

Trustees Report for Insulinoma Charity UK (ICUK)

For the Year Ending 31 December 2024

1. Introduction

The Trustees of Insulinoma Charity UK (ICUK) are pleased to present the Directors' Report for the financial year 2024. ICUK was officially registered as a UK charity in September 2023, building upon 17 years of dedicated support for patients and families. ICUK remains the only UK charity solely dedicated to insulinomas, a rare neuroendocrine tumour.

Our organisation is run entirely by volunteers - patients, carers, and advocates—ensuring all donations are used to support our mission.

2. Objectives and Public Benefit

ICUK's primary objectives are:

- To provide support and information to individuals diagnosed with an insulinoma and their families.
- To raise awareness of insulinomas among healthcare professionals and the general public.
- To fund and promote research into the causes, diagnosis, and treatment of insulinomas.
- To advocate for improved diagnostic tools and treatments in the UK, including access to new therapies.

These activities provide direct public benefit, aligning with the UK Charity Commission's guidelines.

3. Achievements in 2024

3.1. Expansion of Patient Support Services

- Established and manage the UK's largest online insulinoma support network, with dedicated groups for:
 - Suspected Insulinomas
 - Malignant Insulinomas
 - Diagnosed Insulinomas
- Created additional groups to support patients with:
 - Insulinomatosis
 - Proinsulinoma
 - Noninsulinoma Pancreatogenous Hypoglycaemia Syndrome (NIPHS)
- Provided one-to-one support for UK patients diagnosed with metastatic insulinoma.

3.2. Medical Partnerships and Advocacy

- Partnered with leading UK-based neuroendocrine tumour (NET) specialists, including:
 - Professor Martyn Caplin BSc (HONS), DM, FRCP, a leading expert in gastroenterology & neuroendocrinology.
 - Neuroendocrine Cancer UK to improve patient education and advocacy.
 - The Children's Hyperinsulinism Charity, collaborating on overlapping challenges.

- Rezolute, a late-stage biopharmaceutical company developing RZ358, a promising therapy for insulinoma
- Helped develop the UK-recognised protocol for the 72-hour fasting test, a key diagnostic tool for insulinoma

3.3. Research and Policy Initiatives

- Launched the Insulinoma Research Project to improve understanding of patient journeys and influence

3.4. Education and Awareness

- Developed a UK-focused website featuring:
 - Comprehensive educational materials
 - Patient stories to support lived-experience advocacy
 - Downloadable guides, including the “Managing Malignant Insulinomas Guide”.
- Published “My Insulinoma”, a collection of patient experiences, to increase understanding of insulinoma
- Launched a quarterly newsletter sharing updates on research, policy developments, and patient support
- Raised public awareness across Facebook, Instagram, Threads, BlueSky, and TikTok.

3.5. Fundraising and Financial Sustainability

- Secured £6,992 through fundraising initiatives, allowing ICUK to:
 - Support UK-based insulinoma research
 - Expand online support services
 - Continue awareness and advocacy efforts

4. Financial Review

ICUK operates on a volunteer-only model, ensuring 100% of donations go towards patient support, education, and research.

For the year ending 31 December 2024:

- Total income: £6,992
- Total expenditure: £0
- Reserves: £6,992

ICUK maintains an appropriate reserve policy to ensure sustainability while maximising the impact of donations.

5. Governance and Compliance

ICUK is registered with the Charity Commission for England and Wales and fully adheres to UK charity law.

The Board of Trustees meets regularly to oversee governance, financial management, and strategic planning.

6. Future Plans for 2025 and Beyond

ICUK aims to:

- Advocate for the first UK NET Specialist Centre to offer RZ358 (ersodetug) for metastatic insulinomas
- Develop an insulinoma-specific UK helpline for direct patient support.
- Increase patient and clinician education through webinars and events.
- Strengthen fundraising efforts to support new research projects.

7. Acknowledgements

The Trustees extend their sincere gratitude to our volunteers, donors, and medical advisors, whose dedication and support has made this report possible. Your support is transforming the lives of those affected by insulinomas in the UK.

8. Approval

This report was approved by the Board of Trustees on 3 February 2025 and signed on behalf of Insulinoma Charity UK.

Enola Wright

Chairperson

Insulinoma Charity UK (ICUK)

Insulinoma@googlemail.com

Charity Commission Annual Return 2024

INSULINOMA CHARITY UK

Charity registration number: 1204926

Most of the information you give in this form will become publicly available on the Register of Charities. Any field that the Charity Commission will not display will be clearly marked.

This document is a record of the information provided in the Annual Return 2024.

Financial period

Financial period start date

26/09/2023

Financial period end date

05/04/2024

Income and spending

Income £

£6,992

Spending £

£0

Number of contracts from government

How many contracts (other than grant agreements) did your charity receive from central government or a local authority during the financial period for this return?

0

Number of grants from government

How many grants did your charity receive from central government or a local authority during the financial period for this return?

0

Income breakdown

Donations and legacies (excluding Endowments Received)

£6,947

Charitable activities

£45

Other trading activities

£0

Investments

£0

Other

£0

Recipients of grants

Please round all figures to the nearest pound (do not enter decimal points or commas).Individuals

£0

Other charities

£0

Other organisations that are not charities

£0

Trustee payments

Excluding out of pocket expenses, for what were any of the trustees paid during the financial period for this return?

☒ e. None of the trustees have been paid

Did any of the trustees resign and take up employment with your charity in the financial period of this return?

No

Income from outside the UK

Did your charity receive income from outside of the United Kingdom in the financial period of this return?

No

Delivering activities outside the United Kingdom

Did your charity deliver charitable activities outside of the United Kingdom in the financial period of this return?

No

Spending outside England & Wales

Did your charity spend funds outside of the United Kingdom in the financial period of this return?

No

Trading subsidiaries

Does the charity have any trading subsidiaries?

No

Charity contact details correct

Is the contact address displayed from the Register of Charities, correct?

Yes

Charity headquarters details correct

Is this the same address that you use as your charity's administrative headquarters?

Yes

Charity contact address

96 EMPRESS AVENUE

WEST MERSEA

COLCHESTER

ESSEX

CO5 8BL

Charity Headquarters address

96 EMPRESS AVENUE

WEST MERSEA

COLCHESTER

ESSEX

CO5 8BL

Membership type

Is your charity part of a wider group structure with a parent body and subsidiary bodies?

no, the charity is not part of a wider group structure

Employment contract types

People were permanently employed by your charity

0

People were on fixed-terms contracts with your charity

0

Self-employed people were working for your charity

0

Governance policies

Internal charity financial controls policy and procedures

Yes

Safeguarding policy and procedures

Yes

Financial reserves policy and procedures

Yes

Complaints policy and procedures

Yes

Serious incident reporting policy and procedures

Yes

Internal risk management policy and procedures

Yes

Trustee expenses policy and procedures

Yes

Trustee conflicts of interest policy and procedures

Yes

Investing charity funds policy and procedures

Not applicable

Campaigns and political activity policy and procedures

Not applicable

Bullying and harassment policy and procedures

Yes

Social media policy and procedures

Yes

Engaging external speakers at charity events policy and procedures

Yes

External risk and impact**Donations,**

Unknown/No Change/Not Applicable

Other income - grants

Unknown/No Change/Not Applicable

Other income - contracts

Unknown/No Change/Not Applicable

Other income - investment

Unknown/No Change/Not Applicable

Expenditure on charitable activities

Unknown/No Change/Not Applicable

Expenditure on overheads

Unknown/No Change/Not Applicable

Number of volunteers

Unknown/No Change/Not Applicable

Number of employees

Unknown/No Change/Not Applicable

Number of trustees

Unknown/No Change/Not Applicable

Fundraising activities

Unknown/No Change/Not Applicable

Capacity to deliver services

Unknown/No Change/Not Applicable

Total service demand

Unknown/No Change/Not Applicable

Volunteers

Excluding trustees, provide an estimate of the number of volunteers who carried out charitable activities on behalf of your charity in the United Kingdom during the financial period of this return?

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Privacy statement

Any information you give us will be held securely and processed only in accordance with the rule on data protection. We will not disclose your personal details to anyone unconnected to the Charity Commission unless:

- you have consented to their release; or
- we are legally obliged to disclose them; or
- we regard disclosure as either (a) necessary so that we can properly carry out our statutory functions or (b) necessary in the public interest.

We may share and disclose information about you with relevant public authorities, regulatory bodies and agencies, outside the Charity Commission but only if:

- we can lawfully do so; and
- we decide that disclosure is necessary for national security, crime detection, prevention, and law enforcement, or other issues in the public interest

Information we collect about you

We will use this information:

To enable us to carry out our statutory functions and duties;

This will include the following actions:

- (a) update, consolidate, and improve the accuracy of our records;
- (b) undertake crime detection and prevention and law enforcement and assist the third parties specified above to investigate or prevent crime and carry out law enforcement;
- (c) data analysis, testing, research, statistical and survey purposes

Information we receive from other sources.

Information we receive from other sources

We may combine this information with information you give to us and information we collect about you.

We may use this information and the combined information for the purposes set out above (depending on the types of information we receive).

We will ensure that any such disclosure and use is proportionate; considers your right to respect for your private life; and is done fairly and lawfully in accordance with the data protection principles of the Data Protection Act.

The Data Protection Act 1998 regulates the use of 'personal data', which is essentially any information, however stored, about identifiable living individuals.

As a 'data controller' under the Act, the Charity Commission must comply with it. Any changes we may make to our privacy statement in the future will be set out in the replacement version of this form.

Please check back frequently to see any updates or changes to our privacy policy.

Declaration

Your role at the charity (select one):

☒ Trustee

Given names

Enola Patricia

Family name

Wright

Telephone number	07944790580
Email	insulinoma@googlemail.com
Date submitted	29/11/2024

It is a criminal offence under section 60 of the Charities Act 2011 for anyone to knowingly or recklessly provide false or misleading information to the commission; this includes suppressing, concealing or destroying documents.