

# ROHHAD Association

Scotland · Charity number SC045645

## Details

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Status	Active
Legal form	SCIO (Scottish Charitable Incorporated Organisation)
Registered	2015-05-28
Register	<a href="#">View on the OSCR register</a>

## Contact

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Address	11A Lomond Crescent Alexandria G83 0RJ
Website	<a href="http://www.rohhadassociation.com">www.rohhadassociation.com</a>

## Activities

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**Activities:** 'It carries out activities or services itself'

**Purposes:** 'the advancement of education', 'the advancement of health', 'the saving of lives', 'the relief of those in need by reason of age, ill-health, disability, financial hardship or other disadvantage'

**What the charity does:** The Rohhad Association supports people affected by ROHHAD Syndrome through improved quality of life initiatives, raising awareness, and advancing research. We work closely with the ROHHAD International Consortium—founded by our co-founder Elisabeth Hunter during the COVID pandemic—and collaborate with charities worldwide, including ROHHAD Fight Inc, ROHHAD Association Argentina, Belgium, and Nordic. Each year, our core activities include awareness campaigns, fundraising, advocacy, forming strategic partnerships, hosting online support groups, providing one-to-one peer and family support, and funding ongoing research with teams within the Consortium.

**Beneficiaries:** 'Children or young people', 'People with disabilities or health problems', 'Other defined groups'

**Objectives:** The organisations purposes are: The Saving of Lives by funding and promoting research that will lead to new understanding and treatments, and brings us closer to a cure for the rare medical condition ROHHAD The advancement of health by funding and promoting research that will lead to new understanding and treatments, and brings us closer to a cure for the rare medical condition ROHHAD. The relief of those in need by providing support for those suffering with ROHHAD, their carers, families and siblings. The advancement of Education by funding and promoting research that will lead to new understanding and treatments and brings us closer to finding a cure for the rare medical condition ROHHAD. The ROHHAD association will achieve the 4 purposes detailed above by embarking on an extensive raising awareness campaign so that the needs of the children(and rarely adults) with ROHHAD and everyone who cares for them are recognised by wider society. The ROHHAD association will also embark on an extensive fundraising campaign.

## Geography

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- **Main operating location:** West Dunbartonshire
- **Geographical spread:** UK and overseas

## Finances

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Period end	Income	Expenditure	Assets	Employees
2025-05-31	£33,227	£11,103	-	0
2024-05-31	£15,075	£3,824	-	0
2023-05-31	£42,605	£16,483	-	0
2022-05-31	£52,417	£64,191	-	0
2021-05-31	£24,849	£180,160	-	0

**ROHHAD Association**

Scotland - Charity number SC045645

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# Accounts

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## **Independent Examiner's Report**

Report to the members of Rohhad Association

On the accounts for the year ended 31 May 2025

### **Respective Responsibilities of Trustees and Examiner**

The charity's trustees are responsible for the preparation of the accounts in accordance with the terms of the Charities and Trustee Investment (Scotland) Act 2005 and The Charities Accounts (Scotland) Regulations 2006 (as amended). The charity trustees consider that the audit requirement of Regulation 10 (1) (a) to (c) of the 2006 Accounts Regulations does not apply. It is my responsibility to examine the accounts as required under section 44 (1) (c) of the Act and to state whether particular matters have come to my attention.

### **Basis of Independent Examiner's Statement**

My examination is carried out in accordance with Regulation 11 of the 2006 accounts regulations. 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 seeks 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 I do not express an audit opinion on the view given by the accounts.

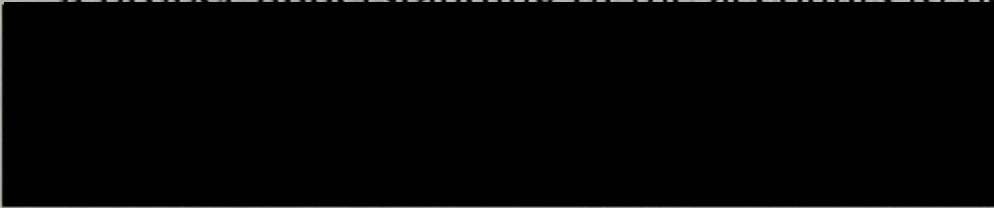
### **Independent Examiner's Statement**

In the course of my examination, no matter has come to my attention.

1. which gives me reasonable cause to believe that in any material respect the requirements:
  - . to keep accounting records in accordance with Section 44(1) (a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations.
  - . to prepare accounts which accord with the accounting records and comply with Regulation 8 of the 2006 Accounts Regulations.

have not been met, or

to which in my opinion, attention should be drawn in order to enable  
a proper understanding of the accounts to be reached.

Name: -----

Lomond Accountants Ltd

480 Main Street

Bonhill

G83 9HY

Date:---5 February 2026-----

ROHHAD Association  
 Receipts and Payments accounts from  
 1st of June 2024 to 31st of May 2025

SC045645

**Section A Statement of Receipts and Payments**

	Unrestricted Funds	Restricted Funds	Expendable Endowment Funds	Permanent Endowment Funds	Total Funds Current Period	Total Funds Last Period
	To nearest £	To Nearest £	To nearest £	To nearest £	To nearest £	To nearest £

**A1 Receipts**

Donations	£8,895				£8,895	£2,408
Legacies	£0				£0	
Grants	£0				£0	
Receipts from fundraising activities	£23,354				£23,354	£11,883
Gross Trading Receipts	£0				£0	
Rents from land & buildings	£0				£0	
Gross Receipts from other charitable	£0				£0	
Loan Repayment	£0				£0	
Bank Account Interest	£978				£978	£784
<b>A1 Sub Total</b>	<b>£33,227</b>	<b>£0</b>	<b>£0</b>	<b>£0</b>	<b>£33,227</b>	<b>£15,075</b>

**A2 Receipts from Asset and Investment sales**

Proceeds from Sale of fixed Assets	£0.00				£0	
Proceeds from Sale of Investments	£0.00				£0	
<b>A2 Subtotal</b>	<b>£0.00</b>				<b>£0</b>	
<b>TOTAL RECEIPTS</b>	<b>£33,227</b>				<b>£33,227</b>	<b>£15,075</b>

**A3 Payments**

Expenses for fundraising activities	£5,019				£5,019	£3,608
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Gross Trading payments	£0				£0	
Investment management costs	£0				£0	
Payments relating directly to charitable activities	£0				£0	
Grants and Donations	£4,590				£4,590	£0
Governance Costs	£0				£0	
Audit/ independent examination	£0				£0	
Preparation of Annual accounts	£228				£228	£216
Legal Costs	£1,266				£1,266	
Other/bank charges	£0.00				£0	
<b>A3 subtotal</b>	<b>£11,103</b>	<b>£0</b>	<b>£0</b>	<b>£0</b>	<b>£11,103</b>	<b>£3,824</b>

ROHHAD Association  
Receipts and Payments accounts from  
1st of June 2024 to 31st of May 2025

SC045645

**Section A Statement of Receipts and Payments continued**

**A4 payments relating to asset and Investment movements**

Purchases and Fixed Assests	£0.00				£0.00	
Purchase of Investments	£0.00				£0.00	
<b>A4 sub total</b>	<b>£0.00</b>				<b>£0.00</b>	

					Current Period	
<b>Total Payments</b>	<b>£11,103</b>				<b>£11,103</b>	<b>£3,824</b>
<b>Net Receipts / (Payments)</b>	<b>£33,227</b>				<b>£33,227</b>	<b>£15,075</b>
<b>A5 Transfers to/ (from) funds</b>						<b>£0.00</b>
<b>Last Period Surplus</b>						
<b>Surplus / (deficit) for Year</b>	<b>£22,098</b>				<b>£22,098</b>	<b>£11,251</b>

**Section B Statement of Balances**

<b>Unrestricted Funds</b>	<b>Restricted Funds</b>	<b>Expendable Endowment Funds</b>	<b>Permanent Endowment Funds</b>	<b>Total Funds Current Period</b>	<b>Total Funds Last Period</b>
To nearest £	To Nearest £	To nearest £	To nearest £	To nearest £	To nearest £

**B1 Cash Funds**

**Details**

Cash and bank balances at start of year	£66,299				£66,299	
Income over the year	£33,227				£33,201	
Surplus/ deficit over the year	£11,103				£11,103	
<b>Cash and Bank Balances at end of year</b>	<b>£88,423</b>				<b>£88,423</b>	

**B2 Investments**

**Details**

Details	Fund to which asset belongs			Market Valuation		Last year
					£0	£0
				<b>Total</b>	<b>£0</b>	<b>£0</b>

ROHHAD Association

SC045645

Receipts and Payments accounts from

1st of June 2024 to 31st of May 2025

**Section B Statement of Balances continued**

**B3 Other Assests**

**Details**

Details	Fund to which Asset belongs			Cost	Current value	Last year
				£0	£0	£0

			<b>Total</b>	£0	£0	£0
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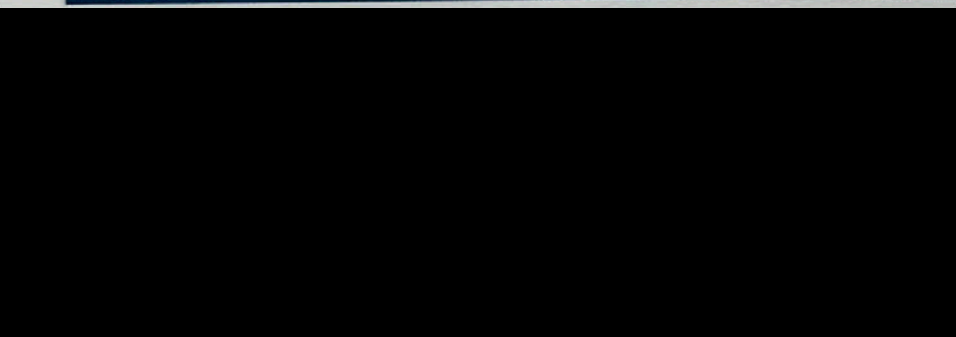
**B4 Liabilities**

Details	Fund to which liability relates			Amount due	Last year
SLA - Ind exam & Acocunts					£0
					£0
			<b>Total</b>		£0

**B5 Contingent Liabilities**

Details	Fund to which asset belongs			Amount due	Last year
					£0
					£0
			<b>Total</b>		£0

**Signatures of the Trustees and Independent Reviewer**

Printed Name	Signature	Date of Approval
		15th February 2026
		15th February 2026
		15th February 2026
		15th FEBRUARY 2026

**Section C Notes To Accounts**

**C1 Nature and Purpose of funds**

The saving of Lives by funding and promoting research that will lead to new understanding And treatments and brings us close to a cure for the rare medical condition ROHHAD. The Advancement of health by funding and promoting research that will lead to new Understanding and treatments, and bring us closer to a cure for the rare medical condition ROHHAD. The relief of those in need by providing support for those suffering with ROHHAD Their carers, famlles and siblings. The advancement of education by funding and promoting research that will lead to new understanding and treatments, and bring us closer To finding a cure for the rare medical condition ROHHAD. The ROHHAD Association will achieve the 4 purposes detailed above by embarking on an extensive raising awareness campaign so that the needs of the children and (rarely adults) with ROHHAD and Everyone who cares for them are recognised by wider society. The ROHHAD Association Will also embark on an extensive fundraising campaign.

**C2 Grants**

Type of Grant Awarded	Name of Institute/Lead consultant or scientist	No of grants	£ awarded
		Made	
	Professor Datanni- GOSH European Collaboration additional funding awarded	1	£4,590.00

**C3a Trustee Remuneration**

<b>If No remuneration was paid during the period to any charity trustee or Person connected to a trustee cross this box (otherwise complete section 3b)</b>	<b>X</b>
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**C3b Trustee Remuneration Details**

<i>Authority under which paid</i>	<b>£</b>
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**C4a Trustee expenses**

<b>If no expenses were paid to any charity trustee during the period then Cross this box otherwise complete section 4b</b>	<b>X</b>
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**C4b Trustee expenses details**

<i>Details of Expenses including no of trustees</i>	<b>£</b>
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**C5 Transactions with trustees and Connected persons/ authorised**

<b>None</b>	
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**C6 Other Information**

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# ROHHAD Association Trustees' Annual Report and Accounts for the Year Ended 31 May 2025

## Charity Information and Trustees' Report

### ROHHAD Association

Scottish Charity Number: SC045645

Charity's Principal Address:

11A Lomond Crescent

Alexandria

G83 0RJ

### Trustees

- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]

### Charity Structure and Incorporation

The ROHHAD Association is a Scottish Charitable Incorporated Organisation (SCIO), registered with OSCR on 28th May 2015.

### Trustee Resignation

Trustee resignations are completed in accordance with the OSCR regulations for Scottish Charitable Incorporated Organisations. During the year, **Natasha Rotchford** resigned as a trustee.

### Charitable Purposes and Objectives

The ROHHAD Association exists to further the following charitable purposes:

- The advancement of education
- The advancement of health
- The saving of lives
- The relief of those in need by reason of age, ill health, disability, financial hardship or other disadvantage.

The principal objectives are:

- To save lives by funding and promoting research that will lead to new understanding and treatments and bring us closer to a cure for the rare medical condition ROHHAD.
- To advance health by funding and promoting research that will lead to new understanding and treatments and bring us closer to a cure for ROHHAD.
- To relieve those in need by providing support for individuals suffering with ROHHAD, as well as their carers, families, and siblings.
- To advance education by funding and promoting research, supporting increased understanding and treatment options, and moving towards a cure for ROHHAD.

In pursuit of these objectives, the Association undertakes extensive awareness campaigns to ensure that the needs of children (and rarely adults) affected by ROHHAD, along with those who care for them, are recognised by wider society. Additionally, the Association runs extensive fundraising campaigns to support its charitable aims.

### Accounting Date

The accounting date for the ROHHAD Association is 31 May annually.

### Activities and Achievements Summary

Throughout the year, the trustees met regularly, including holding the Annual General Meeting (AGM). Various awareness and fundraising campaigns were conducted in line with the trustees' intentions for implementing the ROHHAD Association as a registered SCIO. Key activities included the annual charity ball, local community events, family fundraisers, and awareness initiatives such as the Easter Fayre. The Association also organised online fundraisers and maintained ongoing online support groups, offering support to families engaged in fundraising or raising awareness. The annual Rare Disease Day campaign was a significant event in the calendar, and the Association continued close collaboration with the RIC ROHHAD International Consortium. Funding was provided for further research within current projects, and a new research proposal was considered and agreed for funding.

[For more detailed information about activities, achievements, and the impact on children, adults, and families affected by ROHHAD Syndrome, please refer to the full Trustees' Report attached below.](#)

### Banking and Reserves

The Royal Bank of Scotland served as the Association's bank during the accounting period. Banking and reserve provisions adhered to the financial benchmarks agreed by the trustees, with all funds held on a no-risk cash basis.

All funds within the General Fund are unrestricted.

### Trustees' Remuneration and Expenses

The trustees did not receive any remuneration or expenses during the year.

## Financial Overview

Gross income from donations and other activities in the accounting period totalled £33,227.00

## Approval by the Charity Trustees

The annual report and accounts have been approved by the trustees as follows:

- [Redacted] Date: 15/02/2026
- [Redacted] Date: 15/02/2026
- [Redacted] Date: 15/02/2026
- [Redacted] Date: 15/09/2026

## Independent Examination:

The accounts have been independently checked and verified by:

Mr John McEwan  
Lomond Accountants Ltd  
480 Main Street  
Bonhill  
G83 9HY

~~Signature John McEwan:~~ N/A ↑ Date: N/A

(Prepared 5th February please see  
signed  
Independent  
examiners  
Report)

# Trustees Annual Report Continued:

ROHHAD Association: Detailed Activities and Achievements for Year Ending May 2025

## Introduction

The Trustees of the ROHHAD Association are pleased to present the Annual Report for the period from June 2024 to May 2025. This report provides a more comprehensive overview of our activities, achievements, and the impact we have made on children, adults, and families affected by ROHHAD syndrome over the past year.

## About the ROHHAD Association

The ROHHAD Association is dedicated to supporting individuals living with Rapid-Onset Obesity with Hypothalamic Dysfunction, Hypoventilation, and Autonomic Dysregulation (ROHHAD). Our mission is to improve the quality of life for those affected, raise awareness, and advance research into the condition. We collaborate with the ROHHAD International Consortium (RIC) and related charities, including ROHHAD Fight Inc (USA), ROHHAD Association Belgium, ROHHAD Association Argentina, and ROHHAD Nordic.

## Activities During the Year

- **Awareness Campaigns:** Throughout the year, we organised several awareness campaigns across the UK, Ireland and globally. These included social media initiatives, community events, and collaborations with medical professionals to promote understanding of ROHHAD. Our "ROHHAD Awareness Week" in November 2024 saw participation from schools, hospitals, and local communities, significantly increasing public knowledge about the syndrome. Our "Rare Disease Day Campaign on Social Media" in February 2025 saw us sharing blogs written by patients, family members and siblings again aiding a more in depth understanding of ROHHAD for all who continue to support our charity. We utilised other forms of media including written press, radio and news articles both on television and in print when we could. During Live fundraising events, brochures, and detailed speeches were made for guests to be able to understand why we have asked for their help.
- **Support Services:** We continued in our dedication to the support services for families and individuals affected by ROHHAD. This included running, monitoring and participating in the support groups, and individual support sessions using video calls and emails when requested. We also utilised our social media

platforms to share vital information about ROHHAD research projects. Throughout the year we have provided a platform for sharing experiences and advice, fostering a sense of community and belonging among members.

- ***Advocacy and Partnerships:*** The Association worked closely with healthcare providers, researchers, and policymakers to advocate for better care and resources for ROHHAD patients. We participated and actively contributed within the ROHHAD International Consortium which we proudly founded during the global pandemic. We agreed to join the Endocrine Registries working group EuRREB and agreed in principle to fund the development of the registry as well as contribute to the Dataset that will be a key component of the vital registry. We also agreed in principle to work collaboratively and support the new clinical guidelines for ROHHAD management, which is an ongoing project into this financial year to.
- ***Research Funding and Collaboration:*** We continued our commitment to supporting research into ROHHAD by providing ongoing funding to one of our projects this year and by considering a new project which has since been funded in the next financial year. This project is called “ROHHAD Lived Experience Qualitative Study” via the university of Bristol. Our partnership with various university research teams within the UK and Europe enabled progress in understanding the genetic and environmental factors contributing to the syndrome. We continue to raise vital funds for further ROHHAD Research and for current ROHHAD Research to continue, our global teams in the USA that we previously funded are also in need of substantial funding for the projects to continue as is the European team whose project is still underway.
- ***Fundraising Events, Family events and Community Building:*** The Association hosted several fundraising family and community events, throughout 2024-2025 and continue to do so. These events included the annual ROHHAD Charity Ball, a Family Easter Fayre, and annual psychic evening. These events provided opportunities for families to connect, share experiences, and build lasting friendships. We continued to actively encourage families globally to participate and organise their own fundraisers via our social media pages and the ROHHAD International Consortium Families team. Some families did participate and organised their own fundraising events which we supported with merchandise and brochures when we could as well as letters of support. We entered a team into the Glasgow Kilt walk that raised money via sponsorship and we supported other sponsorship physical events carried out via our Just Giving Page. We held

online fundraisers via our social media pages including a raffle to win a used Rolex watch that was kindly gifted for the Association to Raffle at our Annual Charity Ball. Fundraisers alone raised £23,354.00 before costs to run events which totalled £5019.00 meaning a total of £18,335.00 profit from fundraising will all go directly to ROHHAD Research. Donations from charity supporters totalled £8,895.00.

- **Educational Outreach:** - We met with a research team to discuss creating a PDF handout, an information brochure, and a clear care pathway for children, adults, families, and professionals dealing with ROHHAD. Standards of care vary widely worldwide, and clear guidelines are often lacking for rare diseases like ROHHAD. As a charity, we support developing these educational tools to improve understanding and support. We also recommend producing a child-friendly PDF in simple language, possibly including a story to help young patients understand their condition and how to manage it. This is an ongoing project from 2024 until now and one we will fully support until developed and then continue to update as a deeper understanding of ROHHAD occurs via Research.

## Achievements

- **Increased Awareness:** Our campaigns reached over tens of thousands of people across the UK, Ireland and globally with positive engagement from the public and medical community.
- **Enhanced Support Network:** The continuation of support services resulted in greater awareness and an increase in family engagement and satisfaction. Many families reported feeling less isolated and more empowered to manage their challenges especially those we worked with individually. Many have also commented and reported on the benefits of the 24/7 online support group.
- **Influence on Healthcare Policy:** Our advocacy efforts contributed to the inclusion of ROHHAD in rare disease policy discussions within the UK, which we hope will improve access to specialist care for patients.
- **Advancement in Research:** The research projects we have funded and supported have yielded promising preliminary results. Those preliminary results have also strengthened and highlighted the need for further research. Other global ROHHAD Research has also yielded some very interesting results and led to further research with the ZSCAN1 autoantibodies which is emerging as a promising, specific biomarker for diagnosing ROHHAD Syndrome. This has not

yet been confirmed so further funding is required and a few of the Research Teams we currently support within Europe, and the USA are continuing in the ZSCAN1 autoantibodies research.

- **Community Strengthening:** Our events, awareness activities, ongoing funding of research and ongoing support groups both in person and online continue to foster stronger relationships among families, helping them to share resources and support each other through difficult times.

## Impact on ROHHAD Children, Adults, and Families

The activities and achievements of the ROHHAD Association have had a profound impact on those affected by ROHHAD. Children and adults received improved support, access to information, and opportunities to connect with others facing similar challenges. Family members benefited from increased emotional support and practical guidance, helping them to navigate the complexities of the syndrome with greater confidence.

Feedback from our families highlights the value of the Association's work. Many have expressed gratitude for the sense of community and the practical help received. Our continued efforts to raise awareness and fund research have given hope for future advances in care and treatment.

## Looking Ahead

As we move into the next year, the ROHHAD Association remains committed to its mission. We aim to further expand our support services, strengthen partnerships with the medical community, and continue our advocacy for better care. We will also seek new opportunities to fund research and provide educational resources to those who need them most. We will achieve this by ongoing fundraising events and awareness campaigns.

## Conclusion

On behalf of the Trustees, we thank all the children, adults and families directly affected by a diagnosis of ROHHAD, our charity supporters, and all those actively involved in ROHHAD Research as well as our fellow members of the ROHHAD International Consortium and sister charities for their dedication and hard work over the past year. Together, we have made meaningful progress in supporting the ROHHAD community and will continue to strive for even greater achievements in the year ahead.