FABRY INTERNATIONAL NETWORK

ANNUAL REPORT 2021

With FIN we aim to serve as advocates, we wish to empower both patients and practitioners, but most of all we want to create connections. And sadly, connecting people became one of the biggest challenges during a time of lockdowns and travel restrictions again this year.

However, that doesn't mean we gave up. On the contrary, we shifted gears and pulled out all the stops to move our efforts and projects towards digital grounds.

We continue to define FIN's role and your role in all this, and we must strive to a plan of action designed to achieve a long-term or overall aim towards a global movement.

Strong advocacy is needed to defend the interests of all patients, in all parts of the world. We are proud of everything we were able to accomplish during these challenging times, which we present to you here. And as we look on to the future, we have can only hope to be able to connect with our members and partners in real life again very soon.

We're proud of everything we were able to accomplish during these challenging times, which we've collected in this report. And as we look on to the future, we have can only hope to be able to connect with our members and partners in real life again very soon.

LUT DE BAERE

FIN President

FABRY
International Network

OUR GOALS

Even through these bizarre and challenging times, our goals and strategy for the Fabry International Network remain the same. 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. 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 patients, caregivers and others.

Since we weren't able to meet with our community in person, we've hosted our very first 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 source 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.

In 2021 we were happy to welcome another new member among our midst. This comes to show how our network is ever expanding. With every new member, 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

Over the course of 2021 a dedicated committee within FIN explored FIN's audience, current relationships with stakeholders, current marketing tools (website, newsletter, projects etc) to determine goals and objectives both short term and long term and to define the organization's place in the world. Based on the outcome of this trajectory, we will be rolling out our new strategy.

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

A WARM WELCOME TO

In 2021 we were happy to welcome a new member among our midst. This comes to show how our network is ever expanding. With every new member, we're able to keep on building strong relations, make valuable connections and share our best practices on a growing platform.

Rare Disease Foundation of Iran

Rare Diseases Foundation of Iran is a non-profit institution with national and international sphere of operation. This foundation was established in 2008 with assistance from Dr Ali Davoudian given the requirements of the health system and lack of an organization to support rare disease patients in Iran.

The word 'orphan' meaning 'Nader or Yatim' in Persia is used for those diseases with an incidence of 1 to 5 in every 10000 people. According to the statistics produced by the concerned organizations, a total number of patients suffering from 6000 to 8000 known rare diseases includes 8 percent of the total world population. In the late 1980s and early 1990s those countries with developed social security and medical services found that there were a number of diseases that could not be classified in the classic diseases categories and because of their rare incidence should only be included in a category solely produced for such diseases.

Since then lots of studies done on rare diseases and in a very short period many rare diseases were identified accordingly. In Iran until now 58 rare diseases have been identified; diseases that have affected more than 1.2 million people of Iran.

**Rare Diseases
Foundation of Iran**

As we go on, we continue to reach out to existing organizations concerned with rare diseases or lyosomal storage disorders, and we're glad to lend a helping hand to support newly founded organizations.

Of course, networking goes beyond enlarging our own circle of patient organizations, but also requires getting in touch with medical professionals, interesting companies and staying up to date with the latest ins and outs of all areas of Fabry disease research.

FIN FABRY YOUNG ADULT COMMUNITY

FIN has been 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 several times over the course of 2021 and we continue to do so in 2022, hoping to meet F2F one day. 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.

Young adults can still apply to be part of the group through the application form on the FIN website.

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 2021

In 2021, we organised our very first online FIN Fabry Expert Meeting. We welcomed more than 200 participants from 29 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 16 booths. There were at least 187 unique booth visits, and more than 172 resources were downloaded by the registrants.

There was so much valuable information to be found and downloaded at the exhibition! We learned about Fabry and its impact on sleep, about current and emerging treatments, Fabry & Nutrition and much more. The presentations from the meeting remain available on the FIN YouTube Channel.

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

Presentations

PATIENT REGISTRY

A patient registry is a powerful tool to observe the course of a disease; to understand variations in treatment and outcomes; to examine factors that influence prognosis and quality of life; to describe care patterns, including appropriateness of care and disparities in the delivery of care; to assess effectiveness; to monitor safety and harm; and to measure quality of care.

Different stakeholders benefit from the value of registries in different ways We believe a Fabry patient registry could be of tremendous value to the community.

In 2021 we organised discussion with experts and organisations who have built their own registry and of course with people who will support FIN throughout this process so we can build a solid and sustainable registry.

SURVEY

We would like to share with you the results of the survey we ran at the end of 2021. We want to thank you for taking the time to complete the survey and for sharing your input. We appreciate this very much and know that we will take these outcomes with us to support you better in the future.

This survey was run as a collaboratives project between the Fabry International Network (FIN) and Amicus Therapeutics and our aim was to gather feedback and insights from our membership on your current challenges. We wanted to understand how engaged you feel your communities are and to identify what communication ideas and activities would support you best in the future. The survey was completed by 30 patient organisations from 29 countries. The surveys were translated into local languages.

We learned that your key challenges are

- Supporting newly diagnosed Fabry patients and those who feel they may have Fabry but can't get diagnosed
- Supporting patients to manage their day-to-day symptoms with their healthcare teams
- General ongoing COVID-19 pandemic issues around understanding COVID-19 risk for Fabry patients

Overall, those who participated feel your communities are engaged (40%) or slightly engaged (26.7%) with the patient organisation in general and attending events that the patient group/industry hosts. Over 80% of you think in-person meetings are the most valuable way to engage the Fabry community.

We will share the infographic with you and again, we will take all of these outcomes with us to support you better in the future. Feel free to reach out if you would like to discuss in more detail

Infographic

GOVERNANCE

At the previous AGM Lut de Baere and Erica Van De Mheen were voted to continue as FIN president and FIN Treasurer. Julia Alton and Yifan Xu were appointed as FIN Directors.

FIN Board in 2021

- President: Lut De Baere
- Vice President Americas & Global: Jack Johnson
- Vice President Europe & Russia: Anna Meriluoto
- Treasurer: Erica Van de Mheen
- Secretary: Mary Pavlou
- Director: Julia Alton
- Director: Yifan Xu

The FIN Board have met online every month during 2020 to take forward the business of FIN.

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

GOVERNANCE

The FIN Board regrets to inform you that there Erica van de Mheen is resigning as board member and as of tomorrow she will no longer be part of the FIN Board. The FIN articles of association will be updated accordingly.

We would like to thank Erica for all her efforts and valuable contributions and we wish her all the best. For the time being the FIN Board will move forward in 2022 with 6 Board Members.

WEBSITE & NEWSLETTER

We keep sending out our quarterly newsletters to an audience that has grown to over 500 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

We proudly present the new and improved FIN website. Where visitors will be able to translate all content from now on. The website and the entire organization is now also fully compliant to GDPR guidelines.

www.fabrynetwork.org

COLLABORATIONS & PARTNERSHIPS

FIN is very pleased to have partnered with organisations such as Zamplo 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.

Zamplo

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 2021 we issued a new edition: the Fabry Findings 5. 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 2021!

In 2021 we challenged people to "Break A Sweat for Fabry" and post their picture on social media with the hashtag #BreakASweatForFabry.

We shared that for every diagnosed Fabry patient, there are 10 more who don’t know about their condition. Yet and ask to help spread awareness and take the challenge at breakasweatforfabry.com. By breaking a sweat for people who have difficulties sweating or can't sweat at all, people could show their support and help raise awareness.

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 2021 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

FIN AWARD

FIN awards a patient (association) led initiative that informs and educates the Fabry community and helps raise awareness with a grant of 2500 EUR.

FIN wants to encourage the membership to organise activities and initiate projects by contributing financially and offering a platform to share with the wider community.

Criteria: educate and raise awareness & bringing patients together.

The awardee for 2021 is the Polish Fabry organisation. They are working on an ABC Guidance - First Steps for Fabry patients in Poland. The objective is to provide clear instructions what to do and how to do it to get the proper Fabry diagnosis and start treatment. They aim to also translate this to Ukrainian and distribute it to medical facilities, social media, Fabry patients etc.

Next application round will open in October 2022 (members will be informed)

FINANCIAL REPORT

The closing bank balance 2021 was 223,879.16 EUR. Total income in 2021 was 147,141.28 EUR. Total expenditure in 2021 was 140,320.44 EUR. The surplus of income over expenditure for 2021 is therefore 6,875.93 EUR and this results in equivalent higher equity.

The Fabry International Network is most grateful to Sanofi, Amicus, Takeda, Idorsia, Chiesi, Avrobio, Freeline and Sangamo for the unrestricted educational grants and charitable contributions they have made to FIN in 2021.

The year ending 31 December 2021 accounts were audited by BHKK BV (Belgium) and the Auditor’s letter signed by senior accountant Hans Blockx.

Funds received in 2021

Funder	Percentage of overall income
Sanofi Genzyme	25.52%
Amicus	20.92%
Takeda	18.26%
Freeline	7.06%
Idorsia	7.06%
Avrobio	7.06%
Chiesi	7.06%
Sangamo	7.06%

INDUSTRY PARTNERS

In 2021 FIN met with industry partners in online meetings in May with representatives from Sanofi, Takeda, Amicus, Idorsia, Freeline, Chiesi, Avrobio 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!

Sangamo THERAPEUTICS

idorsia

AVROBIO

Takeda

Amicus Therapeutics

Chiesi Global Rare Diseases

FREELINE

SANOFI GENZYME

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 - Croatioan 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
Guatamal - 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 Enfermedadad de deposito 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

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

Save the date!

FIN Expert Meeting 2023
April 21st -April 23rd, 2023 Amsterdam, The Netherlands