

MILA'S FOUNDATION

England & Wales · Charity number 1206079

Details

Status Registered

Legal form Trust

Registered 2023-12-06

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

Contact

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London
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Activities

Objects: 1. THE RELIEF OF SICKNESS AND THE PRESERVATION OF HEALTH FOR PEOPLE WITH ALEXANDER DISEASE AND OTHER LEUKODYSTROPHIES INCLUDING WITHOUT LIMITATION BY:A. THE PROVISION OF FINANCIAL ASSISTANCE TO PATIENTS, THEIR FAMILIES AND CARERS; AND B. THE PROMOTION OF RESEARCH INTO THE NATURE, CAUSES, DIAGNOSIS, PREVENTION, TREATMENT AND CURE OF ALEXANDER DISEASE AND OTHER LEUKODYSTROPHIES AND THE DISSEMINATION OF SUCH RESEARCH FOR THE PUBLIC BENEFIT.

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Other Defined Groups

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-07-31		-	-	-
2024-07-31	£37,909	£454	-	-

Trustees

Name	Role	Appointed
Nahed Sarig	Chair	2022-07-11
Gil Sarig		
Nicholas James Grant		

MILA'S FOUNDATION

England & Wales - Charity number 1206079

Accounts

Mila's Foundation 2023-24 Trustee Report

Achievements and Performance

For this period, Mila's Foundation focussed on sustainability after a period of rapid growth, ensuring maintenance of service levels, project completions and nurturing stakeholder relationships. During the period we evidenced improved visibility of Mila's Foundation and welcomed new beneficiaries, increasing the number of conditions represented, and delivered support activities to beneficiaries. Connecting beneficiaries with each other for mutual support is one of our key objectives.

Our direct communication with the community has seen consistent improvement. Communications and engagement staff developed their social media skills utilising training and consultancy opportunities, growing engagement across all social media channels over the year.

Donation and fundraising income continued to grow to £37,909. Although the organisation saw a reduction in unrestricted reserves, this was expected due to our consolidation strategy for the year.

Charitable Objectives

Across the year Mila's Foundation staff:

- Welcomed new beneficiaries
- Supported beneficiaries across support activities including one to one conversations, home visits and advocacy, digital wellbeing sessions and face to face get togethers
- Delivered professional counselling sessions and wellbeing calls to beneficiaries
- Connected beneficiaries to build supportive, long-lasting relationships
- Were invited to present at events
- Attended stakeholder conferences and events
- Been involved in stakeholder meetings
- Encouraged engagements on our social media channels
- Attracted website visitors
- Were mentioned in the press

Challenges

We did not have capacity to progress our plans to cement our position as the umbrella organisation for Alexander's disease in the UK and experienced some challenges in attempts to collaborate with a minority of like-minded groups. Our communications strategy for 2024/25 has been adapted accordingly and we will seek to develop a collaborative relationship with one patient group and use learning from this experience to develop future plans.

It has been challenging to secure the honorary contracts required to allow support staff to attend clinics, largely due to slow moving bureaucratic obstacles within the host NHS Trusts. This has been partially resolved late in the period.

Future Impact

It was gratifying to see the organisation exceeding budget expectations during the period, we have set a break-even budget for the following year to further consolidate our position with a view to future growth.

We have recently recruited a Grants and Trusts Fundraiser and look forward to the results of increased capacity in this area for the next period.

Our contract to provide the distribution service for the Addison's Disease Self Help Group ceased in August 2024, however this will give us additional capacity for small grant fundraising which should

mitigate against this income loss.

We will continue to work towards our mission of support and access to treatment for everyone with Alexander's disease.

Financial Review

At the balance sheet date, the charity had unrestricted funds and restricted funds.

It is the policy of the charity that unrestricted funds which have not been designated for a specific use should be maintained at a level the trustees feel are sufficient to cover the running costs of the charity for a period of approximately 3 months.

We expected a drop in unrestricted reserves for this period whilst we continued to invest in our charitable activities. We are looking towards a break-even budget for 2024/25, consolidating our position whilst continuing to increase our level of charitable activities.

Plans for Future Periods

Work areas for 2024/25 include:

- Confirmation of a data sharing agreement with NHS England in order to analyse Registry data and identify priorities for future projects.
- Regular attendance schedule for clinics.
- Commitment to annual Community Weekends.
- Translation of our children's support book to German, French and Spanish.
- Confirm the topic for an additional children's support book, for publication in 2025/26.
- Completion of succession planning and sustainability measures.
- Strategy to review operations and providers across the organisation.

Structure, Governance and Management

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

Recruitment and appointment of new trustees

The Charity seeks to appoint trustees who have relevant and often specialist knowledge. This has always included ensuring that those directly affected by the condition are among the trustees. This is accompanied by appointing trustees with complementary skills, e.g. legal, finance, administration or relevant professional experience and knowledge.

None of the trustees have any beneficial interest in the company. All trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

Key management remuneration

Key personnel remuneration is reviewed annually alongside performance appraisals within an agreed pay structure and applied using the same approach to pay and reward as for all employees. Any significant increases are approved by the Board of Trustees and reviewed within the constraints of the budget.

Risk

The trustees have assessed the major risks to which the charity is exposed. Overall, the trustees are satisfied that systems are in place to mitigate exposure to the major risks.

The charity maintains a Risk Register. This is managed by the Trustee Risk Sub-Committee who present priority risks and proposed mitigations at quarterly Board meetings for approval.

Day to day operations

The trustees have delegated control of day to day operations to the Chief Executive Officer who provides a quarterly report and key performance indicators at Board Meetings.



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name Mila's Foundation	No (if any) 1206079
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CC16a

Receipts and payments accounts

For the period from	Period start date 8/1/2023	To	Period end date 7/31/2024
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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					
Donations - Gift Aid	30,332	-	-	30,332	-
Donations - Non-Gift Aid	7,577	-	-	7,577	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	37,909	-	-	37,909	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	37,909	-	-	37,909	-
A3 Payments					
Bank Charges	30	-	-	30	-
PayPal Fees	424	-	-	424	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	454	-	-	454	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	454	-	-	454	-
Net of receipts/(payments)	37,454	-	-	37,454	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	37,454	-	-	37,454	-

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	HSBC Bank Account	36,410	-	-
	Paypal Bank Account	1,044	-	-
		-	-	-
	Total cash funds	37,454	-	-
	(agree balances with receipts and payments account(s))	OK	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
	Nahed Sarig Nicholas Grant	5/28/2025
		5/28/2025



Section A

Independent Examiner's Report

Report to the trustees/ members of

Charity Name
Mila's Foundation

On accounts for the year ended

31st July 2024

Charity no (if any)

1206079

Set out on pages

1-4

(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended **31 / 07 / 2024**.

Responsibilities and basis of report

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention (~~other than that disclosed below*~~) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

** Please delete the words in the brackets if they do not apply.*

Signed:

Date:

28/05/2025

Name:

Iraj Idafar FCCA

Relevant professional qualification(s) or body (if any):

ACCA

Address:

Blue Accountancy & Business Services
34 South Molton Street
London W1K 5RG

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.