

INTERNATIONAL CARDIOMYOPATHY NETWORK

England & Wales · Charity number 1184472

Details

Other names **ICON**

Status **Registered**

Legal form **CIO**

Registered **2019-07-18**

Register [View on the Charity Commission register](#)

Contact

Address C/O Cardiomyopathy UK
75a Woodside Road
Amersham
Buckinghamshire

Phone 01494791224

Email joel@cardiomyopathy-icon.org

Activities

Objects: (1) TO ADVANCE THE EDUCATION OF HEALTHCARE PROFESSIONAL ON THE SUBJECT OF CARDIOMYOPATHY AND RELATED DISEASES OF THE HEART MUSCLE THROUGH THE PROVISION OF EDUCATIONAL LEARNING OPPORTUNITIES AND OTHER METHODS THAT TRUSTEES SEE FIT SO AS TO IMPROVE THE DETECTION AND TREATMENT OF SUCH DISEASES FOR THE PUBLIC BENEFIT.(2) TO IMPROVE THE HEALTH OF PEOPLE AFFECTED BY CARDIOMYOPATHY AND RELATED DISEASES OF THE HEART MUSCLE THROUGH THE PROMOTION AND FACILITATION OF RESEARCH FOR THE PUBLIC BENEFIT IN ALL ASPECTS OF CARDIOMYOPATHY AND RELATED DISEASES OF THE HEART MUSCLE BY PROVIDING NETWORKING OPPORTUNITIES FOR RESEARCHERS, SUPPORT AND ADVICE TO RESEARCHERS AND OTHER MEANS TRUSTEES SEE FIT.(3) TO ADVANCE THE EDUCATION OF HEALTHCARE PROFESSIONALS WORLDWIDE THROUGH THE DISSEMINATION OF THE RESULTS OF RESEARCH INTO CARDIOMYOPATHY AND RELATED DISEASES OF THE HEART MUSCLE.(4) TO IMPROVE THE HEALTH OF PEOPLE AFFECTED BY CARDIOMYOPATHY AND DISEASES OF THE HEART MUSCLE WORLDWIDE THROUGH THE CREATION, MONITORING AND DEVELOPMENT OF RELEVANT GUIDANCE ON THE TREATMENT OF SUCH DISEASES.(5) TO IMPROVE THE HEALTH OF PEOPLE AFFECTED BY CARDIOMYOPATHY WORLDWIDE THROUGH COLLABORATION WITH RELEVANT STAKEHOLDERS IN ADVOCATING FOR IMPROVE ACCESS TO TREATMENT FOR PEOPLE AFFECTED BY SUCH DISEASES.(6) TO INCREASE AWARENESS OF CARDIOMYOPATHY AND RELATED DISORDERS AMONG THE GENERAL PUBLIC AND THE SUPPORT AND INFORMATION AVAILABLE TO PEOPLE WITH CARDIOMYOPATHY AND RELATED CONDITIONS.

Activities: Education of healthcare professionals regarding cardiomyopathy and related conditionsPromotion of research into cardiomyopathy and related conditionsEstablishment of best practice in the treatment and management of cardiomyopathy and related conditions

Classification

- **How:** Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** People With Disabilities

Geography

- Belgium
- France
- Germany
- Greece
- Ireland
- Italy
- Netherlands
- Spain
- United States
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£40,025	£26,095	-	-
2023-12-31	£45,721	£104,980	-	-
2022-12-31	£120,357	£41,769	-	-
2021-12-31	£0	£0	-	-
2020-12-31	£0	£0	-	-

Trustees

Name	Role	Appointed
Prof. Perry Mark Elliott	Chair	2019-07-18
Dr Aristides Anastasakis		2019-07-18
Dr Juan Pablo Kaski		2019-07-18
Dr Juan Ramon Gimeno Blanes		2019-07-18
Dr Lucie Carrier		2019-07-18
Prof. Ales Linhart		2019-07-18
Prof. Eloisa Arbustini		2019-07-18
Prof. Guiseppe Limongelli		2024-02-23
Prof. Jolanda Van Der Velden		2021-04-12
Professor Iacopo Olivotto		2019-07-18

INTERNATIONAL CARDIOMYOPATHY NETWORK

England & Wales - Charity number 1184472

Accounts

Charity registration number: 1184472

International Cardiomyopathy Network (ICoN)

Annual Report and Financial Statements

for the Year Ended 31 December 2024

Hodson & Co
Wiston House
1 Wiston Avenue
Worthing
West Sussex
BN14 7QL

International Cardiomyopathy Network (ICoN)

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International Cardiomyopathy Network (ICoN)

Reference and Administrative Details

Chairman

Prof Perry Elliott

Charity Registration Number

1184472

Registered Office

C/O Cardiomyopathy UK
75a Woodside Road
Amersham
Buckinghamshire
HP6 6AA

Independent Examiner

Hodson & Co
Wiston House
1 Wiston Avenue
Worthing
West Sussex
BN14 7QL

International Cardiomyopathy Network (ICoN)

Trustees' Report

The trustees, present the annual report together with the financial statements and auditors' report of the charity for the year ended 31 December 2024.

Objectives and activities

Public benefit

The objects of the charity as set out in its governing document are;

- (1) To advance the education of healthcare professionals on the subject of cardiomyopathy and related diseases of the heart muscle through the provision of educational learning opportunities and other methods that trustees see fit so as to improve the detection and treatment of such diseases for the public benefit.
- (2) To improve the health of people affected by cardiomyopathy and related diseases of the heart muscle through the promotion and facilitation of research for the public benefit in all aspects of cardiomyopathy and related diseases of the heart muscle by providing networking opportunities for researchers, support and advice to researchers and other means trustees see fit.
- (3) To advance the education of healthcare professionals worldwide through the dissemination of the results of research into cardiomyopathy and related diseases of the heart muscle.
- (4) To improve the health of people affected by cardiomyopathy and diseases of the heart muscle worldwide through the creation, monitoring and development of relevant guidance on the treatment of such diseases.
- (5) To improve the health of people affected by cardiomyopathy worldwide through collaboration with relevant stakeholders in advocating for improved access to treatment for people affected by such diseases.
- (6) To increase awareness of cardiomyopathy and related disorders among the general public and the support and information available to people with cardiomyopathy and related conditions.

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Achievements and performance

In 2024, Trustees were able to make further progress in line with the charity's objectives.

Trustees came together to discuss the impact of the recently published ICoN manifesto and identify ways on which to build on this work. It was agreed that the focus of the charity's next project would be on advocating for improved access to genetic testing. A project plan and funding proposal has been created and shared with potential funders.

Financial review

Trustees are pleased to report that the charity remains financially secure. During the year, expenses have been kept at a minimum and trustees were able to secure around 50% of funds required for the "Improving Access To Genetic Testing" project.

Policy on reserves

The trustees have examined the charity's requirements for reserves in light of the main risks to the organisation. The trustees actively review the major risks that the charity faces on a regular basis and, combined, with the annual review of the controls over key financial systems, will provide sufficient resources in the event of adverse conditions. The trustees have also examined other operational and business risks faced by the charity and confirm that they have established systems to mitigate the significant risks. The trustees have agreed that the charity should aim to have unrestricted reserves roughly equivalent to three months' running costs in order to guard against risk, unexpected fluctuations in income or other emergencies as well as meeting any obligations in the event of closure. At 31 December 2024 the charity has a small unrestricted reserve fund but intends to increase reserves over the next 12 months.

International Cardiomyopathy Network (ICoN)

Trustees' Report

Plans for future periods

Aims and key objectives for future periods

In 2025 ICoN will begin its Improving Access to Genetic Testing project. This project aims to highlight the value of genetic testing in cardiomyopathy, identify gaps in the provision and work with national stakeholders to put in place sustainable strategies to improve access to genetic testing.

There are three main stages to this project. In the research stage, ICoN will work with national partners to gather real world evidence of the state of access to genetic testing for cardiomyopathy across Europe. This data will underpin the creation of and European engagement strategy and policy narrative that clearly articulates the importance of genetic testing in cardiomyopathy, a description of key tests, the place of genetic testing in an idealised pathways and the cost of inaction at an economic, societal and individual level.

The second stage will see ICoN bring together MEPs, health policy influences, healthcare professionals and other stakeholders for a two-day summit in Brussels, comprising a launch event in the European Parliament attended by key stakeholders including MEPs, health policy influences, patient representatives, healthcare professionals. This event will highlight the case for greater investment in genetic testing for cardiomyopathy and work with national stakeholders to identify ways to remove barriers to improving access to testing in their country.

In the final reporting and dissemination phase, ICoN will produce a project report with accompanying video, digital and print resources for dissemination via the ICoN website. ICoN will also produce peer review journal articles to share the evidence collected and key policy arguments.

The key measurable outputs of this 18 month project will be;

1. The collection of data relating to access to genetic testing across at least 10 European countries.
2. The creation of an EU policy engagement strategy.
3. A summit event to share findings and identify national strategies to improve access to testing.
4. The production and dissemination of a project report online, in print, via social media and through the publication of peer review articles in relevant journals.

Trustees are confident that further funding will be received by March 2025 to begin work on this project.

Going concern

The charity has reviewed its financial performance and general reserves position. The charity has adequate financial resources and is able to manage its business risks. The charity's planning process has taken into consideration the current economic climate and its potential impact on the various sources of income and planned expenditure.

Taking into account all factors the charity has reasonable expectation that it has adequate resources to continue in operational existence for the foreseeable future and believe that there are no material uncertainties that call into the charity's ability to continue in operation.

Trustees and officers

The trustees and officers serving during the year and since the year end were as follows:

International Cardiomyopathy Network (ICoN)

Trustees' Report

Trustees:

Dr Juan Ramon Gimeno Blanes

Prof Lucie Carrier

Prof Perry Elliott

Prof Eloisa Arbustini

Prof Iacopo Olivotto

Prof Juan Pablo Kaski

Prof Jolanda Ven Der Velden

Prof Ales Linhart

Dr Aristides Anastasakis

G Limongelli (appointed 23 February 2024)

Chairman:

Prof Perry Elliott

Structure, governance and management

Nature of governing document

The charity is registered as a charitable incorporated organisation (CIO). The members of the CIO are its charity trustees. The only persons eligible to be members of the CIO are its charity trustees. Membership of the CIO cannot be transferred to anyone else. Any member and charity trustee who ceases to be a charity trustee automatically ceases to be a member of the CIO.

Apart from the first charity trustees, every trustee must be appointed for a term of 3 years by a resolution passed at a properly convened meeting of the charity trustees. In selecting individuals for appointment as charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO.

Recruitment and appointment of trustees

The board has the power to appoint additional trustees as it considers fit to do so. None of the trustees has any beneficial interest in the charity.

Induction and training of trustees

Potential trustees are selected on the basis of their personal qualities, commitment and familiarity with the issues involved. New trustees are made familiar with the charity vision, operation and goals by dialogue with existing personnel and provision literature pertaining to charity activity.

All trustees are already familiar with the practical work of the charity. New trustees are encouraged to attend all management committee meetings. Short training sessions (if required) to familiarise new trustees with the charity and the context within which it operates are provided internally.

Organisational structure

The charity is organised so that the trustees meet regularly to manage its affairs. The trustees meet at least quarterly with additional meetings as required. The charity is overseen by the trustees. The organisation operates in the UK from premises in Amersham.

Key strategic and administrative decisions are made by agreement of the trustees, and delegated as appropriate. Day to day management of the charity is supported by Joel Rose, the Chief Executive of Cardiomyopathy UK.

International Cardiomyopathy Network (ICoN)

Trustees' Report

Relationships with related parties

Cardiomyopathy UK (registered charity no. 1164263) provided governance, administrative, fundraising and accountancy support to ICoN during the year for which it was paid £15,000. Prof. Perry Elliott is the President of Cardiomyopathy UK. Both organisations share the goal of advancing the care and treatment of people affected by cardiomyopathy.

Financial instruments

Objectives and policies

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.

Statement of trustees' responsibilities


The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Charity SORP requires the trustees to prepare financial statements for each financial year. The trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including its income and expenditure, of the charity for that period. In preparing these financial statements, the trustees are required to:

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

The trustees are responsible for keeping accounting records that disclose with reasonable accuracy at any time the financial position of the charity. They 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 annual report was approved by the trustees of the charity on and signed on its behalf by:

..... 

Prof Perry Elliott
Chairman and trustee

International Cardiomyopathy Network (ICoN)

Independent Examiner's Report to the trustees of International Cardiomyopathy Network (ICoN) ('the Company')

I report to the charity trustees on my examination of the accounts of the Charity for the year ended 31 December 2024.

Responsibilities and basis of report

As the charity's trustees you are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 ("the Charities Act") and that an independent examination is needed.

Having satisfied myself that the charity is not subject to audit and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act), and
- to state whether particular matters have come to my attention.

Basis of independent examiner's statement

My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

Independent Examiner's statement

In connection with my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did 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 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.

.....
Matthew Hodson FCA
ICAEW

Wiston House
1 Wiston Avenue
Worthing
West Sussex
BN14 7QL

Date:.....

International Cardiomyopathy Network (ICoN)

Statement of Financial Activities for the Year Ended 31 December 2024 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds £	Restricted funds £	Total 2024 £
Income and Endowments from:				
Charitable activities	3	-	40,000	40,000
Investment income	4	25	-	25
Total income		25	40,000	40,025
Expenditure on:				
Raising funds		-	(176)	(176)
Charitable activities	5	(102)	(25,817)	(25,919)
Total expenditure		(102)	(25,993)	(26,095)
Net (expenditure)/income		(77)	14,007	13,930
Net movement in funds		(77)	14,007	13,930
Reconciliation of funds				
Total funds brought forward		186	19,143	19,329
Total funds carried forward	11	109	33,150	33,259
	Note	Unrestricted funds £	Restricted funds £	Total 2023 £
Income and Endowments from:				
Charitable activities	3	26	45,586	45,612
Investment income	4	109	-	109
Total income		135	45,586	45,721
Expenditure on:				
Raising funds		-	(186)	(186)
Charitable activities	5	-	(104,794)	(104,794)
Total expenditure		-	(104,980)	(104,980)
Net income/(expenditure)		135	(59,394)	(59,259)
Net movement in funds		135	(59,394)	(59,259)
Reconciliation of funds				
Total funds brought forward		51	78,537	78,588
Total funds carried forward	11	186	19,143	19,329

All of the charity's activities derive from continuing operations during the above two periods.

The funds breakdown for 2023 is shown in note 11.

The notes on pages 9 to 15 form an integral part of these financial statements.

International Cardiomyopathy Network (ICoN)

Balance Sheet as at 31 December 2024

	Note	2024 £	2023 £
Current assets			
Cash at bank and in hand	9	48,871	19,911
Creditors: Amounts falling due within one year	10	<u>(15,612)</u>	<u>(582)</u>
Net assets		<u>33,259</u>	<u>19,329</u>
Funds of the charity:			
Restricted income funds			
Restricted funds		33,150	19,143
Unrestricted income funds			
Unrestricted funds		<u>109</u>	<u>186</u>
Total funds	11	<u>33,259</u>	<u>19,329</u>

The financial statements on pages 7 to 15 were approved by the trustees, and authorised for issue on
and signed on their behalf by:



.....
Prof Perry Elliott
Chairman and trustee

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2024

1 Charity status

The charity is a Charitable Incorporated Organisation (CIO) and consequently does not have a share capital.

The address of its registered office is:

C/O Cardiomyopathy UK

75a Woodside Road

Amersham

Buckinghamshire

HP6 6AA

[Authorised for issue date](#)

2 Accounting policies

Summary of significant accounting policies and key accounting estimates

The principal accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all the years presented, unless otherwise stated.

Statement of compliance

The financial statements have been prepared in accordance with 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)) (issued in October 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Basis of preparation

International Cardiomyopathy Network (ICoN) meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern nor any significant areas of uncertainty that affect the carrying value of assets held by the charity. The trustees have a reasonable expectation that the charity will continue in operational existence for the foreseeable future. The financial statements have therefore been prepared on a going concern basis.

Income and endowments

Grants receivable

Grants are recognised when the charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2024

Deferred income

Deferred income represents amounts received for future periods and is released to incoming resources in the period for which, it has been received. Such income is only deferred when:

- The donor specifies that the grant or donation must only be used in future accounting periods; or
- The donor has imposed conditions which must be met before the charity has unconditional entitlement.

Investment income

Dividends are recognised once the dividend has been declared and notification has been received of the dividend due.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Raising funds

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees meetings and reimbursed expenses.

Taxation

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2024

Trade creditors

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if the charity does not have an unconditional right, at the end of the reporting period, to defer settlement of the creditor for at least twelve months after the reporting date. If there is an unconditional right to defer settlement for at least twelve months after the reporting date, they are presented as non-current liabilities.

Trade creditors are recognised initially at the transaction price and subsequently measured at amortised cost using the effective interest method.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees discretion in furtherance of the objectives of the charity.

Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Financial instruments

Classification

The charity only has financial assets and 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.

3 Income from charitable activities

	Unrestricted funds General £	Restricted funds £	Total funds £
Project Fund Management	-	40,000	40,000
Total for 2024	-	40,000	40,000
Total for 2023	26	45,586	45,612

4 Investment income

	Unrestricted funds General £	Total funds £
Interest receivable and similar income;		
Interest receivable on bank deposits	25	25
Total for 2024	25	25
Total for 2023	109	109

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2024

5 Expenditure on charitable activities

	Note	Unrestricted funds General £	Restricted funds £	Total funds £
Project Fund Management		-	22,235	22,235
Governance costs	6	102	3,582	3,684
Total for 2024		102	25,817	25,919
Total for 2023		-	104,794	104,794

	Grant funding of activity £	Total expenditure £
Total for 2023	104,146	104,146

In addition to the expenditure analysed above, there are also governance costs of £3,684 (2023 - £648) which relate directly to charitable activities. See note 6 for further details.

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2024

6

Trustees expenses
Other governance costs

Other governance costs

7

Fees to examiners
The examining of the accounts of the charity

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2024

8 Taxation

The charity is a registered charity and is therefore exempt from taxation.

9 Cash and cash equivalents

	2024 £	2023 £
Cash at bank	48,871	19,911

10 Creditors: amounts falling due within one year

	2024 £	2023 £
Trade creditors	15,000	-
Accruals	612	582
	15,612	582

11 Funds

	Balance at 1 January 2024 £	Incoming resources £	Resources expended £	Balance at 31 December 2024 £
Unrestricted funds				
General	186	25	(102)	109
Restricted funds	19,143	40,000	(25,993)	33,150
Total funds	19,329	40,025	(26,095)	33,259
	Balance at 1 January 2023 £	Incoming resources £	Resources expended £	Balance at 31 December 2023 £
Unrestricted funds				
General	51	135	-	186
Restricted funds	78,537	45,586	(104,980)	19,143
Total funds	78,588	45,721	(104,980)	19,329

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2024

12 Analysis of net assets between funds

	Unrestricted funds General £	Restricted funds £	Total funds at 31 December 2024 £
Current assets	721	48,150	48,871
Current liabilities	(612)	(15,000)	(15,612)
Total net assets	109	33,150	33,259
	Unrestricted funds General £	Restricted funds £	Total funds at 31 December 2023 £
Current assets	768	19,143	19,911
Current liabilities	(582)	-	(582)
Total net assets	186	19,143	19,329

13 Related party transactions

During the year the charity made the following related party transactions:

Cardiomyopathy UK

(Cardiomyopathy UK (registered charity no. 1164263) provided governance, administrative, fundraising and accountancy support to ICoN during the year for which it was paid £15,000. Prof. Perry Elliott is the President of Cardiomyopathy UK. Both organisations share the goal of advancing the care and treatment of people affected by cardiomyopathy.)

At the balance sheet date the amount due to Cardiomyopathy UK was £15,000 (2023 - £Nil).

INTERNATIONAL CARDIOMYOPATHY NETWORK

England & Wales - Charity number 1184472

Accounts

Charity registration number: 1184472

International Cardiomyopathy Network (ICoN)

Annual Report and Financial Statements

for the Year Ended 31 December 2023

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International Cardiomyopathy Network (ICoN)

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International Cardiomyopathy Network (ICoN)

Reference and Administrative Details

Chairman	Prof Perry Elliott
Charity Registration Number	1184472
Registered Office	C/O Cardiomyopathy UK 75a Woodside Road Amersham Buckinghamshire HP6 6AA
Independent Examiner	Hodson & Co Wiston House 1 Wiston Avenue Worthing West Sussex BN14 7QL

International Cardiomyopathy Network (ICoN)

Trustees' Report

The trustees, present the annual report together with the financial statements of the charity for the year ended 31 December 2023.

Objectives and activities

Public benefit

The objects of the charity as set out in its governing document are;

(1) To advance the education of healthcare professionals on the subject of cardiomyopathy and related diseases of the heart muscle through the provision of educational learning opportunities and other methods that trustees see fit so as to improve the detection and treatment of such diseases for the public benefit.

(2) To improve the health of people affected by cardiomyopathy and related diseases of the heart muscle through the promotion and facilitation of research for the public benefit in all aspects of cardiomyopathy and related diseases of the heart muscle by providing networking opportunities for researchers, support and advice to researchers and other means trustees see fit.

(3) To advance the education of healthcare professionals worldwide through the dissemination of the results of research into cardiomyopathy and related diseases of the heart muscle.

(4) To improve the health of people affected by cardiomyopathy and diseases of the heart muscle worldwide through the creation, monitoring and development of relevant guidance on the treatment of such diseases.

(5) To improve the health of people affected by cardiomyopathy worldwide through collaboration with relevant stakeholders in advocating for improved access to treatment for people affected by such diseases.

(6) To increase awareness of cardiomyopathy and related disorders among the general public and the support and information available to people with cardiomyopathy and related conditions.

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Achievements and performance

In 2023, Trustees were able to make significant progress in line with their agreed programme of activities. During the year, Trustees worked with the support of independent consultants, The Health Policy Partnership, to create their manifesto for the future of cardiomyopathy care. The manifesto was developed based on desk research and structured interviews with experts in cardiomyopathy and relevant fields, including people living with the condition and their family members, healthcare professionals and industry representatives. The manifesto was officially launched in December 2023 at the 2nd European Symposium on Rare and genetic Cardiovascular Diseases in Naples.

Trustees are pleased to report that the charity's website (www.cardiomyopathy-icon.org) has now been launched. This website will ensure that the charity's educational and policy resources can be accessed by a wider audience.

In addition to this, three online clinical "Heart Muscle Talks" were produced during the year providing easy to access learning opportunities for cardiologist and others with an interest in cardiomyopathy. Talks were recorded and are available on the charity's website.

Financial review

During the year, trustees were able to secure sponsorship from Tenaya Therapeutics to add to support secured in 2022 from three pharmaceutical companies: AstraZeneca, Sanofi and Bristol Myers Squibb and from the biotechnology company, Illumina. The total income received during the year was £46K, was enough to deliver the first phase of its policy setting and strategic development work. Trustees are confident that sponsors will continue to support the charity in 2024.

International Cardiomyopathy Network (ICoN)

Trustees' Report

Policy on reserves

The trustees have examined the charity's requirements for reserves in light of the main risks to the organisation. The trustees actively review the major risks that the charity faces on a regular basis and, combined, with the annual review of the controls over key financial systems, will provide sufficient resources in the event of adverse conditions. The trustees have also examined other operational and business risks faced by the charity and confirm that they have established systems to mitigate the significant risks. The trustees have agreed that the charity should aim to have unrestricted reserves roughly equivalent to three months' running costs in order to guard against risk, unexpected fluctuations in income or other emergencies as well as meeting any obligations in the event of closure. At 31 December 2023 the charity has a small unrestricted reserve fund but intends to increase reserves over the next 12 months.

Plans for future periods

Aims and key objectives for future periods

In 2024, Trustees will aim to build on achievements to date and in particular, explore ways in which to bring about changes called for in its manifesto. Trustees also plan to continue to develop the charity's website and provide further "heart muscle talks" and other learning opportunities for clinicians.

Going concern

The charity has reviewed its financial performance and general reserves position. The charity has adequate financial resources and is able to manage its business risks. The charity's planning process has taken into consideration the current economic climate and its potential impact on the various sources of income and planned expenditure.

Taking into account all factors the charity has reasonable expectation that it has adequate resources to continue in operational existence for the foreseeable future and believe that there are no material uncertainties that call into the charity's ability to continue in operation.

Trustees and officers

The trustees and officers serving during the year and since the year end were as follows:

Trustees:

- Dr Juan Ramon Gimeno Blanes
- Prof Lucie Carrier
- Prof Perry Elliott
- Prof Eloisa Arbustini
- Prof Iacopo Olivotto
- Prof Juan Pablo Kaski
- Prof Jolanda Ven Der Velden
- Prof Ales Linhart
- Dr Aristides Anastasakis

Chairman: Prof Perry Elliott

International Cardiomyopathy Network (ICoN)

Trustees' Report

In memoriam

Trustees are very sorry to report that Professor Claudio Rapezzi, one of the founding members of ICoN, sadly passed away. Claudio was a man of keen intellect, good humour and kindness, and had been a pillar of the cardiomyopathy community for more than three decades. He made a substantial scientific contribution to the field, but will be most remembered as an inspirational teacher and mentor with a lifelong passion for improve the lives of people affected by cardiomyopathy.

Structure, governance and management

Nature of governing document

The charity is registered as a charitable incorporated organisation (CIO). The members of the CIO are its charity trustees. The only persons eligible to be members of the CIO are its charity trustees. Membership of the CIO cannot be transferred to anyone else. Any member and charity trustee who ceases to be a charity trustee automatically ceases to be a member of the CIO.

Apart from the first charity trustees, every trustee must be appointed for a term of 3 years by a resolution passed at a properly convened meeting of the charity trustees. In selecting individuals for appointment as charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO.

Recruitment and appointment of trustees

The board has the power to appoint additional trustees as it considers fit to do so. None of the trustees has any beneficial interest in the charity.

Induction and training of trustees

Potential trustees are selected on the basis of their personal qualities, commitment and familiarity with the issues involved. New trustees are made familiar with the charity vision, operation and goals by dialogue with existing personnel and provision literature pertaining to charity activity.

All trustees are already familiar with the practical work of the charity. New trustees are encouraged to attend all management committee meetings. Short training sessions (if required) to familiarise new trustees with the charity and the context within which it operates are provided internally.

Organisational structure

The charity is organised so that the trustees meet regularly to manage its affairs. The trustees meet at least quarterly with additional meetings as required. The charity is overseen by the trustees. The organisation operates in the UK from premises in Amersham.

Key strategic and administrative decisions are made by agreement of the trustees, and delegated as appropriate. Day to day management of the charity is supported by Joel Rose, the Chief Executive of Cardiomyopathy UK.

International Cardiomyopathy Network (ICoN)

Trustees' Report

Relationships with related parties

Cardiomyopathy UK (registered charity no. 1164263) provided governance, administrative, fundraising and accountancy support to ICoN during the year for which it was paid £15,000. Prof. Perry Elliott is the President of Cardiomyopathy UK. Both organisations share the goal of advancing the care and treatment of people affected by cardiomyopathy.

Financial instruments

Objectives and policies

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.

Statement of trustees' responsibilities

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Charity SORP requires the trustees to prepare financial statements for each financial year. The trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including its income and expenditure, of the charity for that period. In preparing these financial statements, the trustees are required to:

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

The trustees are responsible for keeping accounting records that disclose with reasonable accuracy at any time the financial position of the charity. They 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 annual report was approved by the trustees of the charity on 10.06.2024 and signed on its behalf by:



Prof Perry Elliott
Chairman and trustee

International Cardiomyopathy Network (ICoN)

Independent Examiner's Report to the trustees of International Cardiomyopathy Network (ICoN) ('the Company')

I report to the charity trustees on my examination of the accounts of the Charity for the year ended 31 December 2023.

Responsibilities and basis of report

As the charity's trustees you are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 ("the Charities Act") and that an independent examination is needed.

Having satisfied myself that the charity is not subject to audit and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act), and
- to state whether particular matters have come to my attention.

Basis of independent examiner's statement

My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

Independent Examiner's statement

In connection with my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did 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 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.



Matthew Hodson FCA
ICAEW

Wiston House
1 Wiston Avenue
Worthing
West Sussex
BN14 7QL

Date: 12/06/2024

International Cardiomyopathy Network (ICoN)

Statement of Financial Activities for the Year Ended 31 December 2023 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds £	Restricted funds £	Total 2023 £
Income and Endowments from:				
Charitable activities	4	26	45,586	45,612
Investment income	5	109	-	109
Total income		<u>135</u>	<u>45,586</u>	<u>45,721</u>
Expenditure on:				
Raising funds		-	(186)	(186)
Charitable activities	6	-	(104,794)	(104,794)
Total expenditure		<u>-</u>	<u>(104,980)</u>	<u>(104,980)</u>
Net income/(expenditure)		<u>135</u>	<u>(59,394)</u>	<u>(59,259)</u>
Net movement in funds		135	(59,394)	(59,259)
Reconciliation of funds				
Total funds brought forward		<u>51</u>	<u>78,537</u>	<u>78,588</u>
Total funds carried forward	13	<u>186</u>	<u>19,143</u>	<u>19,329</u>
	Note	Unrestricted funds £	Restricted funds £	Total 2022 £
Income and Endowments from:				
Donations and legacies	3	19	-	19
Charitable activities	4	-	120,306	120,306
Investment income	5	32	-	32
Total income		<u>51</u>	<u>120,306</u>	<u>120,357</u>
Expenditure on:				
Charitable activities	6	-	(41,769)	(41,769)
Total expenditure		<u>-</u>	<u>(41,769)</u>	<u>(41,769)</u>
Net income		<u>51</u>	<u>78,537</u>	<u>78,588</u>
Net movement in funds		<u>51</u>	<u>78,537</u>	<u>78,588</u>
Reconciliation of funds				
Total funds carried forward	13	<u>51</u>	<u>78,537</u>	<u>78,588</u>

All of the charity's activities derive from continuing operations during the above two periods.
The funds breakdown for 2022 is shown in note 13.

The notes on pages 9 to 15 form an integral part of these financial statements.

International Cardiomyopathy Network (ICoN)

Balance Sheet as at 31 December 2023

	Note	2023 £	2022 £
Current assets			
Debtors	10	-	37,202
Cash at bank and in hand	11	19,911	83,102
		<u>19,911</u>	<u>120,304</u>
Creditors: Amounts falling due within one year	12	<u>(582)</u>	<u>(41,716)</u>
Net assets		<u>19,329</u>	<u>78,588</u>
Funds of the charity:			
Restricted income funds			
Restricted funds		19,143	78,537
Unrestricted income funds			
Unrestricted funds		<u>186</u>	<u>51</u>
Total funds	13	<u>19,329</u>	<u>78,588</u>

The financial statements on pages 7 to 15 were approved by the trustees, and authorised for issue on ..10.06.2024.. and signed on their behalf by:



Prof Perry Elliott
Chairman and trustee

The notes on pages 9 to 15 form an integral part of these financial statements.

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2023

1 Charity status

The charity is a Charitable Incorporated Organisation (CIO) and consequently does not have a share capital.

The address of its registered office is:

C/O Cardiomyopathy UK
75a Woodside Road
Amersham
Buckinghamshire
HP6 6AA

These financial statements were authorised for issue by the trustees on 10 June 2024.

2 Accounting policies

Summary of significant accounting policies and key accounting estimates

The principal accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all the years presented, unless otherwise stated.

Statement of compliance

The financial statements have been prepared in accordance with 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)) (issued in October 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Basis of preparation

International Cardiomyopathy Network (ICoN) meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern nor any significant areas of uncertainty that affect the carrying value of assets held by the charity. The trustees have a reasonable expectation that the charity will continue in operational existence for the foreseeable future. The financial statements have therefore been prepared on a going concern basis.

Income and endowments

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

Donations and legacies

Donations are recognised when the charity has been notified in writing of both the amount and settlement date. In the event that a donation is subject to conditions that require a level of performance by the charity before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that these conditions will be fulfilled in the reporting period.

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2023

Grants receivable

Grants are recognised when the charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

Deferred income

Deferred income represents amounts received for future periods and is released to incoming resources in the period for which, it has been received. Such income is only deferred when:

- The donor specifies that the grant or donation must only be used in future accounting periods; or
- The donor has imposed conditions which must be met before the charity has unconditional entitlement.

Investment income

Dividends are recognised once the dividend has been declared and notification has been received of the dividend due.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Raising funds

These are costs incurred in attracting voluntary income, the management of investments and those incurred in trading activities that raise funds.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees meetings and reimbursed expenses.

Taxation

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2023

Trade debtors

Trade debtors are amounts due from customers for merchandise sold or services performed in the ordinary course of business.

Trade debtors are recognised initially at the transaction price. They are subsequently measured at amortised cost using the effective interest method, less provision for impairment. A provision for the impairment of trade debtors is established when there is objective evidence that the charity will not be able to collect all amounts due according to the original terms of the receivables.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Trade creditors

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if the charity does not have an unconditional right, at the end of the reporting period, to defer settlement of the creditor for at least twelve months after the reporting date. If there is an unconditional right to defer settlement for at least twelve months after the reporting date, they are presented as non-current liabilities.

Trade creditors are recognised initially at the transaction price and subsequently measured at amortised cost using the effective interest method.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees discretion in furtherance of the objectives of the charity.

Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Financial instruments

Classification

The charity only has financial assets and 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.

3 Income from donations and legacies

	Unrestricted funds General £	Total funds £
Total for 2023	-	-
Total for 2022	19	19

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2023

4 Income from charitable activities

	Unrestricted funds General £	Restricted funds £	Total funds £
Project Fund Management	26	45,586	45,612
Total for 2023	<u>26</u>	<u>45,586</u>	<u>45,612</u>
Total for 2022	<u>-</u>	<u>120,306</u>	<u>120,306</u>

5 Investment income

	Unrestricted funds General £	Total funds £
Interest receivable and similar income; Interest receivable on bank deposits	109	109
Total for 2023	<u>109</u>	<u>109</u>
Total for 2022	<u>32</u>	<u>32</u>

6 Expenditure on charitable activities

	Note	Restricted funds £	Total funds £
Project Fund Management		104,146	104,146
Governance costs	7	648	648
Total for 2023		<u>104,794</u>	<u>104,794</u>
Total for 2022		<u>41,769</u>	<u>41,769</u>

	Grant funding of activity £	Total expenditure £
Project Fund Management	104,146	104,146
Total for 2022	<u>41,176</u>	<u>41,176</u>

In addition to the expenditure analysed above, there are also governance costs of £648 (2022 - £593) which relate directly to charitable activities. See note 7 for further details.

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2023

7 Analysis of governance and support costs

Governance costs

	Restricted funds £	Total 2023 £
Other governance costs	66	66
	<u>66</u>	<u>66</u>
	Restricted funds £	Total 2022 £
Other governance costs	53	53
	<u>53</u>	<u>53</u>

8 Independent examiner's remuneration

	2023 £	2022 £
Fees to examiners		
The examining of the accounts of the charity	<u>582</u>	<u>540</u>

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2023

9 Taxation

The charity is a registered charity and is therefore exempt from taxation.

10 Debtors

	2023 £	2022 £
Trade debtors	-	37,202

11 Cash and cash equivalents

	2023 £	2022 £
Cash at bank	19,911	83,102

12 Creditors: amounts falling due within one year

	2023 £	2022 £
Trade creditors	-	41,176
Accruals	582	540
	582	41,716

13 Funds

	Balance at 1 January 2023 £	Incoming resources £	Resources expended £	Balance at 31 December 2023 £
Unrestricted funds				
General	51	135	-	186
Restricted funds	78,537	45,586	(104,980)	19,143
Total funds	78,588	45,721	(104,980)	19,329
		Incoming resources £	Resources expended £	Balance at 31 December 2022 £
Unrestricted funds				
General		51	-	51
Restricted funds		120,306	(41,769)	78,537
Total funds		120,357	(41,769)	78,588

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2023

14 Analysis of net assets between funds

	Unrestricted funds General £	Total funds at 31 December 2023 £
Current assets	19,911	19,911
Current liabilities	(582)	(582)
Total net assets	<u>19,329</u>	<u>19,329</u>

	Unrestricted funds General £	Total funds at 31 December 2022 £
Current assets	120,304	120,304
Current liabilities	(41,716)	(41,716)
Total net assets	<u>78,588</u>	<u>78,588</u>

15 Related party transactions

During the year the charity made the following related party transactions:

Cardiomyopathy UK

(Cardiomyopathy UK (registered charity no. 1164263) provided governance, administrative, fundraising and accountancy support to ICoN during the year for which it was paid £15,000. Prof. Perry Elliott is the President of Cardiomyopathy UK. Both organisations share the goal of advancing the care and treatment of people affected by cardiomyopathy.)

At the balance sheet date the amount due to/from to Cardiomyopathy UK was £Nil (2022 - £15,000).

INTERNATIONAL CARDIOMYOPATHY NETWORK

England & Wales - Charity number 1184472

Accounts

Charity registration number: 1184472

International Cardiomyopathy Network (ICoN)

Annual Report and Financial Statements

for the Year Ended 31 December 2022

Hodson & Co
Wiston House
1 Wiston Avenue
Worthing
West Sussex
BN14 7QL

International Cardiomyopathy Network (ICoN)

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International Cardiomyopathy Network (ICoN)

Reference and Administrative Details

Chairman	Prof Perry Mark Elliott
Charity Registration Number	1184472
Registered Office	C/O Cardiomyopathy UK 75a Woodside Road Amersham Buckinghamshire HP6 6AA
Independent Examiner	Hodson & Co Wiston House 1 Wiston Avenue Worthing West Sussex BN14 7QL

International Cardiomyopathy Network (ICoN)

Trustees' Report

The trustees, present the annual report together with the financial statements of the charity for the year ended 31 December 2022.

Objectives and activities

Public benefit

The objects of the charity as set out in its governing document are;

- (1) To advance the education of healthcare professionals on the subject of cardiomyopathy and related diseases of the heart muscle through the provision of educational learning opportunities and other methods that trustees see fit so as to improve the detection and treatment of such diseases for the public benefit.
- (2) To improve the health of people affected by cardiomyopathy and related diseases of the heart muscle through the promotion and facilitation of research for the public benefit in all aspects of cardiomyopathy and related diseases of the heart muscle by providing networking opportunities for researchers, support and advice to researchers and other means trustees see fit.
- (3) To advance the education of healthcare professionals worldwide through the dissemination of the results of research into cardiomyopathy and related diseases of the heart muscle.
- (4) To improve the health of people affected by cardiomyopathy and diseases of the heart muscle worldwide through the creation, monitoring and development of relevant guidance on the treatment of such diseases.
- (5) To improve the health of people affected by cardiomyopathy worldwide through collaboration with relevant stakeholders in advocating for improved access to treatment for people affected by such diseases.
- (6) To increase awareness of cardiomyopathy and related disorders among the general public and the support and information available to people with cardiomyopathy and related conditions.

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Achievements and performance

During the year, Trustees were able to continue their programme of charitable activity and produced six additional online clinical "Heart Muscle Talks" providing easy to access learning opportunities for cardiologist and others with an interest in cardiomyopathy. Talks were recorded and are available on the charity's website at www.cardiomyopathy-icon.org

Trustees had expected to launch their policy development activity in 2022 however this activity has continued to be delayed as trustees, all of whom are senior clinicians, focused on managing the ongoing impact of the COVID-19 pandemic. Trustees did continue to meet throughout the period to develop plans.

Financial review

During the year, trustees were able to secure sponsorship from three pharmaceutical companies: AstraZeneca, Sanofi and Bristol Myers Squibb and from the biotechnology company, Illumina. The total income received, £120K is enough to deliver the first phase of the charity's policy setting and strategic development work. Trustees are confident that sponsors will continue to support the charity in 2023.

Total income for the year was £120,357 with expenditure of £41,769. Unrestricted reserves were £51 and restricted reserves were £78,537. Total reserves at 31 December 2022 were £78,588.

International Cardiomyopathy Network (ICoN)

Trustees' Report

Policy on reserves

The trustees have examined the charity's requirements for reserves in light of the main risks to the organisation. The trustees actively review the major risks that the charity faces on a regular basis and, combined, with the annual review of the controls over key financial systems, will provide sufficient resources in the event of adverse conditions. The trustees have also examined other operational and business risks faced by the charity and confirm that they have established systems to mitigate the significant risks. The trustees have agreed that the charity should aim to have unrestricted reserves roughly equivalent to three months' running costs in order to guard against risk, unexpected fluctuations in income or other emergencies as well as meeting any obligations in the event of closure. At 31 December 2022 the charity has a small unrestricted reserve fund but intends to increase reserves over the next 12 months.

Plans for future periods

Aims and key objectives for future periods

Trustees have contracted the healthcare policy consultancy, Health Policy Partnership (HPP) to undertake the charity's policy setting work during 2023. With the support of HPP, trustees will bring together clinicians, researchers, patients, policy leaders and industry representatives for a series of meetings during the year with the aim of developing and disseminating its policy manifesto.

Trustees will aim to develop ICoN's website and social media presence as well as continuing to provide "heart muscle talks" and other learning opportunities for clinicians.

Going concern

The charity has reviewed its financial performance and general reserves position. The charity has adequate financial resources and is able to manage its business risks. The charity's planning process has taken into consideration the current economic climate and its potential impact on the various sources of income and planned expenditure.

Taking into account all factors the charity has reasonable expectation that it has adequate resources to continue in operational existence for the foreseeable future and believe that there are no material uncertainties that call into the charity's ability to continue in operation.

Trustees and officers

The trustees and officers serving during the year and since the year end were as follows:

Trustees:

- Dr Juan Ramon Gimeno Blanes
- Dr Lucie Carrier
- Prof Perry Mark Elliott
- Prof Eloisa Arbustini
- Professor Iacopo Olivotto
- Dr Juan Pablo Kaski
- Prof Jolanda Ven Der Velden
- Prof Ales Linhart
- Dr Aristides Anastasakis

International Cardiomyopathy Network (ICoN)

Trustees' Report

Chairman: Prof Perry Mark Elliott

Structure, governance and management

Nature of governing document

The charity is registered as a charitable incorporated organisation (CIO). The members of the CIO are its charity trustees. The only persons eligible to be members of the CIO are its charity trustees. Membership of the CIO cannot be transferred to anyone else. Any member and charity trustee who ceases to be a charity trustee automatically ceases to be a member of the CIO.

Apart from the first charity trustees, every trustee must be appointed for a term of 3 years by a resolution passed at a properly convened meeting of the charity trustees. In selecting individuals for appointment as charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO.

Recruitment and appointment of trustees

The board has the power to appoint additional trustees as it considers fit to do so. None of the trustees has any beneficial interest in the charity.

Induction and training of trustees

Potential trustees are selected on the basis of their personal qualities, commitment and familiarity with the issues involved. New trustees are made familiar with the charity vision, operation and goals by dialogue with existing personnel and provision literature pertaining to charity activity.

All trustees are already familiar with the practical work of the charity. New trustees are encouraged to attend all management committee meetings. Short training sessions (if required) to familiarise new trustees with the charity and the context within which it operates are provided internally.

Organisational structure

The charity is organised so that the trustees meet regularly to manage its affairs. The trustees meet at least quarterly with additional meetings as required. The charity is overseen by the trustees. The organisation operates in the UK from premises in Amersham.

Key strategic and administrative decisions are made by agreement of the trustees, and delegated as appropriate. Day to day management of the charity is supported by Joel Rose, the Chief Executive of Cardiomyopathy UK.

International Cardiomyopathy Network (ICoN)

Trustees' Report

Relationships with related parties

Cardiomyopathy UK (registered charity no. 1164263) provided governance, administrative, fundraising and accountancy support to ICoN during the year for which it was paid £15,000. Prof. Perry Elliott is the President of Cardiomyopathy UK. Both organisations share the goal of advancing the care and treatment of people affected by cardiomyopathy.

Financial instruments

Objectives and policies

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.

Statement of trustees' responsibilities

The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Charity SORP requires the trustees to prepare financial statements for each financial year. The trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including its income and expenditure, of the charity for that period. In preparing these financial statements, the trustees are required to:

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

The trustees are responsible for keeping accounting records that disclose with reasonable accuracy at any time the financial position of the charity. They 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 annual report was approved by the trustees of the charity on 7 July 2023 and signed on its behalf by:



Prof Perry Mark Elliott
Chairman and trustee

International Cardiomyopathy Network (ICoN)

Independent Examiner's Report to the trustees of International Cardiomyopathy Network (ICoN) ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 December 2022.

Responsibilities and basis of report

As the charity's trustees you are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 ("the Charities Act") and that an independent examination is needed.

Having satisfied myself that the charity is not subject to audit and is eligible for independent examination, it is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act), and
- to state whether particular matters have come to my attention.

Basis of independent examiner's statement

My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

Independent Examiner's statement

In connection with my examination, no material matters have come to my attention which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did 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 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.



Matthew Hodson FCA
ICAEW

Wiston House
1 Wiston Avenue
Worthing
West Sussex
BN14 7QL

7 July 2023

International Cardiomyopathy Network (ICoN)

Statement of Financial Activities for the Year Ended 31 December 2022 (Including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

	Note	Unrestricted funds £	Restricted funds £	Total 2022 £
Income and Endowments from:				
Donations and legacies	3	19	-	19
Charitable activities	4	-	120,306	120,306
Investment income	5	32	-	32
Total income		51	120,306	120,357
Expenditure on:				
Charitable activities	6	-	(41,769)	(41,769)
Total expenditure		-	(41,769)	(41,769)
Net income		51	78,537	78,588
Net movement in funds		51	78,537	78,588
Reconciliation of funds				
Total funds carried forward	13	51	78,537	78,588
			Note	Total 2021 £
Income and Endowments from:				
Expenditure on:				
Net income/(expenditure)				-
Net movement in funds				-
Reconciliation of funds				
Total funds carried forward			13	-

All of the charity's activities derive from continuing operations during the above two periods. The funds breakdown for 2021 is shown in note 13.

The notes on pages 9 to 15 form an integral part of these financial statements.

International Cardiomyopathy Network (ICoN)

Balance Sheet as at 31 December 2022

	Note	2022 £
Current assets		
Debtors	10	37,202
Cash at bank and in hand	11	<u>83,102</u>
		120,304
Creditors: Amounts falling due within one year	12	<u>(41,716)</u>
Net assets		<u>78,588</u>
Funds of the charity:		
Restricted income funds		
Restricted funds		78,537
Unrestricted income funds		
Unrestricted funds		<u>51</u>
Total funds	13	<u>78,588</u>

The financial statements on pages 7 to 15 were approved by the trustees, and authorised for issue on 7 July 2023 and signed on their behalf by:



Prof Perry Mark Elliott
Chairman and trustee

The notes on pages 9 to 15 form an integral part of these financial statements.

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2022

1 Charity status

The charity is a Charitable Incorporated Organisation (CIO) and consequently does not have a share capital.

The address of its registered office is:

C/O Cardiomyopathy UK
75a Woodside Road
Amersham
Buckinghamshire
HP6 6AA

These financial statements were authorised for issue by the trustees on 7 July 2023.

2 Accounting policies

Summary of significant accounting policies and key accounting estimates

The principal accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all the years presented, unless otherwise stated.

Statement of compliance

The financial statements have been prepared in accordance with 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)) (issued in October 2019) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) and the Companies Act 2006.

Basis of preparation

International Cardiomyopathy Network (ICoN) meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy notes.

Going concern

The trustees consider that there are no material uncertainties about the charity's ability to continue as a going concern nor any significant areas of uncertainty that affect the carrying value of assets held by the charity. The trustees have a reasonable expectation that the charity will continue in operational existence for the foreseeable future. The financial statements have therefore been prepared on a going concern basis.

Income and endowments

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

Donations and legacies

Donations are recognised when the charity has been notified in writing of both the amount and settlement date. In the event that a donation is subject to conditions that require a level of performance by the charity before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that these conditions will be fulfilled in the reporting period.

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2022

Grants receivable

Grants are recognised when the charity has an entitlement to the funds and any conditions linked to the grants have been met. Where performance conditions are attached to the grant and are yet to be met, the income is recognised as a liability and included on the balance sheet as deferred income to be released.

Deferred income

Deferred income represents amounts received for future periods and is released to incoming resources in the period for which, it has been received. Such income is only deferred when:

- The donor specifies that the grant or donation must only be used in future accounting periods; or
- The donor has imposed conditions which must be met before the charity has unconditional entitlement.

Investment income

Dividends are recognised once the dividend has been declared and notification has been received of the dividend due.

Expenditure

All expenditure is recognised once there is a legal or constructive obligation to that expenditure, it is probable settlement is required and the amount can be measured reliably. All costs are allocated to the applicable expenditure heading that aggregate similar costs to that category. Where costs cannot be directly attributed to particular headings they have been allocated on a basis consistent with the use of resources, with central staff costs allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use. Other support costs are allocated based on the spread of staff costs.

Charitable activities

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Support costs

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Governance costs

These include the costs attributable to the charity's compliance with constitutional and statutory requirements, including audit, strategic management and trustees meetings and reimbursed expenses.

Taxation

The charity is considered to pass the tests set out in Paragraph 1 Schedule 6 of the Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes. Accordingly, the charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 of the Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2022

Trade debtors

Trade debtors are amounts due from customers for merchandise sold or services performed in the ordinary course of business.

Trade debtors are recognised initially at the transaction price. They are subsequently measured at amortised cost using the effective interest method, less provision for impairment. A provision for the impairment of trade debtors is established when there is objective evidence that the charity will not be able to collect all amounts due according to the original terms of the receivables.

Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and call deposits, and other short-term highly liquid investments that are readily convertible to a known amount of cash and are subject to an insignificant risk of change in value.

Trade creditors

Trade creditors are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if the charity does not have an unconditional right, at the end of the reporting period, to defer settlement of the creditor for at least twelve months after the reporting date. If there is an unconditional right to defer settlement for at least twelve months after the reporting date, they are presented as non-current liabilities.

Trade creditors are recognised initially at the transaction price and subsequently measured at amortised cost using the effective interest method.

Fund structure

Unrestricted income funds are general funds that are available for use at the trustees discretion in furtherance of the objectives of the charity.

Restricted income funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Financial instruments

Classification

The charity only has financial assets and 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.

3 Income from donations and legacies

	Unrestricted funds General £	Total funds £
Donations and legacies;		
Donations from individuals	19	19
Total for 2022	19	19

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2022

4 Income from charitable activities

	Restricted funds	Total funds
	£	£
Project Fund Management	120,306	120,306
Total for 2022	<u>120,306</u>	<u>120,306</u>

5 Investment income

	Unrestricted funds	Total funds
	General	funds
	£	£
Interest receivable and similar income; Interest receivable on bank deposits	32	32
Total for 2022	<u>32</u>	<u>32</u>

6 Expenditure on charitable activities

		Restricted funds	Total funds
	Note	£	£
Project Fund Management		41,176	41,176
Governance costs	7	593	593
Total for 2022		<u>41,769</u>	<u>41,769</u>

	Grant funding of activity	Total expenditure
	£	£
Project Fund Management	41,176	41,176

In addition to the expenditure analysed above, there are also governance costs of £593 (2021 - £Nil) which relate directly to charitable activities. See note 7 for further details.

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2022

7 Analysis of governance and support costs

Governance costs

	Restricted funds £	Total funds £
Other governance costs	53	53
Total for 2022	53	53

8 Independent examiner's remuneration

Other fees to examiners

The examining of the accounts of the charity

2022
£

540

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2022

9 Taxation

The charity is a registered charity and is therefore exempt from taxation.

10 Debtors

	2022 £ <u>37,202</u>
Trade debtors	

11 Cash and cash equivalents

	2022 £ <u>83,102</u>
Cash at bank	

12 Creditors: amounts falling due within one year

	2022 £ <u>41,176</u>
Trade creditors	
Accruals	<u>540</u>
	<u>41,716</u>

13 Funds

	Incoming resources £	Resources expended £	Balance at 31 December 2022 £
Unrestricted funds			
General	51	-	51
Restricted funds	<u>120,306</u>	<u>(41,769)</u>	<u>78,537</u>
Total funds	<u>120,357</u>	<u>(41,769)</u>	<u>78,588</u>

International Cardiomyopathy Network (ICoN)

Notes to the Financial Statements for the Year Ended 31 December 2022

14 Analysis of net assets between funds

	Unrestricted funds General £	Total funds at 31 December 2022 £
Current assets	120,304	120,304
Current liabilities	<u>(41,716)</u>	<u>(41,716)</u>
Total net assets	<u>78,588</u>	<u>78,588</u>

15 Related party transactions

During the year the charity made the following related party transactions:

Cardiomyopathy UK

(Cardiomyopathy UK (registered charity no. 1164263) provided governance, administrative, fundraising and accountancy support to ICoN during the year for which it was paid £15,000. Prof. Perry Elliott is the President of Cardiomyopathy UK. Both organisations share the goal of advancing the care and treatment of people affected by cardiomyopathy.)

At the balance sheet date the amount due to Cardiomyopathy UK was £15,000 (2021 - £Nil).

INTERNATIONAL CARDIOMYOPATHY NETWORK

England & Wales - Charity number 1184472

Accounts

International Cardiomyopathy Network (ICoN)

Trustees' annual report and financial statements

1st January 2021 – 31st December 2021

The trustees present their report with the financial statements of the charity for the period 1st January 2021 to 31st December 2021.

The trustees have adopted the provisions of 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)

Objectives and Activities

The objects of the charity as set out in its governing document are;

- (1) To advance the education of healthcare professionals on the subject of cardiomyopathy and related diseases of the heart muscle through the provision of educational learning opportunities and other methods that trustees see fit so as to improve the detection and treatment of such diseases for the public benefit.
- (2) To improve the health of people affected by cardiomyopathy and related diseases of the heart muscle through the promotion and facilitation of research for the public benefit in all aspects of cardiomyopathy and related diseases of the heart muscle by providing networking opportunities for researchers, support and advice to researchers and other means trustees see fit.
- (3) To advance the education of healthcare professionals worldwide through the dissemination of the results of research into cardiomyopathy and related diseases of the heart muscle.
- (4) To improve the health of people affected by cardiomyopathy and diseases of the heart muscle worldwide through the creation, monitoring and development of relevant guidance on the treatment of such diseases.
- (5) To improve the health of people affected by cardiomyopathy worldwide through collaboration with relevant stakeholders in advocating for improved access to treatment for people affected by such diseases.
- (6) To increase awareness of cardiomyopathy and related disorders among the general public and the support and information available to people with cardiomyopathy and related conditions.

Achievements and Performance

During the year, Trustees were able to start their programme of charitable activity and produced a series of online clinical "Heart Muscle Talks" providing easy to access learning opportunities for cardiologist and others with an interest in cardiomyopathy. Talks were recorded and are available on the charity's website at www.cardiomyopathy-icon.org

Trustees had originally expected to begin their policy development and strategic planning activity in 2021. By the start of the year, however, it had become clear that plans for this activity would still be delayed by the COVID-19 pandemic, especially as all trustees and the intended beneficiaries of activity hold front line roles in the NHS and other European health services.

Trustees did continue to meet throughout the period to develop plans with these regular meetings also providing a valuable forum for trustees, who represent leading experts in cardiomyopathy throughout Europe, to discuss the impact of the pandemic on people with cardiomyopathy and how different health systems were coping with the needs of cardiomyopathy patients.

Future Plans

Trustees are confident that as the impact of the pandemic eases, they will be able to begin the work of developing national and international health policy positions as well as formalising the organisations long-term strategic plan.

Financial Review

There was no income or expenditure recorded during the reporting period. Since this reporting period, Trustees have been able to secure the support of a number of sponsors from the pharmaceutical industry. Trustees expect that income received in 2022 will be around £100,000.

Structure, Governance and Management

The charity is registered as a charitable incorporated organisation (CIO).

The members of the CIO are its charity trustees. The only persons eligible to be members of the CIO are its charity trustees. Membership of the CIO cannot be transferred to anyone else. Any member and charity trustee who ceases to be a charity trustee automatically ceases to be a member of the CIO.

Apart from the first charity trustees, every trustee must be appointed for a term of 3 years by a resolution passed at a properly convened meeting of the charity trustees. In selecting individuals for appointment as charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO.

Reference and Administrative details

International Cardiomyopathy Network (ICoN)
Registered charity number: 1184472

Correspondence address

C/O Cardiomyopathy UK
75a Woodside Road
Amersham
Buckinghamshire
HP6 6AA

International Cardiomyopathy Network
Trustees' annual report and financial statements 1st January – 31st December 2021

Trustees

Prof. Perry Elliott (UK) - Chair	Appointed July 2019
Dr Aris Anastasakis (Greece)	Appointed July 2019
Prof. Eloisa Arbustini (Italy)	Appointed July 2019
Prof. Iacopo Olivotto (Italy)	Appointed July 2019
Dr Juan Pablo Kaski (UK)	Appointed July 2019
Dr Juan Ramon Gimeno Blanes (Spain)	Appointed July 2019
Prof. Lucie Carrier (Germany)	Appointed July 2019
Professor Jolanda van der Velden (Netherlands)	Appointed April 2021
Prof. Claudio Rapezzi (Italy)	Appointed November 2021
Prof. Ales Linhart (Czech Republic)	Appointed July 2019

Declarations

The Trustees declare that they have approved the trustees' report above. Signed on behalf of the charity's trustees



Prof. Perry Elliott, Chair of Trustees 31st August 2022



CHARITY COMMISSION
FOR ENGLAND AND WALES

International Cardiomyopathy Network	1184472
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Receipts and payments accounts

CC16a

For the period from	01/01/2021	To	31/12/2021
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Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Grants and Donations	0	0	0	0	N/A
Charitable activity	0	0	0	0	N/A
Sub total (Gross income for AR)	0	0	0	0	N/A
A2 Asset and investment sales, (see table).					
	0	0	0	0	N/A
Sub total	0	0	0	0	N/A
Total receipts	0	0	0	0	N/A
A3 Payments					
Fundraising	0	0	0	0	N/A
Charitable activity	0	0	0	0	N/A
Overheads and Administration	0	0	0	0	N/A
Sub total	0	0	0	0	N/A
A4 Asset and investment purchases, (see table)					
	0	0	0	0	N/A
Sub total	0	0	0	0	N/A
Total payments	0	0	0	0	N/A
Net of receipts/(payments)	0	0	0	0	N/A
A5 Transfers between funds	0	0	0	0	N/A
A6 Cash funds last year end	0	0	0	0	N/A
Cash funds this year end	0	0	0	0	N/A

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds		0	0	0
		0	0	0
		0	0	0
	Total cash funds	0	0	0
	(agree balances with receipts and payments account(s))	OK	OK	OK


Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		0	0	0
		0	0	0
		0	0	0
		0	0	0
		0	0	0
		0	0	0

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			0	0
			0	0
			0	0
			0	0
			0	0

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			0	0
			0	0
			0	0
			0	0
			0	0
			0	0
			0	0
			0	0
			0	0

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			0	
			0	
			0	
			0	
			0	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
	Prof. Perry Elliott	31.08.2022

INTERNATIONAL CARDIOMYOPATHY NETWORK

England & Wales - Charity number 1184472

Accounts

International Cardiomyopathy Network (ICoN)

Trustees' annual report and financial statements

18th July 2019 – 31st December 2020

The trustees present their report with the financial statements of the charity for the period 18th July 2019 (the date of registration) to the year ended 31 December 2020.

The trustees have adopted the provisions of 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)

Objectives and Activities

The objects of the charity as set out in its governing document are;

- (1) To advance the education of healthcare professionals on the subject of cardiomyopathy and related diseases of the heart muscle through the provision of educational learning opportunities and other methods that trustees see fit so as to improve the detection and treatment of such diseases for the public benefit.
- (2) To improve the health of people affected by cardiomyopathy and related diseases of the heart muscle through the promotion and facilitation of research for the public benefit in all aspects of cardiomyopathy and related diseases of the heart muscle by providing networking opportunities for researchers, support and advice to researchers and other means trustees see fit.
- (3) To advance the education of healthcare professionals worldwide through the dissemination of the results of research into cardiomyopathy and related diseases of the heart muscle.
- (4) To improve the health of people affected by cardiomyopathy and diseases of the heart muscle worldwide through the creation, monitoring and development of relevant guidance on the treatment of such diseases.
- (5) To improve the health of people affected by cardiomyopathy worldwide through collaboration with relevant stakeholders in advocating for improved access to treatment for people affected by such diseases.
- (6) To increase awareness of cardiomyopathy and related disorders among the general public and the support and information available to people with cardiomyopathy and related conditions.

Achievements and Performance

Trustees had originally expected to begin their programme of charitable activity in January 2020 following registration of the charity in July 2019. By the start of 2020, however, it had become clear to Trustees that all charitable activity should be put on hold given that all trustees and the intended beneficiaries of activity hold front line roles in the NHS and other European health services.

Trustees however did continue to meet throughout the period to develop plans for 2021 on the assumption that pandemic restrictions across Europe would begin to ease in the latter half of that year.

These regular meeting also provided a valuable forum for trustees, who represent leading experts in cardiomyopathy throughout Europe, to discuss the impact of the pandemic on people with cardiomyopathy and how different health systems were coping with the needs of cardiomyopathy patients.

Future Plans

Trustees aim to begin delivering charitable activity in 2021 and will focus on the provision of online learning opportunities for healthcare professionals through a series of short “heart muscle talks”. Trustee also plan to work with relevant partners to deliver an international cardiomyopathy focused conference towards the end of the year.

Trustees will also begin the process of raising income for future activity and raising the profile of the charity through establishing an online presence.

Financial Review

There was no income or expenditure recorded during the reporting period and the charity currently holds no funds. Trustees expect to be in a position to approach potential funders in 2021. It is expected that the primary source of income will come from the pharmaceutical industry.

Structure, Governance and Management

The charity is registered as a charitable incorporated organisation (CIO).

The members of the CIO are its charity trustees. The only persons eligible to be members of the CIO are its charity trustees. Membership of the CIO cannot be transferred to anyone else. Any member and charity trustee who ceases to be a charity trustee automatically ceases to be a member of the CIO.

Apart from the first charity trustees, every trustee must be appointed for a term of 3 years by a resolution passed at a properly convened meeting of the charity trustees. In selecting individuals for appointment as charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO.

Reference and Administrative details

International Cardiomyopathy Network (ICoN)
Registered charity number: 1184472

Correspondence address

C/O Cardiomyopathy UK
75a Woodside Road
Amersham
Buckinghamshire
HP6 6AA


International Cardiomyopathy Network
Trustees' annual report and financial statements 18th July – 31st December 2020

Trustees

Prof. Perry Elliott (UK) - Chair	Appointed July 2019
Dr Aris Anastasakis (Greece)	Appointed July 2019
Prof. Eloisa Arbustini (Italy)	Appointed July 2019
Prof. Iacopo Olivotto (Italy)	Appointed July 2019
Dr Juan Pablo Kaski (UK)	Appointed July 2019
Dr Juan Ramon Gimeno Blanes (Spain)	Appointed July 2019
Prof. Lucie Carrier (Germany)	Appointed July 2019
Prof. Ales Linhart (Czech Republic)	Appointed July 2019
Professor Jolanda van der Velden (Netherlands)	Appointed April 2021

Declarations

The Trustees declare that they have approved the trustees' report above. Signed on behalf of the charity's trustees

Signature  Date 26th October 2021

Prof. Perry Elliott, Chair of Trustees



CHARITY COMMISSION
FOR ENGLAND AND WALES

International Cardiomyopathy Network 1184472

Receipts and payments accounts

CC16a

For the period from 18/07/2019 To 31/12/2020

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Grants and Donations	0	0	0	0	N/A
Charitable activity	0	0	0	0	N/A
Sub total (Gross income for AR)	0	0	0	0	N/A
A2 Asset and investment sales, (see table).					
Sub total	0	0	0	0	N/A
Total receipts	0	0	0	0	N/A
A3 Payments					
Fundraising	0	0	0	0	N/A
Charitable activity	0	0	0	0	N/A
Overheads and Administration	0	0	0	0	N/A
Sub total	0	0	0	0	N/A
A4 Asset and investment purchases, (see table)					
Sub total	0	0	0	0	N/A
Total payments	0	0	0	0	N/A
Net of receipts/(payments)	0	0	0	0	N/A
A5 Transfers between funds	0	0	0	0	N/A
A6 Cash funds last year end	0	0	0	0	N/A
Cash funds this year end	0	0	0	0	N/A

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds		0	0	0
		0	0	0
		0	0	0
	Total cash funds	0	0	0
	(agree balances with receipts and payments account(s))	OK	OK	OK


Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		0	0	0
		0	0	0
		0	0	0
		0	0	0
		0	0	0
		0	0	0

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			0	0
			0	0
			0	0
			0	0
			0	0

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			0	0
			0	0
			0	0
			0	0
			0	0
			0	0
			0	0
			0	0
			0	0

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			0	
			0	
			0	
			0	
			0	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
	Perry ELLIOTT	26th Oct 2021