

FABRY INTERNATIONAL NETWORK

# ANNUAL REPORT 2020





What a year it's been. 2020 was definitely one for the books. But not – as we all know – in a positive way. A global pandemic turned everyone's world upside down. We found ourselves confined to our homes. And as an organization, we've had to rethink the ways to stay true to our mission. 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.

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.

Whether through a series of online webinars or the shift towards a complete Virtual Expert Meeting in April 2021 as a replacement for the event we've had to postpone last year. In the meantime, our thoughts are with everyone who has had to confront the virus or is still battling with everything in its wake. 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*





## 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 webinar in April of 2020. Throughout the rest of the year we've organized multiple webinars with different expert panels on the topic of COVID-19 and Fabry disease. 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 Fabry brochure. This publication lists 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.

# 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 2020 we were happy to welcome some new members 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.



# A WARM WELCOME TO

In 2020 we were happy to welcome some new members 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.

## Association Tunisienne des Maladies Lysosomales

L'ATML is an association recently founded by patients and relatives of patients suffering from rare and orphan diseases who are engaged in a daily fight against these diseases.



## Mexican Federation of Rare Diseases

FEMEXER is the national alliance of rare disease patients' associations. FEMEXER is a non-governmental and totally voluntary alliance of patient organizations, directed exclusively by patients and their families; They represent more than 70 rare disease patient organizations in Mexico, which cover 450 rare diseases (RAID) among the population.



## Proyecto Pide un Deseo México

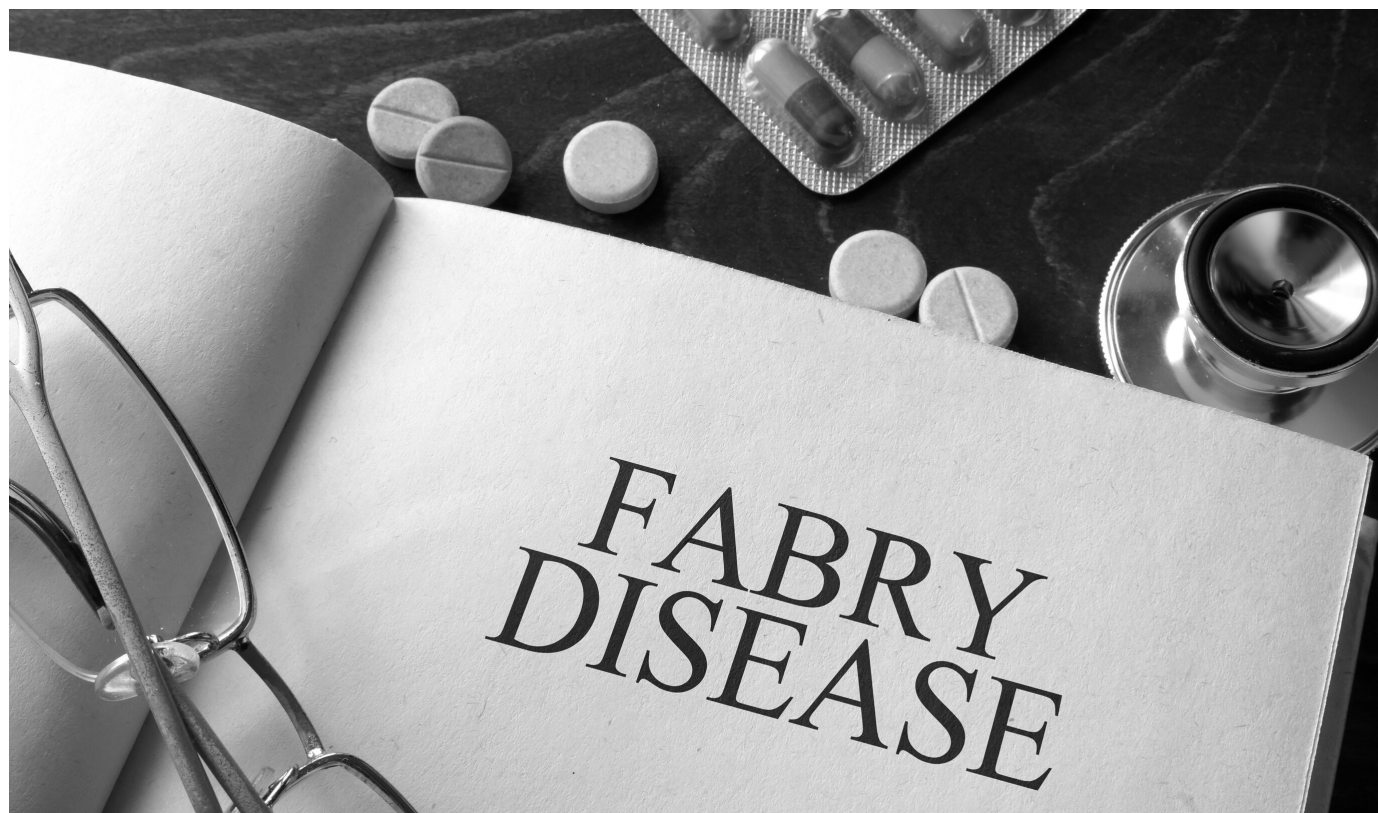
PPuDM is the lysosomal patient association and is an organization dedicated to the support of Gaucher and Fabry patients in Mexico and is part of Palito and Toto Make a Wish AC (PyTPuDac), which is a grantee authorized by the SAT that meets all the requirements of Mexican law to be a non-profit organization. In addition, it belongs to the Mexican Federation of Rare Diseases (FEMEXER) as a founding member.



As we go on, we continue to reach out to existing organizations concerned with rare diseases or lysosomal 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.

# OPEN LETTER TO FABRY CENTRES



Based on the outcome of a Virtual Round table Meeting held in December – Advocating for better care for the Fabry Community, FIN drafted a letter that could be sent to the Fabry Expert centres in each country. The letter was signed by the patient organisation leaders present at the roundtable; similarly the letter is available to all members (regardless of webinar participation) for adaptation to your respective Fabry treatment centres.

The objectives are:

- Highlight the need for continuous care and monitoring for Fabry disease patients
- Remind them of action needed for newly diagnosed patients, those in the midst of the diagnostic process or those experiencing symptoms for the first time and needing assessment
- Emphasise the need for ongoing clear and consistent communication from the centres about patients' care and having regular appointments (in-person or telehealth)

[Open Letter](#)



# YOUNG ADULT COMMUNITY



FIN aims to build a community and train the next generation of patient advocates. We try to do this by connecting young adults from all over the world and forming a highly motivated group of 16-35-year-olds from the rare disease community. Currently we have young adults from all around the world joining the community. Among them, young adults from The Netherlands, Italy, Armenia, Germany, Spain, Canada, South-Korea, Taiwan, Poland, Tunisia ... this pandemic has turned out to be specifically hard on the mental well-being of younger people. In our newsletter of December 2020 our Young Adult Community therefore shared a list of tips to keep a healthy and relaxed mind.

We met online with the group of young adults several times in 2020 and we continue to do so in 2021, hoping to meet F2F one day. 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](#)





# CONGRESSES

WORLDSymposium™ – Orlando, USA – FEBRUARY 2020: Right before the global pandemic hit, most of the FIN board travelled to the WORLDSymposium™ in Orlando in February. This year's meeting was attended by over 1.900 scientific attendees from more than 50 different countries, plus almost 40 exhibiting companies. Our FIN Booth at the exhibition hall turned out to be a success and it helped provide the boards with lots of new contacts. Both during conversations at the exhibition and the different presentations we learned that research on Fabry disease is making many advances and more clinical trials have begun in Canada, Europe, the United States and Australia.

ECRD – Online – MAY 2020: The ECRD is recognized globally as the largest, patient-led rare disease event in which collaborative dialogue, learning and conversation takes place, forming the groundwork to shape future rare disease policies. The conference was originally planned to take place in Stockholm, Sweden, but due to the pandemic, it was to be held completely online. With more than 1.500 participants from 57 countries attending this 2-day event, it was definitely a success, even in these difficult circumstances. What FIN takes away from this event? There are a lot of innovations in healthcare which promise positive develop for a diagnosis.

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## WEBINARS

Since we weren't able to meet with our community in person, we've hosted our very first webinar in April of 2020. Throughout the rest of the year we've organized multiple webinars with different expert panels on the topic of COVID-19 and Fabry disease. A lovely way to get in touch and keep our community informed during these challenging times.



Webinars

# PATIENT REGISTRY

A patient registry can be a powerful tool to observe the course of 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. Through functionalities such as feedback of data, registries are also being used to study quality improvement.

Different stakeholders benefit from the value of registries in different ways. For patients and patient advocacy organizations, a registry increases understanding of the natural history of a disease, contribute to the development of treatment guidelines, or facilitate research on treatment.

We believe a Fabry patient registry could be of tremendous value to the community.

We are currently in an investigational phase and working on a feasibility study for a Fabry patient Registry.



# GOVERNANCE



At the 2020 AGM Mary Pavlou was voted to continue as Secretary and Anne Grimsbo and Martynas Davidonis resigned as FIN Director.

## FIN Board in 2020

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

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.



# 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](http://www.fabrynetwork.org)



# RARE DISEASE INTERNATIONAL

FIN joined RDI, [Rare Disease International](#), RDI is the global alliance of people living with a rare disease of all nationalities across all rare diseases.

RDI brings together national and regional rare disease patient organisations from around the world as well as international rare disease-specific federations to create the global alliance of rare disease patients and families.

They are:

- Patient driven
- Internationally focused
- Inclusive



THE RARE DISEASE INTERNATIONAL ALLIANCE

RARE  
DISEASES  
INTERNATIONAL

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## 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 2020 we issued two new editions: the Fabry Findings 3 and 4. 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

길고 긴 겨울 밤  
잠 못 이루고 뒤척이다 깨어서  
긴 밤 홀로 깨어있네

졸음에 겨워 설핏 잠들었다  
이내 다시 깬다

졸다 깨다 반복하며 영영 오지 않을 것 같은 새벽을 기다린다

길고 긴 겨울 지나  
봄이 오고 쌓인 눈 녹듯

아픔도 봄 눈 녹듯  
스르르 녹아내리길...

*Spring*

*In a long winter night  
I'm awake after tossing and turning  
I'm awake all night alone*

*Fell asleep for a while  
Soon, I wake up again*

*I'm waiting for the dawn that never seems to come, while dozing off*

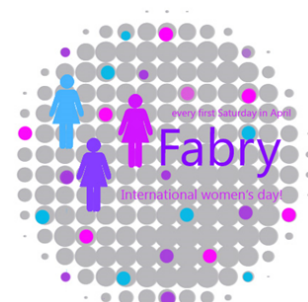
*After passing through a long winter  
Like spring comes and snow melts*

*Hope the pain goes away  
Like snow melts in spring...*

Let's get Fabry creative: Each year in April, we aim to increase the awareness of Fabry Disease by increasing understanding of this rare condition and the impact of living with Fabry Disease, both as a patient or a family member. Fabry Awareness Month is all about raising awareness around the globe and sharing details of life with this condition with family, friends, acquaintances and doctors. In 2020, we put on a contest: Let's get Fabry creative. The goal of this contest: to let the Fabry community express what it means to live with a rare disease in their most creative ways. Through pictures, video's, drawings, sculptures, songs, dances and so forth. We've tremendously enjoyed the creative expressions of our community during the whole Fabry awareness month. In our June newsletter we were able to announce Geonwoo Kim as the winner, with her wonderful poem titled 'Spring'.

## 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 2020 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

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## FIN AWARD

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

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.

Winner 2020: ATML (Tunisia) for a documentary that follows patients and explain their daily struggles, so that anyone that sees what they are going through can understand their condition without being overwhelmed by scientific details. As seeing patients and caregivers or parents live their lives instead of hearing about symptoms helps bring people together. It can also be subtitled in other languages so they can reach wider audiences around the world.

Next application round will open in September 2021. (members will be informed)

# FINANCIAL REPORT

The closing bank balance 2020 was 216.364,47 EUR

Total income in 2020 was 164.910,15 EUR

Total expenditure in 2020 was 117.173,92 EUR. The surplus of income over expenditure for 2020 is therefore 47.917,76 EUR and this results in equivalent higher equity.

The Fabry International Network is most grateful to Sanofi Genzyme, Amicus, Takeda, Idorsia, Chiesi, Avrobio, Freeline and Sangamo for the unrestricted educational grants and charitable contributions they have made to FIN in 2020.

The year ending 31 December 2020 accounts were audited by BHKK BV (Belgium) and the Auditor's letter signed by senior accountant Hans Blockx.

## Funds received in 2020

<b>Funder</b>	<b>Percentage of overall income</b>
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 2020 FIN met with industry partners in February at WorldSymposium™ 2020 in Orlando. The FIN Board also met online in individual meetings in May with representatives from Sanofi Genzyme, Takeda, Amicus, Idorsia, Protalix, 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!







# 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 - [بنیاد خیریه بیماری های خاص](#)  
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 - [Asociacion Peruana de Pacientas con Enfermedad 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 Genetickyh 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](mailto:coordinator@fabrynetwork.org)



Fabry International Network

Registered address Alice Nahonlaan 7, 9120 Melsele - BE

Visiting address: Floralaan 35A, 9120 Beveren - BE

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



**Save the date!**

FIN Expert Meeting 2022

May 6th-8th, 2022, Amsterdam, The Netherlands



**FABRY**  
International Network