosomales
Hong Kong - 香港黏多醣症暨罕有遗传病互助小组
Hungary - The Hungarian Foundation for Patients with Fabry Disease
India - LSDSS
Indonesia - MPS & LSD Indonesia
Iran - radoir.org
Ireland - Fabry Ireland
Italy - AIAF
Japan - JFA
Japan - Fabry Next
Lithuania - Lietuvos asociacijos "Gyvastis"
Luxembourg - Maladies Rares Luxembourg
Malaysia - Malaysia Metabolic Society
Marocco - Association Espoir Vaincre les Maladies Lysosomales au Maroc
Mexico FEMEXER & Pide un Deseo
New Zealand - Fabry Support Group New Zealand
Norway - Fabry Foreningen Norge
Peru - Associacion Peruana de Pacientas con Enfermedad de deposito Lisosomal
Peru - Esperantra Peru

Our members

Philippines - Philipine Society for Orphan Disorders
Poland - Stowarzyszenie Rodzin z Chorobą Fabry
Portugal - Associação Portuguesa de Doenças do Lisossoma
Romania - Asociata pacientilor cu boala Fabry din România
Russia - Road to Life
Russia - Fabry Russia
Singapore - Rare Disease Society Singapore
Slovakia - Zdruzenie Ojedinelych Genetickych Ochoreni RD PO
Slovenia - Slovenian Fabry Association
South Africa - Rare Disease Society of South Africa
South-Korea - Fabry Korea
Spain - Spanish Fabry MPS Association
Sweden - patientforeningen for Fabrysjuka i Sverige
Switzerland - Fabrysuisse
Taiwan - TAFD
The Netherlands - FSIGN
Tunisia - ATML
Turkey - MPS Society Turkey
UK - MPS Society UK
Uruguay- Asociacion Uruguay de Pacientes con Enfermedadas Lisosomales
USA - FSIG
USA - National Fabry Disease Foundation

MEMBERS

Don't hesitate to get in touch

What can we do for you and your organisation? Please do not hesitate to reach out to us, should you have any questions or suggestions - emails can be send to coordinator@fabrynetwork.org

Fabry International Network
Registered address: Borsbeeksebrug 34/1, 2600 Antwerp, Belgium

Charity Registration number 1022.929.138

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Empowering people living with Fabry

Fabry International Network
info@fabrynetwork.org | www.fabrynetwork.org
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