

Trustee's Annual Report  
for the Period

**02 September 2023 to 31 December 2024**

For The Mikaere Foundation

## **CONTENTS OF THE FINANCIAL STATEMENTS**

for the Period **02 September 2023 to 31 December 2024**

- 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**

15 Palmitine House  
90 York Rd  
London  
SW11 3GT

### **TRUSTEES**

CHAIR:	Melanie Gedye
TREASURER:	Kirsty Lester
SECRETARY:	Sam Hulance
TRUSTEE:	Wendy Hulance
TRUSTEE:	Andy Hulance
TRUSTEE:	Jamie Irving
TRUSTEE:	Tony Collins

## **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.

We have increased the financial period of this year (2023-2024) to align with the calendar year. The financial periods moving forward will run from the 1st of January to the 31st of December.

In August, Mikaere Hulance, the namesake of the charity, died. There was an overwhelming wave of support for both his family and the charity, and the family raised over £16,000 in his memory. This has been moved to a high yield, savings account and will be moved to an investment fund in the next financial year, where it is hoped the returns will support children with NKH for many years to come. A second savings account was opened to hold funds between quarters.

The charity has partnerships with Professor Nick Greene at UCL, Professor Johan van Hove at the University of Colorado and been in touch with Allison Slabaugh at the University of Notre Dame to understand current NKH research and have chosen to fund projects in line with our objectives.

The charity successfully launched the NKH Informational Booklet in February 2024, working with both 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 create.

The charity was successfully accredited by the Patient Informational Forum, which indicates the medical information within the booklet is trustworthy and can be distributed safely by medical professionals, medical support services and NHS Trusts. We distributed the booklet with the UK Metabolic Referral service, allowing the greatest reach to newly diagnosed families, providing clear information when they need it most.

The community response was overwhelmingly positive, and we understand the booklet is both reaching newly diagnosed families and is positively impacting the NKH diagnosis experience. We've had requests for booklets from Paediatric nursing teams, Hospice support teams and families.

The charity held an NKH Family Meet up in July, at the British Motor Museum. 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. The meet up was such a great experience 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 joined several donation platforms which allow our community to donate/raise funds. This year we added Stripe, Much Loved and Twitch/Stream Labs to the line up.

#### Partnerships:

The charity has maintained partnerships with The Ultra Challenge Series, Skyline and the London Landmark Half Marathon, which allow our community to raise funds for the Mikaere Foundation in exchange for a partly paid registration fee/discount.

We've also entered into a partnership with the London Marathon for the 2026 event, and Free Wills UK to create a legacy giving programme.

We joined 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 released a Fundraising Pack to support those wishing to fundraise on our behalf.

## ACHIEVEMENTS AND PERFORMANCE

### SUMMARY OF THE MAIN ACHIEVEMENTS OF THE CHARITY DURING THE YEAR

#### Income

A total of £61,553.48 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 - £7,443.17
- Books for Wednesdays Royalties - £1,171.36
- CSR Corporate Programmes - £2,031.32
- Donations from events/sponsorship/tribute/family fundraising - £50,837.70
- Investments/Interest - £69.93

#### 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 mentions to Dylan Swift and Jack Mooney), Skydiving events by Elly + friends (thank you to Katy Irving and Gareth Humphries) and Jack Davies, the NKH Awareness Day Drive and the The Christmas Appeal
- Corporate support by Bazaarvoice, Creative Equals and the Toddington Methodist Church
- Celebrations by Penny and Tony Collins
- Fundraising by the NKH Community (Evita Duage in honour of Alex, Toni Mannion in honour of Daisy, Amber Travers in honour of Zander, Humberto Samuel in honour of Reese, Mr and Mrs S/A Shaw in honour of Eleni, Amy Maxwell and Jack Davies in honour of Freya, Laura Sayin in honour of Teo and Emma Gilmore-Jones in honour of Charlie)
- Paul Askew's ongoing Twitch Fundraiser
- Memorials in honour of Kai Hulance, and Andrew Ogorzalek.

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. There have been several research updates and a family webinar. The research updates are documented at [mikaerefoundation.org/research-updates](https://mikaerefoundation.org/research-updates). We also entered a new partnership with Dr Johan Van Hove at the University of Colorado, who is exploring treatments for NKH.

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 £40,000.00 towards NKH Research. £35,000 to UCL and £5,000 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 £7,775.04 in the charity accounts. At the end of the financial year we held £25,356.45, which is over the reserve amount of £1,500.00 due to the timing of several grants and as we are still in the preliminary phase of establishing a memorial investment fund. This will be rectified 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 £61,533.48, and had £43,972.07 in outgoings.

We donated £40,000.00 towards NKH Research at UCL and the University of Colorado, with the remaining outgoings going towards the NKH Info Pack and accreditation (£681.18), the Family Meet up (£148.00) and investing in fundraising partnerships (£3142.89), where we had a positive fundraising return on our investments.

Specifically:

- Skyline - we had three funded jumps. We are invoiced for jumps only when the jumper has fundraised the minimum amount agreed. In this case, we were invoiced £840.00 by Skyline, and the three jumpers raised £8705.79.
- We use the My Virtual Mission platform for the NKH 100 Mile Challenge, which is charged per user. We were charged £195 for the platform and raised £7,539.00 across the campaign. One family also requested t-shirts (costing approximately £120), which they covered the cost of.
- We were invoiced by the London Landmark Half Marathon £1770 for 12 places for the 2025 April Run. These places are highly coveted, and each runner is expected to raise a minimum of £395 + pay a registration fee of £30. We expect to make upwards of £5000 from this investment. We also paid £220 for tshirts for the 2024 runners. Paired with the cost of places for the 2024 run, each 2024 runner cost the charity £186.50, but raised, on average, £585 each.



### **THE MIKAERE FOUNDATION POUND BREAKDOWN**

For every pound we spent in the financial year 02 September 2023 - 31 December 2024:

- 91p was spent on NKH Research
- 1p was spent on Family Support (this includes Family Meet Ups and the NKH Info Booklet)
- 7p was spent on fundraising.

For every 7p that was spent on fundraising, we generated £44.04 in returns.

This fundraising investment includes things such as London Landmark Half Marathon Places, Ultra Challenge event places, Sponsored Skydives etc

## DECLARATION

### **THE TRUSTEES DECLARE THEY HAVE APPROVED THE TRUSTEES REPORT ABOVE**

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the period ended 31 December 2024

#### **The chair acknowledges her responsibilities for:**

- A. ensuring that the company keeps accounting records which comply with Sections 386 and 387 of the Companies Act 2006 and
- B. preparing financial statements which give a true and fair view of the state of affairs of the company as at the end of each financial year and of its profit or loss for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the company.

The financial statements have been prepared in accordance with the micro-entity provisions.

The financial statements were approved by the Chair on 12 January 2024 and were signed by:



Full name: M Gedye

Position: Chair

Date: 12.01.2025

# **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 period of 02 September 2023 - 31 December 2024.

## **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.



30/04/2025

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

## RECEIPTS AND PAYMENTS ACCOUNTS

for the Period **02 September 2023 to 31 December 2024**

	Unrestricted Funds	Restricted Funds	Endowment Funds	Total Funds
<b>A1 Receipts</b>				
Donations/Sponsorship	£60,312.19	-	-	£60,312.19
Donated Amazon Royalties	£1,171.36	-	-	£1,171.36
Savings Account Interest	£69.93	-	-	£69.93
<b>Subtotal (Gross income for AR)</b>	£61,553.48	-	-	£61,553.48
<b>A2 Asset and investment sales</b>				
-	-	-	-	-
<b>Subtotal</b>	-	-	-	-
<b>TOTAL RECEIPTS</b>	£61,553.48	-	-	£61,553.48
<b>A3 Receipts Payments</b>				
NKH Research Grants	£40,000.00	-	-	£40,000.00
PIF TIC Accreditation	£600.00	-	-	£600.00
NKH Info Booklet Printing Costs	£81.18	-	-	£81.18
NKH Family Visit	£148.00	-	-	£148.00
Fundraising Event Costs/Partnerships	£3,142.89	-	-	£3,142.89
<b>Subtotal</b>	£43,972.07	-	-	£43,972.07
<b>A4 Asset and investment purchases</b>				
-	-	-	-	-
<b>Subtotal</b>	-	-	-	-
<b>TOTAL PAYMENTS</b>	£43,972.07	-	-	£43,972.07
<b>Net of receipts/(payments)</b>	£17,581.41	-	-	£17,581.41
<b>A5 Transfers between funds</b>	-	-	-	-
<b>A6 Cash funds last year end</b>	£7,775.04	-	-	£7,775.04
<b>CASH FUNDS THIS YEAR-END</b>	£25,356.45	-	-	£25,356.45

## STATEMENT OF ASSETS AND LIABILITIES AT THE END OF THE PERIOD

for the Period **02 September 2023 to 31 December 2024**

Categories	Details	Unrestricted Funds	Restricted Funds
<b>B1 Cash Funds</b>			
	Cash at Bank	£25,356.45	-
<b>Total Cash Funds</b>		£25,356.45	-
<i>(agree balances with receipts and payments account(s))</i>		OK	OK

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**B2 Other monetary assets**

**B3 Investment assets**

**B4 Assets retained for the charity's own use**

**B5 Liabilities**

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



Full name: M Gedy

Position: Chair

Date: 12.01.2024