

**Report of the Trustees and
Unaudited Financial Statements
for the Year Ended 31 December 2021
for
FH EUROPE**

Haines Watts
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178 Buckingham Avenue
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FH EUROPE

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for the year ended 31 December 2021**

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**Reference and Administrative Details
for the year ended 31 December 2021**

Trustees	J D Reeve D Zgodka S Gidding M Geanta J Taylor G Nisato A Dol (appointed 16/2/2022) G Jambrik (appointed 16/2/2022)
Principal address	Star House Star Hill Rochester Kent ME1 1UX
Registered charity number	1170731
Independent examiner	Haines Watts Chartered Accountants 178 Buckingham Avenue Slough Berkshire SL1 4RD

FH EUROPE

Report of the Trustees for the year ended 31 December 2021

The Trustees are pleased to present their report and the accounts for the year 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.

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Report of the Trustees for the year ended 31 December 2021

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.

On 21 October 2020 Giovanni Nisato was elected Chair, effective 1 January 2021. On 18 May 2021 John Reeve was elected Chair, taking over from Giovanni. 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 Kayikcioglu, 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 Inaki Gutierrez-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:

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Report of the Trustees for the year ended 31 December 2021

- 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.

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Report of the Trustees for the year ended 31 December 2021

- 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 countries (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.

Income for the year was £316,241 (2020 £71,818 - 10 months) and expenditure £176,871 (2020 £87,697), leaving a surplus of £139,370 (2020 deficit of £15,879). We carry forward reserves of £234,270, 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.

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Report of the Trustees
for the year ended 31 December 2021

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.

Independent examiners

Haines Watts were re-appointed as independent examiners to the charity during the year and have expressed their willingness to continue in that capacity.

12/04/2022

Approved by order of the board of trustees on and signed on its behalf by:



.....
J D Reeve - Trustee

**Independent Examiner's Report to the Trustees of
FH Europe**

Independent examiner's report to the trustees of FH Europe

I report to the charity trustees on my examination of the accounts of FH Europe (the Trust) for the year ended 31 December 2021.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a registered member of ICAEW which is one of the listed bodies.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Jonathan Moughton
ICAEW
Haines Watts
Chartered Accountants
178 Buckingham Avenue
Slough
Berkshire
SL1 4RD

12/04/2022

Date:

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**Statement of Financial Activities
for the year ended 31 December 2021**

	Notes	Unrestricted fund £	Restricted fund £	Year ended 31/12/21 Total funds £	Period 1/3/20 to 31/12/20 Total funds £
Income and endowments from Charitable activities					
Sponsorship income		19,034	297,207	316,241	71,712
Other income		-	-	-	106
Total		19,034	297,207	316,241	71,818
Expenditure on Charitable activities					
Expenditure on charitable activities		-	176,871	176,871	87,697
NET INCOME/(EXPENDITURE)		19,034	120,336	139,370	(15,879)
Reconciliation of funds					
Total funds brought forward		8,332	86,568	94,900	110,779
Total funds carried forward		<u>27,366</u>	<u>206,904</u>	<u>234,270</u>	<u>94,900</u>

The notes form part of these financial statements


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**Balance Sheet
31 December 2021**

	Notes	Unrestricted fund £	Restricted fund £	2021 Total funds £	2020 Total funds £
Current assets					
Debtors	4	-	58,314	58,314	15,140
Cash at bank		<u>27,366</u>	<u>160,444</u>	<u>187,810</u>	<u>90,300</u>
		27,366	218,758	246,124	105,440
Creditors					
Amounts falling due within one year	5	-	(11,854)	(11,854)	(10,540)
		<u>27,366</u>	<u>206,904</u>	<u>234,270</u>	<u>94,900</u>
Net current assets					
		<u>27,366</u>	<u>206,904</u>	<u>234,270</u>	<u>94,900</u>
Total assets less current liabilities		<u>27,366</u>	<u>206,904</u>	<u>234,270</u>	<u>94,900</u>
NET ASSETS		<u>27,366</u>	<u>206,904</u>	<u>234,270</u>	<u>94,900</u>
Funds	6				
Unrestricted funds				27,366	8,332
Restricted funds				<u>206,904</u>	<u>86,568</u>
Total funds				<u>234,270</u>	<u>94,900</u>

12/04/2022

The financial statements were approved by the Board of Trustees and authorised for issue on and were signed on its behalf by:



.....
J D Reeve - Trustee

The notes form part of these financial statements

**Notes to the Financial Statements
for the year ended 31 December 2021**

1. Accounting policies

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

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 in general. As a result the Trustees have concluded that they can continue to adopt the going concern basis in preparing the annual report and accounts.

Charity status

The charity is a charitable incorporated organisation. The members of the company are the Trustees named on page 1.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Debtors

Trade and other debtors are recognised at the settlement amount after any trade discounts offered.

Cash at bank

Cash at bank includes only cash held at bank available for the charities use.

Liabilities and provisions

Liabilities are recognised when there is an obligation at the balance sheet date as a result of a past event, it is probable that a transfer of economic benefit will be required in settlement and the amount of settlement can be estimated reliably. Liabilities are recognised at the amount that the charity anticipates it will pay to settle the debt or the amount it has received as advanced payments for the goods or services it must provide. Provisions are measured at the best estimate of the amounts required to settle the obligation.

Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest method.

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**Notes to the Financial Statements - continued
for the year ended 31 December 2021**

2. Trustees' remuneration and benefits

There were no trustees' remuneration or other benefits for the year ended 31 December 2021 nor for the period ended 31 December 2020.

Trustees' expenses

There were no trustees' expenses for the year ended 31 December 2021 nor for the period ended 31 December 2020.

3. Comparatives for the statement of financial activities

	Unrestricted fund £	Restricted fund £	Total funds £
Income and endowments from Charitable activities			
Sponsorship income	8,332	63,380	71,712
Other income	-	106	106
Total	8,332	63,486	71,818
Expenditure on Charitable activities			
Expenditure on charitable activities	-	87,697	87,697
NET INCOME/(EXPENDITURE)	8,332	(24,211)	(15,879)
Reconciliation of funds			
Total funds brought forward	-	110,779	110,779
Total funds carried forward	8,332	86,568	94,900

4. Debtors: amounts falling due within one year

	2021 £	2020 £
Trade debtors	38,685	887
Other debtors	370	4,526
VAT	19,259	9,727
	58,314	15,140

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**Notes to the Financial Statements - continued
for the year ended 31 December 2021**

5. Creditors: amounts falling due within one year

	2021 £	2020 £
Other creditors	<u>11,854</u>	<u>10,540</u>

6. Movement in funds

	At 1/1/21 £	Net movement in funds £	At 31/12/21 £
Unrestricted funds			
General fund	8,332	19,034	27,366
Restricted funds			
Charitable activities	86,568	120,336	206,904
TOTAL FUNDS	<u>94,900</u>	<u>139,370</u>	<u>234,270</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	19,034	-	19,034
Restricted funds			
Charitable activities	297,207	(176,871)	120,336
TOTAL FUNDS	<u>316,241</u>	<u>(176,871)</u>	<u>139,370</u>

Comparatives for movement in funds

	At 1/3/20 £	Net movement in funds £	At 31/12/20 £
Unrestricted funds			
General fund	-	8,332	8,332
Restricted funds			
Charitable activities	110,779	(24,211)	86,568
TOTAL FUNDS	<u>110,779</u>	<u>(15,879)</u>	<u>94,900</u>

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Notes to the Financial Statements - continued
for the year ended 31 December 2021

6. Movement in funds - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	8,332	-	8,332
Restricted funds			
Charitable activities	63,486	(87,697)	(24,211)
	<u>71,818</u>	<u>(87,697)</u>	<u>(15,879)</u>

7. Related party disclosures

There have been no related party transaction during the current financial period.

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**Detailed Statement of Financial Activities
for the year ended 31 December 2021**

	Year ended 31/12/21 £	Period 2020 to 31/12/20 £
Income and endowments		
Charitable activities		
Sponsorships	313,138	71,712
Honoraria	<u>3,103</u>	<u>-</u>
	316,241	71,712
Other income		
Bank interest	<u>-</u>	<u>106</u>
Total incoming resources	316,241	71,818
Expenditure		
Charitable activities		
Insurance	-	246
Telephone, internet, website, IT & subscriptions	12,965	3,620
Printing, postage and stationery	40	93
Hotels, travel and subsistence	657	174
Events	5,331	981
Agency fees	22,221	2,317
Consultancy fees	118,411	65,959
Translation costs	<u>3,664</u>	<u>2,888</u>
	163,289	76,278
Support costs		
Management		
Accountancy fees	12,887	11,021
Finance		
Bank charges	637	398
Exchange rate variance	<u>58</u>	<u>-</u>
	695	398
Total resources expended	<u>176,871</u>	<u>87,697</u>
Net income/(expenditure)	<u>139,370</u>	<u>(15,879)</u>

This page does not form part of the statutory financial statements