

Fabry International Network Annual Report 2022



FIN

Fabry International Network



With FIN we aim to serve as advocates, we wish to empower people living with Fabry, but most of all we want to create connections.

We are an independent and vibrant network of Fabry patient associations whose purpose is to collaborate, communicate and promote best practice to support those affected by Fabry disease. Vibrant & diverse like our members.

Strong advocacy is needed to defend the interests of all patients, in all parts of the world FIN stands for a global movement.

We are proud of everything we were able to accomplish together, which we present to you here.

Lut De Baere
FIN President

FIN
Fabry International Network

Our Goals

FIN is an independent and vibrant network of Fabry patient associations whose purpose is to collaborate, communicate and promote best practice to support those affected by Fabry disease. We back 62 patient organizations in 57 countries. We connect health professionals and we ally with industry partners.

We aim to achieve our mission by tackling the different aspects of our role as an international umbrella organization. In short, these aspects could be broken down into four main areas of work: advocacy, empowerment, networking and the raising of awareness. Four domains we've kept our focus on all through last year and which will remain on our collective agendas for the foreseeable future.

Advocacy & Empowerment

Our overall vision has always remained clear: we aim to create a world where every single person affected by Fabry disease has the best quality of life possible through early diagnosis, treatment and cure.

Therefore, we need to serve as advocates for everyone affected by this condition and take up their interests with the powers at be. FIN carries out this advocacy work with both national and international institutions and international organizations such as the WHO, ensuring that the concerns, needs and priorities of patients living with Fabry disease are included in the decision-making process for policies and other related health initiatives.

As Fabry disease is a rare condition, which remains relatively unknown to most people and physicians, our constant aim remains to support our members all over the world in their work and mission at national level through the exchange of best practices, activities such as educational seminars and helping to establish new associations in countries where they do not yet exist.

Awareness

Much of our work focusses on the creation of awareness, both of the Fabry disease itself, with lawmakers, governments and health organizations, but also on a smaller scale, of the impact, symptoms and treatments of Fabry for people living Fabry, caregivers and others.

Since we weren't able to meet with our community in person, we've hosted our second online FIN Fabry Expert Meeting. Throughout the rest of the year we've organized multiple webinars with different expert panels. A lovely way to get in touch and keep our community informed during these challenging times.

To be able to give (newly) diagnosed patients, caregivers and family members the information they're looking for, we've published the FIN Fabry Findings. The English version is available on our websites, while the sources file may be shared with our members to have it locally translated.

Networking

Creating an ever-growing international platform and network is at the core of our organization. So even though networking and connecting turned out to be one of the biggest challenges of the past year, we've kept up our efforts to grow our global network.

With every new member or partner, we're able to keep on building strong relations, make valuable connections and share our best practices on a growing platform.

FIN Strategy 2022-2023

On behalf of our members, we strive to be a leading organisation in advocacy on an international level. FIN is fully committed to raise awareness to locate more Fabry patients, to advocate for better care and monitoring and to engage and empower developing Fabry communities.

We inspire patients

As with all rare diseases, gathering & sharing all kinds of knowledge can make a huge difference. By informing & inspiring patients as a confident source, we make them feel less alone.

We empower organizations

As smart patient advocates, we believe in collective action. So, we support groups of patients to organize better and to stand up together. That makes us strong.

We are a global voice

Striving to tighten the global network of Fabry patients, we louden their voices. Fabry disease, and the people dealing with it, have no borders. Nor have we.

We are an open platform

We bring patients, health professionals and industry partners together. Our platform stimulates equal connections and exchange, in an open and transparent way.

We organize patients, connect health professionals, and ally with industry partner

Rebranding

We were excited to announce that as of October 1st 2022, we rebranded with a new logo and colour scheme as part of the ongoing evolution of our organisation.

Our network is growing and evolving and we felt it is time for a change. We have refreshed our logo to reflect who we are today and to symbolize our future. We analysed our values as an organization and created a brand identity that reflects those values.

After careful consideration, we chose a new logo that reflects a more modern look and captures our mission to build a better future for all those affected by Fabry disease and empower Fabry patients worldwide.

FIN is strong and bold, yet also human and approachable. With an easily recognisable logo, FIN aims to connect Fabry patients and professionals

FIN Fabry Young Adult Community



FIN is still very committed to building a community to train the next generation of patient advocates. We have connected a group of young adults from all over the world from the rare disease community. Amongst them, young adults from The Netherlands, Italy, Armenia, Germany, Spain, Canada, South-Korea, Taiwan, Poland, Tunisia.

We met online with the group of young adults 4 times over the course of 2022. We talked about a lot of topics such as nutrition & lifestyle, mental wellbeing, home treatment, family planning, patient advocacy together with experts in those fields.

The group has become very close and we have been able to create a safe and fun environment for them and we support them where we can. We shared a survey with the group to gain more insights in exact needs, what topics the group wants to address, frequency of meetings etc. And of course we very much look forward to the F2F Weekend in Barcelona in June 2023, where we finally get to meet each other in person.

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 2022

In 2022, we organised our second FIN Fabry Expert Meeting. We welcomed more than 200 participants from 26 different countries. The platform was available for another 30 days after the meeting, which the Fabry community found very helpful.

There was also the opportunity to take part in the exhibition where we had 9 booths. There were at least 254 unique booth visits, and more than 305 times visitors downloaded the resources available. There was so much valuable information to be found and downloaded at the exhibition!

This was an excellent way to connect with the Fabry community again and we were very happy with the overall positive feedback.

The presentations from the meeting remain available on the [FIN YouTube Channel](#).

[**Presentations**](#)



Patient registry

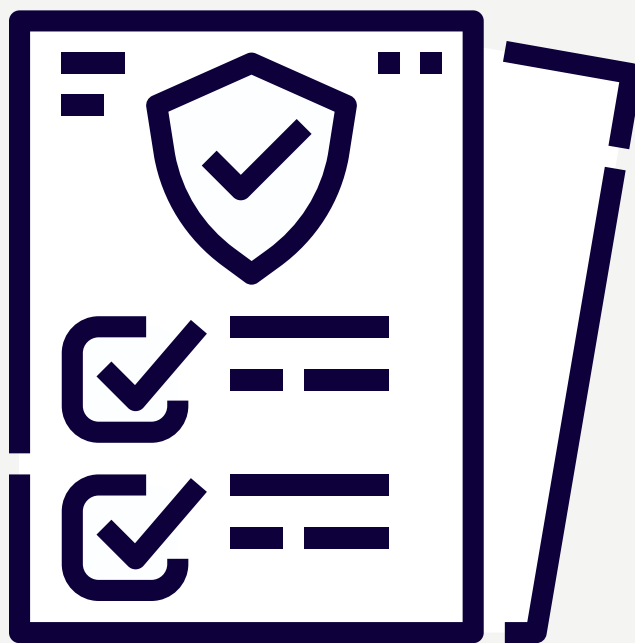
Our initial market assessment revealed broad interest in a global, patient-centric Fabry registry aligned to core design principles. We used stakeholder interviews and analyzed clinical trial activity to help prioritize its initial geographic scope.

We hope to initially fund its registry through a membership model that provides value back to its partners and intend to work with sites to collect high-quality clinical data, supplemented with direct-to-patient surveys.

The next steps for short term (years 0-2) we are planning are to seek investment funding and build a membership model.

We will initiate vendor contracts for refined registry design and feasibility assessments and start to rollout to pilot countries.

We will socialize this strategy with our partners and based on feedback refine the scope of your registry, the roll out approach and subsequently the cost.



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 awardee for 2022 is the Rare Disease Croatia for their educational and awareness project 'Little big signs of diagnosis'. The idea was born through their cooperation with a team of medical students. It is a long-term project in which students answer medical questions that they receive through Croatian Helpline for rare diseases.

The aim of this project is to create a 'rare library' with materials for students of medicine, industry partners, physiotherapist and many more in the field. The materials will include short videos that will explain the first and most important symptoms of Fabry disease that patients can remember and associate with the diagnosis. The symptoms will be explained by the patients themselves or their family members. They will also film experts talking about the first symptoms, diagnosis, and treatment, as well as advice for a better quality of life, as well as other experts, talk about other aspects of the disease, help and support.

Applications will be accepted again in November 2023.



Governance

At the previous AGM in 2021 Erica Van de Mheen resigned as FIN Treasurer. Anna Meriluoto and Jack Johnson were voted to continue as FIN Vice President Europe & Africa and FIN Vice President Global. Julia Alton has resigned as FIN Board Member in 2022.

FIN Board

- President: Lut de Baere
- Vice President Americas & Global: Jack Johnson
- Vice President Europe & Africa : Anna Meriluoto
- Treasurer & Secretary: Mary Pavlou
- FIN Director: Yifan Xu

The FIN Board have met online every month during 2022 to take forward the business of FIN.

Charlotte Wauters is still as appointed as coordinator for FIN. She is based in Belgium.

Collaborations & partnerships

FIN is very pleased to have partnered with organisations over the course of 2022 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 600 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. We've also improved the format, to make it as accessible and enjoyable as possible for our widespread community.

[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. In the course of 2022 we issued a new edition: the Fabry Findings 6 - Fabry & Clinical Guidelines.

In this issue we focus on Fabry clinical guidelines, the signs and symptoms they include and whether these promote or delay the beginning of treatment for Fabry.

All issues remain 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



We were very proud to present the FIN's Fabry Awareness Month Campaign in 2022!

In 2022 our campaign aimed at parents with interests in rare diseases and medical experts. We wanted to engage the community and involve patient members in the campaign.

More specifically we wanted them to: share their Cool Down Story and interact with social media posts.

We also wanted parents to visit the FIN campaign website to learn more about Fabry (symptoms), read Cool Down Stories, get help (via contact form).

Thank you all for contributing to the campaign!

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 2022 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 closing bank balance 2022 was 104.139,69 EUR. Total income in 2022 was 115759,15 EUR. Total expenditure in 2022 was 108.447,36 EUR. The surplus of income over expenditure for 2022 is therefore 7.311,79 EUR and this results in equivalent higher equity.

The Fabry International Network is most grateful to Sanofi, Amicus, Takeda, Idorsia, Chiesi, Freeline and Sangamo for the unrestricted educational grants and charitable contributions they have made to FIN in 2022.

The year ending 31 December 2022 accounts were audited by BHKK BV (Belgium) and the Auditor's letter signed by senior accountant Hans Blockx.

Funds received in 2022

Funder	Percentage of overall income
Sanofi	24%
Amicus	21%
Takeda	19%
Freeline	9%
Idorsia	9%
Chiesi	9%
Sangamo	9%

Industry Partners

In 2022 FIN met with industry partners in online meetings in May with representatives from Sanofi, Takeda, Amicus, Idorsia, Freeline, Chiesi and Sangamo.

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 - [NAPRD](#)

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 - [Croatian Alliance for Rare Diseases](#)

Cyprus - [ΑΣΠΙΔΑ ΖΩΗΣ](#)

Czech Republic - [Sdružení META](#)

Denmark - [Fabry Patientforening Danmark](#)

Ecuador - [Fepel Dasha](#)

Finland - [Suomen Fabry Yhdistys](#)

France - [APMF](#)

France - [VML](#)

Germany - [Morbus Fabry Selbsthilfegruppe](#)

Greece - [ΠΑΝΕΛΛΗΝΙΟΣ ΣΥΛΛΟΓΟΣ ΑΣΘΕΝΩΝ ΚΑΙ ΦΙΛΩΝ ΜΕ ΛΥΣΟΣΩΜΙΚΑ ΝΟΣΗΜΑΤΑ "Η ΑΛΛΗΛΕΓΓΥΗ"](#)

Guatemala - [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 [Asociación Peruana de Pacientes con Enfermedad de depósito Lisosomal](#)

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: Bloemistenstraat 16, 2140 Antwerp, Belgium

Charity Registration Number 04080030 - The Chamber of Commerce Drenthe
The Netherlands

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Empowering people living with Fabry

Fabry International Network
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Charity Registration Number 04080030

