

INSULINOMA CHARITY UK

England & Wales · Charity number 1204926

Details

Status Registered

Legal form CIO

Registered 2023-09-26

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

Contact

Address 96 Empress Avenue
West Mersea
Colchester
Essex
CO5 8BL

Phone 01206386343

Email insulinoma@googlemail.com

Website www.insulinoma.co.uk

Activities

Objects: THE RELIEF OF PERSONS SUFFERING OR AT RISK OF SUFFERING FROM INSULINOMA AND THEIR FAMILIES BY ADVANCING THE EDUCATION OF THE PUBLIC, INCLUDING MEDICAL PRACTITIONERS, IN ALL ASPECTS OF INSULINOMA BY PROMOTING RESEARCH INTO ITS CAUSES, AND TREATMENT AND BY DISSEMINATING THE USEFUL RESULTS OF SUCH RESEARCH.

Activities: We provide support, education, and advocacy for individuals and families affected by an insulinoma, a rare type of neuroendocrine tumour. Operating throughout the UK, we offer peer support groups, evidence-based resources, patient-friendly summaries of clinical guidelines, and promote research to improve care and awareness. Our work empowers patients and enhances treatment outcomes.

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, The Advancement Of Health Or Saving Of Lives
- **Who:** The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-05	£4,112	£1,056	-	-
2024-04-05	£6,992	£0	-	-

Trustees

Name	Role	Appointed
Enola Patricia Wright	Chair	2023-09-26
Andrew Derek Davis		2026-02-23
Peter David Collins		2023-09-26

INSULINOMA CHARITY UK

England & Wales - Charity number 1204926

Accounts



Trustees' Annual Report for the period

From **06/04/2024** Period start date To **05/04/2025** Period end date

Charity name: **Insulinoma Charity UK**

Charity registration number: **1204926**

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	Insulinoma Charity UK exists to relieve sickness and preserve health by supporting people affected by insulinoma and related neuroendocrine tumours. The charity aims to raise awareness of insulinoma, improve understanding of the condition among patients, families, and professionals, and provide information, advocacy, and support to those impacted. The charity also seeks to promote education and public awareness of rare endocrine conditions to improve diagnosis, care, and outcomes.
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	During the period, the charity focused on awareness raising, patient support, and information sharing. Activities included providing guidance and signposting to individuals affected by insulinoma, sharing lived experience stories to improve public and professional understanding, and supporting families navigating complex diagnostic and treatment pathways. The charity also engaged with patients and carers to reduce isolation and ensure that accurate, accessible information about insulinoma was available to those who need it.
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	The trustees have had due regard to the Charity Commission's guidance on public benefit. The activities undertaken during the period were carried out to benefit people affected by insulinoma and the wider public by increasing awareness of a rare condition, supporting informed decision making, and promoting earlier recognition and understanding of symptoms.

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	The charity does not operate a grant making programme and does not make personal financial grants to individuals. Any payments made are strictly for services provided, such as the preparation and sharing of lived experience material and are documented and proportionate.
Policy on social investment including program related investment	Para 1.38	The charity has not undertaken any social investments during the period.
Contribution made by volunteers	Para 1.38	The charity relies significantly on voluntary input. Trustees and volunteers contribute time, expertise, and lived experience to support beneficiaries, develop resources, and raise awareness of insulinoma.
Other		

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	During the period, Insulinoma Charity UK established a clear presence as a support and awareness organisation for people affected by insulinoma. The charity supported individuals and families during diagnosis and treatment, shared personal stories to raise awareness of rare disease impact, and helped reduce isolation for those affected. The work undertaken contributed to greater understanding of insulinoma and highlighted the real-world challenges faced by patients and carers.

Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	The charity successfully delivered its core objectives of awareness raising and patient support during the period, despite being at an early stage of development.
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<p>Performance of fundraising activities against objectives set</p>	<p>Para 1.41</p>	<p>Fundraising activity during the period was limited and primarily involved voluntary donations via online platforms. No formal fundraising campaigns were undertaken.</p>
<p>Investment performance against objectives</p>	<p>Para 1.41</p>	<p>The charity did not undertake any investments during the reporting period. Accordingly, there is no investment performance to report against objectives. The trustees' approach during the period was to hold funds as cash only, ensuring liquidity and prudent financial management while the charity remains at an early stage of development. This approach was consistent with the charity's objectives and risk management priorities.</p>
<p>Other</p>		

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	At the end of the period, the charity's financial position consisted solely of unrestricted funds held in cash. All funds were held either directly by the charity or temporarily on its behalf by the JustGiving platform. No payments, asset purchases, or investments were made during the period.
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	The trustees have reviewed the charity's reserves policy. Given the early stage of the charity and its current scale of activity, funds are held to meet short term operational needs and to ensure continuity of charitable activities.
Amount of reserves held	Para 1.22	£6,992
Reasons for holding zero reserves	Para 1.22	N/A
Details of fund materially in deficit	Para 1.24	None
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	The trustees consider Insulinoma Charity UK to be a going concern and believe it has adequate resources to continue its activities for the foreseeable future.

Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	The charity's principal source of funds during the period was voluntary donations received via online fundraising platforms.
Investment policy and objectives including any social investment policy adopted	Para 1.46	The charity does not currently operate an investment policy. All funds are held as cash.
A description of the principal risks facing the charity	Para 1.46	The trustees have identified the charity's principal risks as reliance on voluntary income, limited resources, and trustee capacity. These risks are mitigated through careful financial oversight, prudent decision making, and gradual, sustainable development of activities.
Other		

Structure, Governance and Management

Description of charity's trusts:		Insulinoma Charity UK does not operate or administer any trusts. The charity does not hold funds on trust for specific beneficiaries or purposes beyond its general charitable objectives. All funds received are held and applied in accordance with the charity's governing document and Charity Commission regulations.
Type of governing document (trust deed, royal charter)	Para 1.25	Insulinoma Charity UK is constituted as an unincorporated association and is governed by its constitution.
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	Unincorporated association
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Appointed by founding trustee Enola Wright

Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	Trustees receive induction appropriate to their role and are supported to understand their legal duties and responsibilities under charity law.
The charity's organisational structure and any wider network with which the charity works	Para 1.51	The charity is trustee led and operates without paid staff. Trustees collectively manage strategy, governance, and operations.
Relationship with any related parties	Para 1.51	There are no undisclosed related party transactions.
Other		

Reference and Administrative details

Charity name	Insulinoma Charity UK
Other name the charity uses	None
Registered charity number	1204926

Charity's principal address	96 Empress Ave West Mersea Colchester CO5 8BL

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Enola Patricia Wright	Founder		Enola Patricia Wright
2	Peter David Collins	Treasurer		
3	Paula Anne Davies	Secretary		

Corporate trustees – names of the directors at the date the report was approved

Director name		
N/A		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	
N/A		

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	The charity did not hold any funds or other assets as custodian trustee on behalf of others during the reporting period.
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	Not applicable, as no assets were held on behalf of another charity or third party.
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	Not applicable. As no custodial assets were held, there were no arrangements required for custody or segregation beyond the charity's standard financial controls for its own funds.

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Exemptions from disclosure

Reason for non-disclosure of key personnel details

The charity has not disclosed detailed information about key personnel in order to protect personal privacy and security. Given the small size of the charity and the limited number of individuals involved in its governance and operations, the trustees consider that disclosure of detailed personal information is not necessary for transparency and could place individuals at risk. This approach is consistent with Charity Commission guidance and data protection principles.

Other optional information

During the reporting period, the charity continued to operate at an early stage of development, focusing on establishing sound governance, compliance with Charity Commission requirements, and a clear framework for future activity. The trustees remained mindful of proportionality, ensuring that resources were used effectively and in line with the charity's objects. The charity did not employ staff during the period and relied on trustee and volunteer input to deliver its activities.

Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)	<i>Enola Wright</i>	<i>P Collins</i>
Full name(s)	Enola Patricia Wright	Peter David Collins
Position (eg Secretary, Chair, etc)	Founder	Treasurer
Date	12 January 2026	



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name Insulinoma Charity UK	No (if any) 1204926
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Receipts and payments accounts

For the period from	Period start date 06/04/2024	To	Period end date 05/04/2025
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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					
Initial donation	-	-	-	-	250
Corporate donations	-	-	-	-	200
Insulinoma e-Book proceeds	4	-	-	4	45
Private donations	3,650	-	-	3,650	1,150
Just Giving funds - Enola Wright	-	-	-	-	1,127
Just Giving funds - Insulinoma Charity UK	4,605	-	-	4,605	4,220
Adjustment - Just Giving funds - Insulinoma Charity UK - amount incorrectly shown as receipt in A1 Receipts in 2024 and in B2 Other Monetary Asset in 2024 - receipt was actually post Year End in 2024	- 4,220	-	-	- 4,220	-
Deposit Account Interest	73	-	-	73	-
Sub total (Gross income for AR)	4,112	-	-	4,112	6,992
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	4,112	-	-	4,112	6,992
A3 Payments					
Fund raising event costs/fees	900	-	-	900	-
Software and Website fees/licenses	156	-	-	156	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	1,056	-	-	1,056	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	1,056	-	-	1,056	-
Net of receipts/(payments)	3,056	-	-	3,056	6,992
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	3,056	-	-	3,056	6,992

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	Co-operative Bank - Current Account	725	-	-
	Co-operative Bank - Deposit Account	9,323	-	-
		-	-	-
	Total cash funds	10,048	-	-
	(agree balances with receipts and payments account(s))	Agreement Error	OK	OK

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

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

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

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

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
		Enola Wright	17/12/2025
		Peter Collins	17/12/2025

INSULINOMA CHARITY UK

England & Wales - Charity number 1204926

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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 ending 31 December 2024. ICUK was officially registered as a UK charity in September 2023, building upon 17 years of dedicated support for patients and their 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**Number of employees****Number of trustees****Fundraising activities****Capacity to deliver services****Total service demand**

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?

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.