

Trustee's Annual Report
for the Period

01 January 2025 to 31 December 2025

For The Mikaere Foundation

CONTENTS OF THE FINANCIAL STATEMENTS

for the Period **01 January 2025 to 31 December 2025**

- 1 Reference and administration details
- 2 Structure, Governance and Management
- 3 Objectives and Activities
- 4 Achievements and Performance
- 5 Financial Review
- 6 Declaration
- 7 Receipts and Payments Accounts
- 8 Statement of assets and liabilities at the end of the period
- 9 Balance Sheet

REFERENCE AND ADMINISTRATION DETAILS

ORGANISATION NAME

Mikaere Foundation

CHARITIES COMMISSION REFERENCE NUMBER

1200720

HMRC CHARITIES REFERENCE NUMBER

ZD09269

REGISTERED ADDRESS

90 York Rd
London
SW11 3GT

TRUSTEES

CHAIR:	Melanie Gedye
TREASURER:	Kirsty Lester
SECRETARY:	Sam Hulance
TRUSTEE:	Wendy Hulance
TRUSTEE:	Andy Hulance
TRUSTEE:	Tony Collins
TRUSTEE:	Jamie Irving (Resigned 25 March 2025)
TRUSTEE:	Sreeram Ramagopalan (Joined 30 October 2025)

STRUCTURE, GOVERNANCE AND MANAGEMENT

TYPE OF GOVERNING DOCUMENT

CIO Foundation Constitution

HOW THE CHARITY IS CONSTITUTED

Charitable Incorporated Organisation (CIO) Foundation, with 7 Trustees

TRUSTEE SELECTION METHOD

Appointed by the chairperson.

ADDITIONAL GOVERNANCE INFORMATION

All Trustees give their time voluntarily and receive no remuneration or other benefits.

OBJECTIVES AND ACTIVITIES

OBJECTS OF THE CHARITY

The object of the CIO is to relieve the need by reason of ill health of persons with Nonketotic Hyperglycinemia/Glycine Encephalopathy, in particular, but not exclusively by the provision of support, advice, grants and information for such persons, their families, carers and/or those working with affected individuals.

SUMMARY OF THE MAIN ACTIVITIES UNDERTAKEN FOR THE PUBLIC BENEFIT IN RELATION TO THESE OBJECTS

The Mikaere Foundations beneficiaries include the estimated 50-100 families living with NKH in the UK. There isn't (yet) a registry of people diagnosed with NKH. The incidence of NKH in the UK is estimated to be 1 in 76,000 people.

In planning the strategy for the upcoming year, the trustees have kept the Charity Commission's guidance on public benefit and our duty to the Equality Act in mind, specifically in our Trustees' meetings and will continue to do so moving forward.

This year we regretfully accepted Jamie Irving's resignation as Trustee, and welcomed Sreeram Ramagopalan on board. With Ram's experience in the research/pharmaceutical sector we're excited to be more strategic with our research funding.

The charity has deepened our partnerships with Professor Nick Greene at UCL and Professor Johan van Hove at the University of Colorado. Both featured in our Christmas Campaign, and we created a Mikaere Foundation fund with the University of Colorado. We've worked with both to understand the current state of NKH Research and continue to fund projects in line with our objectives.

We launched nkh.org, a digital version of our NKH Informational Booklet, working again with Prof Nick Greene (NKH Research lead at UCL) and Dr James Davison (Chair of the British Inherited Metabolic Diseases Group, Metabolic Consultant at Great Ormond St Hospital) to help with the medical content. Both our booklet and nkh.org are accredited by the Patient Information Forum for trusted health information content.

We also have new resources in the works to support newly diagnosed families, and we hope to publish these in the next year.

We held two NKH Family Meet Ups, one in May in Bristol and one in November in Warwick. These meet ups offer connection, emotional support and provide a safe space to share struggles, find empathy and reduce isolation for families. It also provides an opportunity for families to pool knowledge and share practical resources/tips for raising a child with NKH.

These two meet ups were wonderful for all involved, and the community response we received was also positive. By providing opportunities like this, we hope to strengthen relationships and support within the NKH Community and families living with NKH.

ADDITIONAL DETAILS OF OBJECTIVES AND ACTIVITIES

Donation Channels:

The charity has joined several donation platforms which allow our community to donate/raise funds. This year we added Enthuse to the line up.

Partnerships:

The charity has maintained partnerships with The Ultra Challenge Series, Skyline, the London Landmark Half Marathon and the London Marathon which allow our community to raise funds for the Mikaere Foundation in exchange for a partly paid registration fee/discount. We also have a partnership with Free Wills as part of our legacy giving programme.

We've also entered into a partnership with the Run for Charity organisation, which we hope will provide more opportunities for families to fundraise across a wider number of events across the UK.

We are now registered with the Fundraising Regulator, and commit to safe, fair and transparent fundraising. We continue to be a member of the Chartered Institute of Fundraising, the membership body of UK Fundraising, to improve our skills and ensure we're being efficient and effective with the resources we have.

We've also joined the Genetic Alliance UK/Rare Disease UK and the Gene People partnership network, so we can give children and families impacted by NKH a voice within a national coalition whose influence is respected, and shapes policy, research, and NHS services for rare conditions.

Volunteers:

We took on a handful of volunteers this year to help with grants, collection tins, marketing and website support. We're grateful to each one for their contribution to our cause, and we moved further this year because of their generosity with their time and skills.

ACHIEVEMENTS AND PERFORMANCE

SUMMARY OF THE MAIN ACHIEVEMENTS OF THE CHARITY DURING THE YEAR

Income

A total of £51,658.16 was raised during this financial year. This comprises both personal donations and royalties donated by the Books for Wednesdays organisation, and was split as follows:

- Direct Donations - £4,628.36
- Books for Wednesdays Royalties - £716.20
- CSR Corporate Programmes - £1,456.96
- Donations from events/community fundraising - £38,932.09
- Investments/Interest - £720.81
- Grants - £5,203.74

Fundraising Events

Fundraising highlights include:

- Events, such as The NKH 100 Mile Challenge, the London Landmarks Half Marathon, The Halloween Walk, UWCB fights (with special mention to Dayle Browse), the NKH Awareness Day Drive, Kai's 9th Birthday Raffle and the The Christmas Appeal
- Corporate support by Bazaarvoice with b:generous week, Creative Equals and the many organisations that supported Kai's 9th Birthday Raffle
- Special thanks to Belinda Freeman, Laura Sayin (and family, in honour of Teo) and Rossana Tortora (in honour of Aurora) who were super supporters this year.
- Additional thank you to the NKH Community (Emma Gilmore and Margaret Jones in honour of Charlie, Nigel Gravelle, Jack Davies and family, in honour of Freya, Emma and Kris Moore and family, in honour of Mason, Evita Duage in honour of Alex, Samuel Humberto in honour of Reese) for their fundraising efforts.
- Memorials in honour of Kai Hulance, and Hugh Nicolson.

We also have several regular donors ("The Hive") who donate each month, either directly or via payroll giving with employee matching. We're grateful for their continued and ongoing support.

Research Events

We have continued our partnership with UCL and our team under Prof Nick Greene and with the University of Colorado and the team under Johan Van Hove. There have been several research updates, documented at mikaerefoundation.org/research-updates. It's the belief of the trustees that our goals are best served by continuing to support the work done at UCL under Prof. Nick Greene and Prof. Johan van Hove, and as such we granted £23,500.00 towards NKH Research. £17,000 to UCL and £6,500 to the University of Colorado.

FINANCIAL REVIEW

BRIEF STATEMENT OF THE CHARITIES POLICY ON RESERVES

Surplus funds are held in the charity's bank account to meet any unforeseen expenditure, working capital and potential grants. All expenditure decisions are taken in line with the Charity's Reserve Policy, in line with our Financial Controls Policy.

The year started with £25,356.45 in the charity accounts. At the end of the financial year we held £41,643.25, which is over the reserve amount of £5,000.00 due a few different factors: as yet unspent restricted grant funds, research grants due to be granted, and we are waiting for the 95 day grace period to pass before transferring the memorial funds to an investment fund.

This will be rectified early in the next financial year.

DETAILS OF ANY FUNDS MATERIALLY IN DEFICIT

n/a.

FURTHER FINANCIAL REVIEW DETAILS

The principal sources of funds were donations and fundraising events, and across this financial period we raised £51,658.16, and had £35,371.36 in outgoings.

Outgoings:

Research Grants (£23,500.00)

We gave grants for NKH Research to UCL (£17,000.00) and the University of Colorado (£6,500.00). This is where the bulk of our outgoings was spent.

Family Support (£1,373.33)

These costs included the NKH Family Meet Ups and the NKH Information Resources. For the Family Meet Ups we had a sponsor generously gift half the costs, with the families paying the other half. The costs associated with the NKH Information Resources (such as the PIF Tic accreditation) were funded via a grant from the Lifetimes Charity.

Charity Costs (£1,424.58)

This includes costs needed to meet our legal obligations as a charity, such as accountancy and insurance, as well as other costs, such as our website. For some of these costs we were able to get a grant. We worked hard to keep these costs as low as possible.

Fundraising/event investment (£9,073.45)

Our investment in fundraising and fundraising events had a positive return again this year. For example:

- We use the My Virtual Mission platform for the NKH 100 Mile Challenge, which is charged per user. We invested £238.70, which included platform costs and t-shirts (which participants paid for if they wanted one). We raised £4,452.04.
- We had five participants walk with the Ultra Challenge events, costing £281.30 (for places and shirts) and we raised £2,351.00.
- We invested £412.60 into a fundraising raffle (which included non-sponsored prizes, licences and prize postage), and we raised £1,510.00.
- We invested £1,990.11 into the 2025 LLHM event, which included places, shirts and cheer station paraphernalia (which we can use each year moving forward, and at other events/meet ups), and we raised £7,052.70. We've invested in more places for 2026 (17, up from 12), and expect to see a bigger return. Similarly, we've also invested in 4 places with the London Marathon, and expect to see an equally positive return.

Investment/Interest

While we did our due diligence with starting an investment fund, we held the memorial funds in a long term (95 days) savings reserve to generate interest in the meantime and have requested the funds to be transferred across. Understandably, this will take 95 days, of which we are only part way through.

We are calling our investment fund 'The Forever Fund', as some families have donated funds to build a legacy for their loved ones. These funds are not spent and are instead invested in perpetuity, with the returns to be used in line with the charity objectives. Only gifts that have explicitly requested to be added to the Forever Fund have been used in this way.

THE MIKAERE FOUNDATION POUND BREAKDOWN

For every pound we spent in the financial year 01 January 2025 - 31 December 2025:

- 66p was spent on NKH Research
- 26p was spent on Fundraising Events
- 4p was spent on Family Support
- 4p was spent on Charity costs.

For every £1 that was spent on fundraising, we generated £2.73 in returns.

This fundraising investment includes things such as London Landmark Half Marathon and London Marathon Places, Ultra Challenge event places, Raffles, the NKH 100 Mile Challenge platform etc

DECLARATION

THE TRUSTEES DECLARE THEY HAVE APPROVED THE TRUSTEES REPORT ABOVE

The charity is a Charitable Incorporated Organisation (CIO) registered with the Charity Commission for England and Wales (registered charity number 1200720) and is governed by its Constitution.

The accounts have been prepared on a Receipts and Payments basis in accordance with section 133 of the Charities Act 2011, which permits non-company charities with gross income of £250,000 or less to prepare accounts on this basis.

The charity is not subject to statutory audit. As gross income for the year exceeded £25,000, the accounts are subject to independent examination under section 145 of the Charities Act 2011.

The trustees acknowledge their responsibilities for:

- A. ensuring that the charity keeps proper accounting records in accordance with section 130 of the Charities Act 2011; and
- B. preparing a Trustees' Annual Report and accounts which comply with the requirements of the Charities Act 2011 and the Charities (Accounts and Reports) Regulations 2008, and which are consistent with the charity's Constitution.

The trustees confirm that, to the best of their knowledge, the Trustees' Annual Report and the accompanying Receipts and Payments Account and Statement of Assets and Liabilities give a fair summary of the financial activities and position of the charity for the period 1 January 2025 to 31 December 2025.

The Trustees' Annual Report and accounts were approved by the trustees on 04 May 2026 and signed on their behalf by:



Full name: M Gedye

Position: Chair

Date: 04 May 2026

INDEPENDENT EXAMINERS REPORT TO THE TRUSTEES OF THE MIKAERE FOUNDATION

I report to the Trustees on my examination on the accounts of the charity for the year ended 31st December 2025

Respective responsibilities of trustees and examiner

As the charity's trustees you are responsible for the preparation of the accounts: you consider that the audit requirement of section 144(2) of the Charities Act 2014 (the Act) does not apply and that an independent examination is needed.

It is my responsibility to:

- examine the accounts (under section 145 of the Act);
- to follow the procedures specified in the General Directions given by the Charity Commissioners under section 145(5)(b) of the Act and;
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. 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 you as 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 connection with 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 130 of the Act; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Act;

have not been met; or

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



05/05/2026

Nicholas Lawrence, ACA
61 Benskin Road, Watford
WD18 0HN

RECEIPTS AND PAYMENTS ACCOUNTS

for the year ended **31 December 2025**

	Unrestricted Funds	Restricted Funds	Endowment Funds	Total Funds
A1 Receipts				
Donations/Sponsorship	£37,649.29	-	£7,368.12	£45,017.41
Donated Amazon Royalties	£716.20	-	-	£716.20
Interest/Investment Income	£134.91	-	£585.90	£720.81
Grants	£4,000.00	£1,203.74	-	£5,203.74
A1 Subtotal (Gross income for AR)	£42,500.40	£1,203.74	£7,954.02	£51,658.16
A2 Asset and investment sales	-	-	-	-
A2 Subtotal	-	-	-	-
TOTAL RECEIPTS	£42,500.40	£1,203.74	£7,954.02	£51,658.16
A3 Receipts Payments				
Research	£23,500.00	-	-	£23,500.00
Family Support	£998.19	£375.14	-	£1,373.33
Fundraising/Events	£9,073.45	-	-	£9,073.45
Charity Costs	£1,424.58	-	-	£1,424.58
A3 Subtotal	£34,996.22	£375.14	-	£35,371.36
A4 Asset and investment purchases	-	-	-	-
A4 Subtotal	-	-	-	-
TOTAL PAYMENTS	£34,996.22	£375.14	-	£35,371.36
Net of receipts/(payments)	£7,504.18	£828.60	£7,954.02	£16,286.80
A5 Transfers between funds	-£13,650.59	-	£13,650.59	-
A6 Cash funds last year end	£25,356.45	-	-	£25,356.45
CASH FUNDS THIS YEAR-END	£19,210.04	£828.60	£21,604.61	£41,643.25

STATEMENT OF ASSETS AND LIABILITIES AT THE END OF THE PERIOD

As at **31 December 2025**

	2025 Unrestricted Funds	2025 Restricted Funds	2025 Endowment Funds	2025 Total Funds	2024 Total Funds
B1 Cash Funds					
Cash at bank	£19,210.04	£828.60	£21,604.61	£41,643.25	£25,356.45
Total Cash Funds	£19,210.04	£828.60	£21,604.61	£41,643.25	£25,356.45
B2 Other monetary assets	-	-	-	-	-
B3 Investment assets					
Forever Fund	-	-	£21,571.45	£21,571.45	-
B4 Assets retained for the charity's own use	-	-	-	-	-
B5 Liabilities					
Forever Fund	-	-	£21,500.00	£21,500.00	-

Signed by one or two trustees on behalf of all the trustees



Full name: M Gedy

Position: Chair

Date: 04 May 2026