

Charity registration number: 1184472

# International Cardiomyopathy Network (ICoN)

Annual Report and Financial Statements

for the Year Ended 31 December 2023

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**

<b>Chairman</b>	Prof Perry Elliott
<b>Charity Registration Number</b>	1184472
<b>Registered Office</b>	C/O Cardiomyopathy UK 75a Woodside Road Amersham Buckinghamshire HP6 6AA
<b>Independent Examiner</b>	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](http://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 Olivetto  
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**

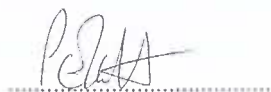
The trustees are responsible for preparing the trustees' report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

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 £
<b>Income and Endowments from:</b>				
Charitable activities	4	26	45,586	45,612
Investment income	5	109	-	109
Total income		135	45,586	45,721
<b>Expenditure on:</b>				
Raising funds		-	(186)	(186)
Charitable activities	6	-	(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	13	186	19,143	19,329
	Note	Unrestricted funds £	Restricted funds £	Total 2022 £
<b>Income and Endowments from:</b>				
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
<b>Expenditure on:</b>				
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
<b>Reconciliation of funds</b>				
Total funds carried forward	13	51	78,537	78,588

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

# **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
<b>Total for 2023</b>	<b>26</b>	<b>45,586</b>	<b>45,612</b>
<b>Total for 2022</b>	<b>-</b>	<b>120,306</b>	<b>120,306</b>

#### 5 Investment income

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

#### 6 Expenditure on charitable activities

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

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

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 £
<b>Fees to examiners</b>		
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
	<u>582</u>	<u>41,716</u>

#### 13 Funds

	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>	<u>78,537</u>	<u>45,586</u>	<u>(104,980)</u>	<u>19,143</u>
<b>Total funds</b>	<u>78,588</u>	<u>45,721</u>	<u>(104,980)</u>	<u>19,329</u>
		Incoming resources £	Resources expended £	Balance at 31 December 2022 £
<b>Unrestricted funds</b>				
General		51	-	51
<b>Restricted funds</b>		<u>120,306</u>	<u>(41,769)</u>	<u>78,537</u>
<b>Total funds</b>		<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 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).

