

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)**

## **Contents**

Reference and Administrative Details	1
Trustees' Report	2 to 5
Independent Examiner's Report	6
Statement of Financial Activities	7
Balance Sheet	8
Notes to the Financial Statements	9 to 15

# **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 £
<b>Income and Endowments from:</b>				
Charitable activities	3	-	40,000	40,000
Investment income	4	25	-	25
Total income		25	40,000	40,025
<b>Expenditure on:</b>				
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
<b>Reconciliation of funds</b>				
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 £
<b>Income and Endowments from:</b>				
Charitable activities	3	26	45,586	45,612
Investment income	4	109	-	109
Total income		135	45,586	45,721
<b>Expenditure on:</b>				
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)
<b>Reconciliation of funds</b>				
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 £
<b>Current assets</b>			
Cash at bank and in hand	9	48,871	19,911
<b>Creditors: Amounts falling due within one year</b>	10	<u>(15,612)</u>	<u>(582)</u>
<b>Net assets</b>		<u>33,259</u>	<u>19,329</u>
<b>Funds of the charity:</b>			
<b>Restricted income funds</b>			
Restricted funds		33,150	19,143
<b>Unrestricted income funds</b>			
Unrestricted funds		<u>109</u>	<u>186</u>
<b>Total funds</b>	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
<b>Total for 2024</b>	-	40,000	40,000
<b>Total for 2023</b>	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
<b>Total for 2024</b>	25	25
<b>Total for 2023</b>	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
<b>Total for 2024</b>		102	25,817	25,919
<b>Total for 2023</b>		-	104,794	104,794

	Grant funding of activity £	Total expenditure £
<b>Total for 2023</b>	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 £
<b>Unrestricted funds</b>				
General	186	25	(102)	109
<b>Restricted funds</b>	19,143	40,000	(25,993)	33,150
<b>Total funds</b>	19,329	40,025	(26,095)	33,259
	Balance at 1 January 2023 £	Incoming resources £	Resources expended £	Balance at 31 December 2023 £
<b>Unrestricted funds</b>				
General	51	135	-	186
<b>Restricted funds</b>	78,537	45,586	(104,980)	19,143
<b>Total funds</b>	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).