A word from the President:

Dear All

With the beginning of summer, we are very proud to present you with the latest news from FIN! This newsletter will serve as good reading materials during your planned vacation!

Looking back to the Barcelona FIN Fabry Expert meeting, we are very thankful to have had your presence there and receive your valuable input during the workshops. We received very positive feedback and we will take into account all of your suggestions for future meetings! If you were not able to attend the meeting in person, we have some great news for you! The live stream is still accessible via the links provided in this newsletter.

As communicated in Barcelona, included in this newsletter you will find the link to the first issue of Fabry Findings.

In order to make this newsletter as informative as possible we are always welcoming news and information from you as (family of) patients, patient organizations and patient representatives. Please send it to our mailbox: info@fabrynetwork.org

Please enjoy reading the FIN newsletter and have a great summer!

Lut, FIN president
Every year the Fabry International Network organizes the Fabry Expert Meeting. This year it was held from May 24th to 26th in Spain – in the capital of Catalonia – beautiful Barcelona and was hosted by the president of the society for Mucopolysaccharide Diseases in Spain, Jordi Cruz, who also gave a presentation about the association he represents. During the meeting we had 78 attendees and among them there were patient organisation leaders, physicians with tremendous levels of expertise in the field of Fabry disease and representatives of the pharmaceutical companies. This team led us all to experience interesting presentations, discussions and casual conversations not only during the meetings but also during the dinners.

This year we had two patients speaking – Francisco Albiol who is a Fabry patient from Spain and Wojciech Nadolski – a Fabry patient from Poland. Francisco told us his personal story of Fabry disease and what he had to experience during his journey to diagnosis and treatment. Wojciech guided us through the difficulties they face in Poland where reimbursement for treatment is not provided and this leads many people to develop severe symptoms. He also told us about very interesting initiatives they do to raise awareness about the disease among the government officials.

Doctor Nadia Ali told us about the psychological impact of Fabry disease and about Fabry fog. She also gave us a glimpse to the cognitive function examination procedures and informed all that she is coordinating a 12 hour-long cognitive testing for Fabry patients.

Professor Dominique Germain gave a really clear and understandable description of X chromosome inactivation explaining the variable impact of Fabry in woman. He also gave a presentation about family planning when one of the partners has Fabry Disease.

A representative from the Japanese association presented the results of their survey related to Fabry disease. We were also updated on kidney, heart, pain issues and other interesting topics.
This year’s Fabry Expert Meeting also had a new initiative – a day dedicated to workshops. We had topics such as “Understanding the psychological needs of Fabry disease”, “Symptom management”, “Let’s talk Fabry men” and “Let’s talk Fabry women”. All the patients and their caregivers were divided in to smaller groups to discuss one particular topic and each participant could choose three workshops to participate in. FIN is working on a summary report based on the outcome of the workshops and will share this in the next newsletter. Participant feedback highlighted the desire for continuing the workshop program at future meetings.

As during all past meetings, the annual general meeting of the membership was held to discuss Fabry International Network matters and also re-elected 3 directors of the board for the three-year term. Of course the FIN board and pharmaceutical companies meetings prior to the Fabry Expert Meeting are to be mentioned. During these we received updates concerning what is happening in the area of treatment and discussed how the industry partners could help us accomplish FIN’s mission – “a world where every single person affected by Fabry disease has the best quality of life possible through early diagnosis, treatment and cure”. We will share that information among the membership through our newsletter, website and future meetings.

Thank you for your attendance and valuable contributions to the meeting!

We look forward to welcoming you in Amsterdam to the FIN Fabry Expert Meeting on April 24th-26th, 2020!
15th Fabry Women’s Day in the Netherlands!

Saturday, April 6th Fabry Support and Information Group Netherlands (FSIGN), celebrated its 15th Fabry Women’s Day!!

FSIGN organized a workshop at ‘cakes by SUUS’ in the exact middle of the country, so everyone was able to attend.. (the longest travel is a two hour drive).

Another location in this town we also use for our Annual Membership Meeting every year.

The workshop ‘decorate cakes’ was a very big success!

Every woman took a very tasteful cake home with her, to celebrate our special Fabry Women’s Day at home with her family.

We celebrate this special day every year on the first Saturday of April and it meets a need that we could not imagine...

After all these years we now know each other better, we have shared each other's joys and sorrows. We can comfort each other after bad results and support each other in difficult decisions. This is invaluable!

I would like to share a few experiences of participants:

“What a great day it was. The ‘cakes by SUUS’ were delicious and so good to see you all again, it really has something special, it feels a bit like family... So much fun to talk with each other again and see how it goes. After the workshop we went for dinner. Was delicious and cosy. We sat at a nice table with a new member, so fun and very clever! When we are together, we feel strong!”

“Have you missed this party or are you still unsure if you should come? I would say: do it, the more the merrier....”

“We love to be every now and then, in a company of people who, like no other, understand what you're talking about if you tell about how Fabry takes up space in your life. And after all these years of membership, those people are just a little 'family'. We think it's very nice to see and speak to each other now and then. And so we met again, last April 6th, cosy with a large group of chatting ladies at ‘cakes by SUUS’ in Almere, on the annual international women's day!”

As one of the two female board members of FSIGN, I hope that other patient organizations are also able to bring together women involved with Fabry, as there are Fabry-affected, mothers of Fabry-affected, wives of Fabry-affected, daughters of Fabry-affected, sisters of Fabry-affected, friends of Fabry-affected, so we can support each other!

Our only stipulation is that you need to become a member of our patient organization...

This is one of the reasons our patient organization in our small country (17 million inhabitants) has almost 150 members, of which 53% are Fabry-affected.

Good luck with organizing your own International Fabry Women’s Day, April 4, 2020!

Erica van de Mheen
On April 21st, 2019 the very first Fabry Patient Meeting ever was held in Athens, Greece. The meeting took place in Myrtillo café inside the beautiful Kapaps Park. Myrtillo café is a Social Cooperative Enterprise with a Special Purpose; the integration of vulnerable groups into the labor market. It was the ideal place to celebrate vulnerable and special people like Fabry patients during the Fabry Awareness Month. The Board of the Pan-Hellenic Association of Lysosomal diseases “Solidarity” organized a special gathering for Fabry patients. It was an opportunity to discuss and exchange experiences, dreams and fears. The atmosphere was lively and friendly. First the President, Kate Theohari, did an introduction and then the Vice President of the association and Secretary of FIN, Mary Pavlou, did a short presentation about Fabry Disease, the history of the association and we also talked about the new and emerging treatments for Fabry. Afterwards, coffee and a light lunch was in order, talking again about dreams and new adventures. Pictures were taken to create beautiful memories of the meeting. It was for sure a good first step to communicate better with our members and also to find ways to overcome the burden of the disease. We promise to organize it again next year!

Mary Pavlou
AVROBIO, a leader in lentiviral-based gene therapies, is a clinical stage company developing disruptive therapies that have the potential to transform patients’ lives in a single dose.

Gene therapy involves the transplantation of normal genes into cells in order to correct genetic disorders. Gene therapy uses a vector (see illustration below) to carry and deliver a working copy of a gene to the body’s cells. A vector is a deactivated virus that is unable to reproduce and spread (#1 below). There are different types of vectors. AVROBIO’s Plato™ is a gene therapy platform which uses a lentiviral vector and is designed to target underlying genetic disease by restoring normal gene function (#2 below) and enzyme production.

For more information about AVROBIO’s pipeline and technology please visit https://www.avrobio.com/.
Fabry Awareness Month 2019

Each year, during April, we aim to increase the awareness of Fabry Disease by increasing understanding of this rare condition and impact of living with Fabry Disease as a patient and family.

Fabry Awareness Month is all about telling the world about this rare disease. The more people that are aware, the more patients we can help get that early diagnosis. We hope that this year you also join us in sharing details about Fabry Disease with your family, friends and doctors!

Here are some of the events that were held by our members during this month:

Fabry Canada is continuing to travel across Canada holding their Patient Empowerment Meetings and bringing both awareness and education. Through the month of April they shared patient stories, gene therapy experiences, and a female perspective with media across the country.

MPS Turk published this video on their social media.

The U.S. National Fabry Disease Foundation (NFDF) coordinated with Fabry community members across the country to request state governor’s proclamations for April 2019 Fabry Disease Awareness Month. Of the 50 states in the U.S., 35 state governor’s proclamations were received this year as highlighted in green on the map.

The states highlighted in yellow on the map are states where proclamations were possible but attempts this year were unsuccessful for various reasons. The states highlighted in red have requirements that are difficult to meet or the state does not participate in a governor’s proclamation program. Each year the NFDF and Fabry community state representatives work together to obtain as many proclamations as possible to maximize Fabry disease awareness.

In addition to obtaining formal governor’s proclamations, the NFDF published a daily Fabry disease awareness post on their Facebook page at www.facebook.com/FabryDisease. The daily posts addressed a wide range of Fabry disease awareness topics to help people better understand, manage, and cope with Fabry disease and to better understand Fabry community programs.

The number of people who viewed the daily awareness posts in April ranged from about 1,300 to over 11,000. The number of people who follow the NFDF face book page is over 3,200 to date and growing.

You can see photos of many governor’s proclamations and participating community members in the “2019 Fabry Disease Awareness Month Photo Album” at www.facebook.com/FabryDisease.

The 2019 Chinese Fabry Patient Conference, cosponsored by the Shanghai Four leaf Herb Family Care Center (formerly known as the Chinese Organization of Rare Disease, CORD) and the Chinese Fabry Patient Community, was successfully held in Beijing. Nearly 100 people including Fabry experts, representatives of pharmaceutical companies, rare disease genetic testing institutions, social welfare organizations, patient organizations and patient groups attended.

In this conference, the Fabry Patient Community released the status of the domestic Fabry group. Many patients shared their stories living with Fabry. Experts shared the diagnosis and treatment of Fabry Disease and the status of Fabry drugs. An intense discussion was carried out at the conference. During the meeting, Beijing 301 Hospital, Beijing Dongzhimen Hospital, Beijing Anzhen Hospital, and Beijing Tongren Hospital also conducted a free onsite clinic for the Fabry patients who participated in the conference.
Welcome to the 2017 Fabry Outcome Survey (FOS) Annual Report, which provides an overview of FOS as of 5 January 2018. This report includes details of the FOS Steering Committee as well as a summary of patient demographics and the publications that have been developed using the data collected in the registry. FOS (ClinicalTrials.gov identifier: NCT03289065) is a large, global, multicentre, observational registry, sponsored by Shire, for patients with Fabry disease. The registry was established in 2001 with the aim of collecting real-world data on the long-term safety and effectiveness of enzyme replacement therapy (ERT) with agalsidase alfa and the natural history of the disease. FOS became a disease registry during 2017 and is now enrolling any patient with Fabry disease, including those who have received an approved treatment for Fabry disease other than agalsidase alfa.

Key highlights from FOS, as of January 2018

- As of January 2018, there were 3515 patients enrolled in FOS, which represents an increase of 11% compared with January 2017. In total, data have been collected by 137 centres in 25 countries.
- Similarly to previous years, 57% of enrolled patients are female and 12% are children (defined as < 18 years old at FOS entry).
- Overall, 2171 patients (62%) have received one or more doses of approved treatment for Fabry disease: agalsidase alfa (n = 2112), agalsidase beta (n = 63) or migalastat (n = 34); 38 patients have received more than one approved treatment. The relative proportions of patients who have received agalsidase beta or migalastat are lower than would be expected based on worldwide use of Fabry treatments because enrolment of patients receiving approved treatment for Fabry disease other than agalsidase alfa began in 2017.
- Four manuscripts based on FOS data were published during 2017, so that there was a total of 54 FOS publications as of January 2018. In addition, three posters based on FOS data were presented at two meetings in North America and South America.

Takeda would like to take this opportunity to thank all of the patients and their families, and the physicians and their staff, who have participated in FOS and contributed data to the registry.

Click here for the full report
FABRY FINDINGS

Scientific publications that are translated into lay language made available to the Fabry Community;
A new article will be announced in every FIN newsletter.

The first article is based on the publication:
Predictors of objective cognitive impairment and subjective cognitive complaints in patients with Fabry disease
Simon Körver 1, Gert J. Geurtsen2, Carla E. M. Hollak1, Ivo N. van Schaik3, Maria G.

SCIENTIFIC REPORTS (2019) 9:188 DOI:10.1038/s41598-018-37320-0

Click here to read the first issue of Fabry Findings

The Fabry Findings articles are published on the FIN website
http://www.fabrynetwork.org/fabry-findings/

We encourage you to translate the articles into your own language so these can be shared in your community.
This year, the annual meeting of the Romanian Fabry Organization took place on June 5th and 6th in Bucharest. The meeting started with a press conference.

Alexandru Tcaciuc, President of the APBFR association proudly represented the organization. Prof. Ruxandra Jurcut, a cardiologist who follows up Fabry patients in Bucharest with a multidisciplinary team briefly explained the course of the disease. Dorica Dan, Chairman of the Prader Willi PO, Chairman of the national rare disease organization RONARD and Eurordis board member emphasized the importance of networking as a national PO and joining European and international umbrella organizations. Lut de Baere, the day to day operations of MetabERN and FIN were highlighted by her.

According to the calculations, theoretically around 200 Fabry patients are living in Romania. APBFR was established only recently, namely in 2018. They have 3 directors and 26 members. They have a website, an open and closed Facebook group and work intensively with RONARD, various LSD PO’s, Prof. Jurcut (center of expertise), government services and Sanofi Genzyme. In Romania, only Fabrazyme is being reimbursed. During the lecture, a promotional film was shown in which various Fabry patients spoke about their experience with Fabry Disease.

APBFR supports its members in daily life. For example, they mediate when patients experience problems, if the therapy is not given on time or if the dose is not adjusted. Some patients receive the diagnosis, but cannot accept it, deny the severity of the disease and sometimes refuse treatment. It is up to Alexandru to point out to these people that treatment will more or less stabilize the disease and that the treatment will improve their quality of life. Alexandru also addressed the members to support the organization so that the workload can be divided.

The expertise center of Prof Jurcut was founded in 2015. She follows 9 Fabry patients. A total of 25 Fabry patients are being treated currently and 34 have been diagnosed. Fabry patients have an annual check up. They can always reach out to Prof. Jurcut, through the closed Facebook group. The patient is central to the care and a lot of attention is paid to the immediate environment and the caregivers of the patient. The center is responsible for the education of doctors and paramedics in local hospitals.

Of course genetics could not be missing from the program, this was brought by Dr. Viorica Radoi. Prof. Jurcut expertly addressed the problems with the heart. Dr. Elena Rusu was the one who told the attendees more about the functioning of the kidneys. The neurological aspects were examined by Dr. Adriana Dulamea. How the treatment of the children works was explained by Dr. Cristina Stoica. NKO vertigo. Deafness is a common problem and has been clarified by Dr. Madalina Georgescu. The different available treatment options were discussed by Dr. Lucia Ciubotaru

On day two the newcomers could watch the introduction of the association and the promotional video. Afterwards they took part in the given lectures. ‘Pain treatment’ was brought in a very clear way by Dr. Vlad Stefanescu. The topic ‘Depression’ was brought by Dr. Maria Radu. She told in a very intelligible way how one can get stuck in a vicious circle. Most patients suffer from chronic pain or pain at regular intervals. Because of that pain you easily end up in this circle, but it can be broken. She offered those present various options: medication, but also other methods that can lead to breaking this circle, namely positive thoughts, holding on to beautiful moments in life, falling in love, etc.

A separate session was given for nurses to teach them how to correctly administer the ERT.

The psychological impact when the diagnosis is communicated to the patient followed by group therapy for the patients and their caregivers was steered in the right direction by Elena Marinescu

And so this super busy but very fascinating two-day event came to an end.

My sincere thanks to Alexandru for allowing me to get to know him and his PO better.

Wishing him all the best for the association and keep up the good spirit!

Lut De Baere
Did you get a chance to read the FSIG Newsletter? 
[Click here](#) to read it.

**Live Stream FIN Fabry Expert meeting**

If you were not able to attend the FIN Fabry Expert Meeting in person, we have some great news for you!

The live stream is still accessible via the links here below

Saturday, 25th May: [https://youtu.be/czxSFBnREBg](https://youtu.be/czxSFBnREBg)

Sunday, 26th May: [https://youtu.be/H00lhJsBn_l](https://youtu.be/H00lhJsBn_l)
FOCUS ON FABRY LEADERS AROUND THE WORLD
Interview with Megan Fookes from Fabry Australia

When did you join your national patient association?
1994 – when it formed and I am actively involved from 1999.

What was the reason for joining?
My father, uncle and I had Fabry Disease and I saw the importance of forming a Fabry disease community to support one another and raise awareness and funds for research into Fabry disease.

What are the vision and mission of your association?
Fabry Australia’s Mission is Uniting the Australian Fabry Community, by working together to improve the lives of those affected by Fabry disease

Fabry Australia’s goals are:
1. Promote Patient Advocacy
2. Share information, knowledge and resources
3. Promote and support research and development
4. Encourage active involvement with patients, clinicians, medical personnel, partners and industry groups
5. Raise awareness and understanding of Fabry within the Community
6. Work co-operatively with other Australian and international organisations to promote best practice support and lifelong care for people diagnosed with Fabry disease
7. Maintain financial and resource viability
8. The Business Strategy is drafted and reviewed by the Management Committee of Fabry Australia every 2 years and it is shared with the members and supporters on the Fabry Australia website.

How many members are there?
Fabry Australia has over 300 Fabry patients diagnosed. Fabry Australia has 768 followers on its Facebook page and 226 members on its Fabry Australia Discussion Page.

What do you consider to be the major achievements or activities that are you are proud of?
Fabry Australia is very proud of its advocacy in Australia managing to get both Enzyme Replacement Therapies (Replagal and Fabrazyme) listed on the Life Saving Drugs Program (LSDP) of the Australian Department of Health for reimbursed therapy in 2004. This was with the help of the many members, supporters of Fabry Australia who each wrote to their local Federal politicians asking for their support to list the treatments on the LSDP and it was done before computers were readily accessible.

Fabry Australia is proud of the first Fabry Clinic which was set up in 1994 in Melbourne and has been replicated around the country. There are now 5 adult clinics and 5 paediatric clinics across the country managing 300 Fabry patients.

Fabry Australia is proud of its online presence with its website which is accessed by many Fabry affected across the country and the world. We are also very proud of our strong social media presence which has helped us grow and reach members across the country and around the world.

Fabry Australia is proud that it is turning 25 this year and is still going strong.

Fabry Australia is proud to advocate for positive changes to the LSDP with a new listing of Galafold Migalastat for Fabry patients in Australia.

Fabry Australia is also proud it has established a Medical Advisory Committee who have helped strengthen and support the advocacy work of Fabry Australia to ensure people diagnosed with Fabry disease can access quality health care services and access to new clinical trials/research.

Fabry Australia is proud of its ability to host bi-annual Fabry Expert Conferences in Australia to ensure its members are up to date with the latest information and developments in Fabry Disease research as well as tips/tricks to managing their disease with other support services from allied health and social care services.
FOCUS ON FABRY LEADERS AROUND THE WORLD
Interview with Megan Fookes from Fabry Australia

Can you name some challenges that your association is currently facing?

Some of the challenges Fabry Australia faces is ensuring the Clinical care and management of Fabry patients is well supported. We would like to see accreditation be given to Fabry Disease Centres of Excellence that offer ‘in house’ multi-disciplinary clinical services and access to ongoing clinical trials and research. Fabry Australia would like our Government to fund such services and ensure there is incentives to strengthen and grow such services. The demand on the clinics is increasing as more patients are diagnosed or need support. Fabry patients are living longer and this puts more stress and strain on health care services that currently are stretched beyond their capabilities.

We are concerned that we need more Fabry Doctors to train and understand the condition. As the current experts retire, we want to know their knowledge and expertise is passed down to new Fabry doctors who will continue the good work.

Access to reimbursed therapies is challenging in the absence of a Rare Disease Strategy and policy in Australia. The criteria for receiving funded ERT’s or Galafold is strict and needs urgent review. Fabry Australia is concerned that Fabry patients are accessing delayed treatment due to the restrictive criteria. In Australia, a patient must receive 12 months’ ERT before being offered Galafold which is unlike the rest of the world. Fabry Australia would like to see this clause adjusted and removed from the criteria.

In Australia patients receiving ERT are monitored by the clinics each year and all the results and data is sent to the Government (LSDP). This is a lot of paperwork for the clinics and seems unnecessary for Governments to be receiving. Fabry Australia would like to see processes changed to ease the burden to patients/clinics and encourage more patients to receive earlier access to treatments.

In Australia, it is very difficult to receive treatment for Fabry disease as a paediatric and typically it is delayed. Again – Fabry Australia would like to see the criteria reviewed to be more in line with what the rest of the world is doing with treating children diagnosed with Fabry Disease.

Can you name some future goals or plans?

Fabry Australia is hosting its 25th Anniversary Silver Dinner at its Fabry Conference in October this year. This is a huge milestone.

Fabry Australia is planning to host its 3rd Fabry Retreat in 2020 and hopes to bring this to Queensland. Other future plans and goals will be mapped out at the Management Committee’s Strategy Day in October this year. We will be mapping out the next 5 years of goals and plans at the review of the strategy with a facilitator and can share more after this.

Has your association had issues with the national health system or insurance problems?

Yes. Recently – with the listing of Galafold. This took a very long time to get listed with a rejection initially and also with the clause in the criteria that patients must receive 12 months ERT before they can receive Galafold.

How would you describe the current treatment situation in your country?

As mentioned earlier, the current treatment situation in Australia is a bit restrictive. Of the 300 Fabry patients diagnosed only one third are on treatment. Typically, children do no receive treatment or around the age of 15 / 16 they may access it but it is difficult to get.

What are the major issues with Fabry disease in your country?

Access to treatment can prove difficult if the patient doesn’t meet criteria. If you live in rural / country areas, it is a long distance to the treatment centre. In Australia the first 12 infusions must be done in the major Fabry Clinic and for some this can be up to 7 or more hours away. Receiving ERT at home is difficult for some patients who live in remote country / rural areas. The home infusion nurses can’t get to those locations.

Fabry patients must do a lot of tests each year which are sent to the LSDP (Department of Health in Canberra) by May each year to ensure ongoing access to treatment.

Some Fabry Clinics can manage to co-ordinate clinical care / appointments / tests at the Clinics and others, send patients away to other centres. This proves difficult for Fabry patients as this is more time off work / school to attend more appointments and fortnightly infusions. Some patients have lost jobs due to too much time off work.
**FOCUS ON FABRY LEADERS AROUND THE WORLD**

**Interview with Megan Fookes from Fabry Australia**

**How would you further raise global awareness for Fabry disease?**

Fabry Australia collaborated with the Canadian Fabry Association and its ‘Be Rare. Be YOU’ temporary tattoo campaign this year for Rare Disease Day and Fabry Awareness Month. We would like to see this rolled out globally and do this again next year. We would like FIN to promote the campaign and share with other Fabry Patient Groups globally to get behind the campaign to raise awareness of Fabry Disease as part of the rare disease movement and during April Fabry Awareness Month as part of FIN’s social media strategy.

**What are your suggestions for future projects for FIN?**

Fabry Australia would like FIN to do work on the need for a single Fabry Disease Registry (owned by the patient body, independent of industry). Currently there are multiple registries.

Access to treatment. Fabry Australia would like to do work on this with other groups to see what criteria is in place in other countries to access funded therapy. Doing some work on this face to face is important and would help each of our groups globally as we advocate to see reimbursement strengthened. Fabry Australia would like to see global consensus on the criteria to access therapy and clinical management and care of patients. There is Delphi Project being drafted and it would be great to review this when published and have input from the leaders of Fabry patient groups globally to ascertain improved clinical care and management of Fabry patients.

Apart from the annual conference, Fabry Australia would like to see FIN active in other projects that make a real difference to the Fabry patient groups who are supporting Fabry patients. Looking at positive patient empowerment mindfulness approaches to self-management of Fabry disease. There is a lot of focus on treatment / disease itself, but not on the whole patient. Building upon the psycho-social side to Fabry disease, building some useful tools to support Fabry patients would be practical and helpful to patients and the groups supporting them.

**What would you like to explain to other people / doctors / nurses / decisionmakers about Fabry disease?**

Fabry disease is invisible and can’t be judged on first appearances of a person diagnosed with it. Fabry patients often suffer in silence and do find day to day very tough. Fabry pain can be very debilitating and ongoing symptoms of Fabry disease is a challenge. There is a need to make life a little easier for those living with Fabry disease. Often a patient who has Fabry disease, may have experienced long delays in obtaining their diagnosis and have been through the healthcare system with not a lot of support. There is a need to ensure Fabry patients are listened to, heard, correctly managed and can access best possible care / treatment and access to new clinical trials / contributing to research with no delay.

**What kind of information are we still missing about Fabry disease?**

The impact Fabry disease has on the patient, their families and their communities. This is starting to be discussed, but there is a need to do more work on this. There is a need to develop educational tools that support this further (independent of industry and branded by FIN). Having an educational resource / tool to show schools or a similar tool to share with work place is important to communicating a bit more about the condition in simple terms and how it impacts a child or an adult.

**What is your most effective means of taking your mind off Fabry disease?**

Having a bath. Spending time with my family / friends. Sitting under a blanket and watching a good TV show/ movie. Laughing! Yoga.

**Is there anything else you would like to add?**

Thank you for the opportunity to share some thoughts and ideas. It would be great to have all the groups do this collectively so we can bounce ideas off one another and collaborate for the global Fabry community.

Thank you for your time Megan!
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