

2021

2021 Impact Report



FH Europe

The European FH Patient Network

FH Europe

The European FH Patient Network

Charity Registration no: 1170731

12/31/2021

Impact report for the period between 1 January 2021 and 31 December 2021

The Trustees are pleased to present their report and the accounts for the period to 31 December 2021.

Introduction

FH Europe continues to bring together patient organisations around Europe that are supporting people diagnosed with Familial Hypercholesterolaemia (FH) or other related inherited dyslipidaemias – Homozygous Familial Hypercholesterolaemia (HoFH), elevated Lipoprotein (a) (LP(a)) and Familial Chylomicronaemia Syndrome (FCS). The “Network” refers to the 29 patient organisations in 27 European countries, with new organizations from Belgium, Bulgaria, Israel, Lithuania joining the group in 2021. We support the current Network members and assist new organisations to set up, helping them all to learn from each other and to advocate jointly on the European and the national level.

Structure, governance, and management

FH Europe is a foundation Charitable Incorporated Organisation. We have a Board of Trustees that oversees the governance and strategy of the organisation. Day-to-day management is delegated to a part-time Chief Executive, Magdalene Daccord, who works closely with the Board to drive the strategic plan and deliver our charitable objectives.

Our long-time Chair, Jules Payne, retired as planned on 31 December 2020 and there were no new Trustees appointed during the year, although two Trustees were appointed after the year end, on 16th February 2022.

On 18th May 2020 John Reeve was elected Chair, taking over from Giovanni Nisato. Giovanni remains a Trustee and John continues as treasurer.

During the first half of the year the Board worked with the consulting firm EY to develop an enhanced vision, purpose and strategy, which is now being implemented. We are very grateful to EY for their generous support, which was given pro bono.

In addition to its quarterly meetings the Board has an informal fortnightly virtual meeting to keep in touch with developments in this fast-changing world. The Chief Executive has a standing invitation to attend Board meetings. Each year the Trustees agree individual objectives for the coming year and their performance is appraised by the Chair, as is the performance of the Chief Executive. The Chair's performance is appraised by another Trustee.

In 2021 the Public Health and Scientific Advisory Committee was split into 2 separate yet closely-collaborating advisory committees, with some of the advisors leaving the committees and a number of new ones joining. The Scientific Advisory Committee continues to be chaired by Dr Samuel Gidding.

Thirteen international medical and research experts from across Europe form the committee. They include Prof. Maciej Banach, Prof. Alberico Catapano, Prof. Tomas Freiburger, Prof. Urh Groselj, Prof Meral Kayıkçıoğlu, Prof. Pedro Mata, Prof. Borge Nordestgaard, Prof. Kurt Widhalm, Prof. Albert Wiegman, Prof. Catherine Boileau, Prof. Dr Elisabeth Steinhagen-Thiessen and Prof. Vincent Durlach. The newly formed Policy Advisory Committee is chaired by Dr Marius Geanta, and includes international experts in public health policy, European health advocacy as well as medical experts. Among them are Prof. Mafalda Bourbon, Dr Iñaki Gutiérrez-Ibarluzea, Prof. Anthony Wierzbicki, and Nicola Bedlington. The Chief Executive is present in both committees.

Objectives and activities

Charity objectives

- Support development of newer or smaller patient groups and individuals wanting to start a patient group
- Work as one voice across Europe to influence change and positive outcomes for patients
- Share information and best practice across Europe
- Work with experts to focus on themes and topics of interest to the patients and families we represent

Activities

At the start of our financial year, most of Europe was impacted by the COVID-19 pandemic, with numerous local and national lockdowns being introduced. Most planned activities for FH Europe had to be adapted to face the new reality and to support the European community in facing an unknown situation.

Memberships, partnerships, and collaborations

Between January and December 2021, FH Europe

- gained 5 new members from 3 new countries: Bulgaria, Israel, and Lithuania. The Belgian Cardiological League absorbed Belchol (our former member), and became a new member organisation from Belgium
- became an Associate Member of the European Patients' Forum
- joined the newly-formed European Alliance for Cardiovascular Health (EACH) as the first patient organisation to be admitted
- reinforced our partnership with the EAS FHSC and our collaboration with EURORDIS, the Global Heart Hub, ILEP, as well as other international stakeholders like the European Society of Cardiology, the World Heart Federation and the International Atherosclerosis Society

Impact and results

The key achievements of FH Europe between January and December 2021 were

- Acceptance of our statement of Best Practice in FH Paediatric Screening by the European Commission Public Health Best Practice Portal
- Participation in an Advisory Board for Lp(a) testing recommendations which led to a poster presentation at ISPOR in December
- Rare Disease Day campaign for HoFH “Many Faces, One Heart”, with the focus on the prestigious Black Pearl Awards. Our HoFH Patient Ambassador, nominated by FH Europe, reached the final
- Successful completion of the Global FH Advocacy Survey in partnership with the World Heart Federation
- Two webinars on the occasion of the International Women’s Day raising awareness of CVD and FH in women and continuation of the Many Faces, One Heart Campaign in March
- Roundtable session hosted by the WHF, FH Europe and EAS at the 89th EAS Congress – Next steps after the global call to action on June 1st
- Substantial contribution to WHF Cholesterol Whitepaper with FH patient stories
- FH Awareness Day 2021 campaign focusing on awareness raising and promotion of the Ambassador programme. Activities included: a podcast interview with the European Patients’ Forum about FH; creation and dissemination of 24 short videos produced by international experts and FH ambassadors shared on social media, FH Awareness webinar building on the most comprehensive global data from the Global FH registry (EAS FHSC) which was just published in the Lancet; promotion of innovation in diagnosis and treatment of FH as a model approach to wider CVD prevention
- Launch of the European Alliance for Cardiovascular Health on October 8th with a special webinar, including high level officials from the European Commission and the European Parliament and the participation of speakers from FH Europe
- High-level Technical Meeting on FH paediatric screening, an accompanying event of the Slovenian EU Presidency, leading to a consensus among leaders of international scientific and advocacy institutions on the urgency to implement early FH screening across Europe Two scientific articles were submitted for publication as an outcome
- Building on the experience of the Technical Meeting and creating a Task Force dedicated to FH screening in childhood.
- Assisting with an Irish submission for a national systematic FH Screening programme in response to the first Annual Call for new screening programmes from the National Screening Advisory Committee (NSAC).

- FH Europe Annual Network meeting focusing on the expansion of our scope from mostly patient support to increased advocacy, public health policy influencing and building an Ambassador Programme
- Three Industry Roundtable meetings during the year, including representatives of five industry companies, one representative of EFPIA and the FH Europe leadership team.
- Expansion of our organisational expertise in the space of public health policy, including creation of the Policy Advisory Committee which includes five international subject matter experts
- Launch of a new monthly newsletter Heart Beat, which reaches almost 1500 recipients globally.

Plans for the future

We continue to be very active in delivering our charitable activities, especially by supporting the Network in its efforts to raise awareness and to find undiagnosed patients through activities focused on advocacy for childhood screening and early detection. Building on the success of the Technical meeting and the collaboration with EACH as well as increased influence over the EC activities related to NCDs and CVD prevention, our most important activities planned for 2022 are as follows:

- Build a robust Ambassador programme with the Network to raise awareness of inherited lipid conditions and to strengthen collaboration within the Network, with its official launch at the Annual Meeting in November 2022
- Create of up to six national task Forces (Roundtable groups) to advance the agenda of FH paediatric screening at a national level, as preparation for pan-European health policy activities
- Register the organisation as a Foundation in the Netherlands in order to access EU funding for advocacy and paediatric screening related projects
- Recruit up to two patient trustees to the Board and additional operational and project-related support
- Hold a high-level policy meeting in one of the 2022 EU presidency counties (France or Czech Republic)
- Continue to support Network organisations in their work to improve the local situation for people living with inherited lipid conditions
- Publish the outcomes and recommendations based on our advocacy activities in 2021
- Launch the Lp(a) Awareness Day
- Hold the annual Network meeting in November 2022, most possibly face to face in the Czech Republic
- Continue to develop our social media communication channels to reach a wider community of patients and other international stakeholders
- Participate in health care professional conferences and other scientific meetings.

- Develop our relationships with European and international professional and other appropriate societies and networks.

Public benefit statement

The charity trustees have complied with their duty to have due regard to the guidance on public benefit published by the Charity Commission in exercising their powers or duties.

Financial review

The charity's main source of funds remains pharmaceutical companies. The number of donors and sponsors consolidated to 5 strategic supporters, with potential new sponsors identified. In addition, this year we successfully broadened our income opportunities with paid speaking and expert advisory activities. Furthermore, we have appointed an external consultant, Ms. Jill Bonjean, to help raise funds and review our internal policies and terms of reference in regard to any engagement with the industry. We are, however, a fully independent organisation, and our donors have no influence over our activities in any way. We do not engage in fundraising that may reduce the funds available to member organisations.

The impact of COVID-19 continues to be apparent in our financial performance as our physical activities remain largely curtailed and replaced by substantially increased activity online and on social media.

[Numbers will probably change slightly]

Income for the year was £316,241 (2020 £71,818 - 10 months) and expenditure £175,202 (2020 £87,697), leaving a surplus of £141,039 (2020 deficit of £15,879). We carry forward reserves of £235,941, including £27,366 of unrestricted funds. Much of this is already committed to projects started in 2020 but the Trustees are satisfied that uncommitted reserves exceed the minimum according to our reserves policy.

Our greatly enhanced financial performance reflects our decision to start a major effort to promote paediatric screening across Europe, as described above. This has attracted increased public profile and funding, and so we start 2022 well placed to continue to drive this and other projects forward.

We are grateful to those donors and sponsors that supported our work over the year.

Risk management

Responsibility for risk management lies with the Trustees. The main risk that has been identified is sustained funding and the need for further resource to carry out our planned activities.

Reserves policy

A reserves policy has been established which requires a minimum of 6 months' core costs to be retained. This currently equates to £75,000.

Going concern

The Trustees have considered the risks to the organisation arising from COVID-19 and are satisfied that these are being managed appropriately. All funding comes from pharmaceutical companies, and these are trading normally and continuing their support to patient organisations, as evidenced by our increased income this year.

Statement of responsibilities of the Trustees

The Trustees are required to prepare financial statements for each financial year, which give a true and fair view of the state of affairs of the charity and the incoming resources and application of resources, including the net income or expenditure, of the charity for the year. In preparing those financial statements the Trustees are required to:

- select suitable accounting policies and then apply them consistently.
- make judgements and estimates that are reasonable and prudent.
- observe the methods and principles in the Charities SORP.
- state whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements.
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and which enable them to ensure that the financial statements comply with the Charities Act 2011. The Trustees are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The Trustees confirm that to the best of their knowledge there is no information relevant to the independent examination of which the independent examiners are unaware. The Trustees also confirm that they have taken all necessary steps to ensure that they themselves are aware of all relevant examination information and that this information has been communicated to the independent examiners.

The Trustees are the sole members of the charity, but this entitles them only to voting rights. The Trustees have no beneficial interest in the charity.