



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	25	07	2023		24	07	2024

Section A Reference and administration details

Charity name	MLD Support Association UK
Other names charity is known by	MLD Support Association UK 1 MLD Support UK
Registered charity number (if any)	1150542
Charity's principal address	1 st Floor 35 Marine Terrace Margate Postcode CT9 1XJ

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	Jacqueline Imrie	Chair		
2	Vivienne Clark	Treasurer		
3	Nicola Daly	Secretary		
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year
Twila D'Cruz	
Elizabeth Davenport	
Daniel Erskine	

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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Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Charitable Incorporated Organisation Constitution
How the charity is constituted (eg. trust, association, company)	Trust
Trustee selection methods (eg. appointed by, elected by)	Appointed by resolution passed at a properly convened meeting of the Charity Trustees, having regard to the skills, knowledge and experience required for the effective administration of the CIO

Additional governance issues (Optional information)

You may choose to include additional information, where relevant, about: • policies and procedures adopted for the induction and training of trustees; • the charity's organisational structure and any wider network with which the charity works; • relationship with any related parties; • trustees' consideration of major risks and the system and procedures to manage them.	We require all Trustees to undertake DBS checks, and to take an active role in the administration, activities and events of the CIO. We require all Trustees to complete a knowledge and skills form to ensure we have a broad knowledge base to support families and administer activities of the CIO. We collaborate with the MPS Society and Archangel, 2 charities who also support and advocate for families with MLD. We ensure trustees are knowledgeable about safety and risks before any event and risk assessment is carried out for all potential venues.
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Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

The CIO has continued to spread awareness of MLD through our website and family Facebook page. The website is updated regularly to reflect information available, upcoming events and news regarding MLD and therapies available.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

Website updates October 2023 Genomics England includes MLD on its provisional list Update on the Generation Study March 2024 Clinical Trial Update from Takeda Update from Takeda following community lobbying to get enzyme replacement for families that were on the trial. March 2024 Link to FDA announcement that gene therapy now approved in USA June 2024 Orchard Therapeutics celebrates Neonatal Screening Link to press release
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Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

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Section D

Achievements and performance

Summary of the main achievements of the charity during the year

The CIO has continued to spread awareness of MLD through our website and family Facebook page. The website is updated regularly to reflect information available, upcoming events and news regarding MLD and therapies available.

The achievements have included:

. Once again Christmas packages were sent to all MLD families with small gifts for all the family as well as the affected young person or adult.

In February 2024 a day out was organised for families at Charter House near Burnley. There is a sensory room that benefits children and affected adults and was a safe welcoming environment for families to meet and chat

Advocating for new born screening on behalf of families

Supporting families undergoing gene therapy in Manchester

Section E

Financial review

Brief statement of the charity's policy on reserves

No reserves policy is required

Details of any funds materially in deficit

None

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

Section F**Other optional information****Section G****Declaration**

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

Signed on behalf of the charity's trustees

Signature(s)	J.Imrie	
Full name(s)	Jacqueline Imrie	
Position (eg Secretary, Chair, etc)	Chair and Trustee	
Date	20 May 2025	



Charity Name MLD Support Association UK	No (if any) 1150542
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CC16a

Receipts and payments accounts

For the period from	Period start date 25.07.2023	To	Period end date 24.07.2024
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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					
Grants	22,000	-	-	22,000	23,000
Donation	11,610	-	-	11,610	6,462
Fundraising	1,885	-	-	1,885	789
	-	-	-	-	2,016
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	35,495	-	-	35,495	32,266
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	35,495	-	-	35,495	32,266
A3 Payments					
Charitable Donations	12,486	-	-	12,486	-
Bank Charges	134	-	-	134	169
Administration Expenses	661	-	-	661	720
Website Costs	4,099	-	-	4,099	3,125
Marketing Expenses	1,056	-	-	1,056	859
Office Expenses	925	-	-	925	1,012
Travel Expenses	961	-	-	961	583
Subscription Fees	644	-	-	644	256
Accountancy Fees	300	-	-	300	300
Registry of sufferer	-	-	-	-	750
Event costs	2,923	-	-	2,923	8,484
Conference costs	1,493	-	-	1,493	20,761
Sub total	25,681	-	-	25,681	37,019
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	25,681	-	-	25,681	37,019
Net of receipts/(payments)	9,814	-	-	9,814	- 4,753
A5 Transfers between funds	56,234	-	-	56,234	60,987
A6 Cash funds last year end	66,048	-	-	66,048	56,234
Cash funds this year end					

Categories

Details

Unrestricted
funds
to nearest £Restricted
funds
to nearest £Endowment
funds
to nearest £

B1 Cash funds

HSBC Current Account
HSBC Deposit Account

3,103
62,945
-
66,048

-
-
-
-

-
-
-
-

Total cash funds(agree balances with receipts and payments
account(s))

OK

Unrestricted
funds
to nearest £

OK

Restricted
funds
to nearest £

OK

Endowment
funds
to nearest £

B2 Other monetary assets

Details

-
-
-
-
-
-

-
-
-
-
-
-

-
-
-
-
-
-

B3 Investment assets

Details

Fund to which
asset belongs

Cost (optional)

-
-
-
-
-

Current value
(optional)

-
-
-
-
-

B4 Assets retained for the
charity's own use

Details

Fund to which
asset belongs

Cost (optional)

-
-
-
-
-
-
-
-
-

Current value
(optional)

-
-
-
-
-
-
-
-
-

B5 Liabilities

Details

Fund to which
liability relates

Amount due
(optional)

-
-
-
-
-

When due
(optional)

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

Signature


V. Clark

Print Name

JACQUILINE INNES
VIVIENNE CLARK

Date of
approval

20.5.21
13/05/25



Section A

Independent Examiner's Report

Report to the trustees/
members of

Charity Name
MLD Support Association UK

On accounts for the year
ended

24th July 2024

Charity no
(if any)

1150542

Set out on pages

CC16a 1 to 2

(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 24/07/2024.

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:

Michael Letch & Partners LLP

Date:

30/4/25

Name:

Michael Letch & Partners LLP

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

Association of Chartered Certified Accountants

Address:

146 High Street

Billericay

Essex, CM12 9DF

Section B

Disclosure

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