



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	25	07	2022		24	07	2023

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	Floor 5, Amphenol Business Complex Thanet Way Whitstable Postcode CT5 3SB		

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	Vivienne Clark	Chair		
2	Nicola Daly	Secretary		
3				
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	
David Lawson	
Jackie Imrie	
Lesley Warrington	

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
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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)

The following announcements were made on our website: 13 September 2022 Thanks to the National Lottery, we are delighted to confirm that the next MLD Family Funday will take place on Sunday 27 November 2022 at Twycross Zoo. We will have access to an onsite function room with buffet lunch, additional children’s entertainment and zoo admission. This event is open to All UK MLD families. 14 February 2023 The UK Newborn Screening programme desperately needs urgent revision to keep up with other Western countries, many of whom screen for considerably more diseases and have a far more streamlined up to date system, which in turn gives a far more positive outlook for children affected by these associated conditions. With this in mind, the Newborn Screening Collaborative, a collection of 13 rare disease organisations including Genetic Alliance UK, have highlighted three main priorities for 2023 which if given the correct focus will ensure we begin to get on the right track... 5 April 2023 Niamh Hitchman is planning a Skydive to raise awareness of MLD and raise funds for MLD Support Association UK. Niamh’s little brother, James, very sadly passed away with MLD some years ago, so she is keen to help support families who are suffering now and also those who have suffered in the past. Thank you so much to Niamh – your support is very much appreciated. Niamh has set up a Just Giving page. 5 April 2023 Sally Tooms is running the London Marathon for MLD Support Association UK. When she saw the TV coverage about Nala and Teddi and Gene Therapy she contacted us to ask if she could run for our Charity, to support families affected by MLD. I am sure we will all be watching her on TV on Sunday 23 April and cheering her on. We are all so grateful to her for her time and effort. 26 April 2023 Sally Tooms successfully ran the London Marathon for MLD Support Association UK. She finished in just under 5 hours – amazing! So far, she has raised £1,400 for us. We would like to say huge congratulations and many thanks for thinking of our Charity.
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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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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:

Scientific and Family Conference 24-25 March 2023

The third MLD Support Association UK Scientific and Family Conference was held at The Holiday Inn in Telford. The Scientific Conference on Friday 24 March and the Family Conference on Saturday 25 March. This was followed by a Family Fun Day at The Holiday Inn – Telford on Sunday 26 March.

Both Conferences were a huge success with leading clinicians and scientists working in the field of MLD attending and speaking on both days. Many MLD Families attended on the Saturday and then enjoyed the Family Fun Day on Sunday.

The focus of the Conference this year was on Gene Therapy, Clinical Trials, Newborn Screening for MLD from a laboratory and family perspective, Support for MLD families, the need for MLD Centres and other Therapies for MLD sufferers.

Family Fun Days

27 November 2022 – Twycross Zoo

An MLD Family Funday took place on Sunday 27 November 2022 at Twycross Zoo. We had access to an onsite function room with buffet lunch, additional children's entertainment and zoo admission.

This event is open to **All UK MLD families** and is free of charge.

26 March 2023 – Telford

Following a successful Scientific and Family Conference, the next day was a Family Fun Day at The Holiday Inn – Telford on Sunday 26 March

Further details of these and other activities can be found in Section C.

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)	V Clark	
Full name(s)	Vivienne Clark	
Position (eg Secretary, Chair, etc)	Chair and Trustee	
Date	1 May2024	



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

Receipts and payments accounts

CC16a

For the period from	Period start date	To	Period end date
	25.07.2022		24.07.2023

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Grants	23,000	-	-	23,000	8,680
Donation	6,462	-	-	6,462	1,191
Fundraising	789	-	-	789	16,702
Conference	2,016	-	-	2,016	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	32,266	-	-	32,266	26,573
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	32,266	-	-	32,266	26,573
A3 Payments					
Charitable Donations	-	-	-	-	-
Bank Charges	169	-	-	169	71
Administration Expenses	720	-	-	720	507
Website Costs	3,125	-	-	3,125	8,373
Marketing Expenses	859	-	-	859	1,080
Office Expenses	1,012	-	-	1,012	802
Travel Expenses	583	-	-	583	375
Subscription Fees	256	-	-	256	356
Accountancy Fees	300	-	-	300	240
Registry of sufferer	750	-	-	750	-
Event costs	8,484	-	-	8,484	4,877
Conference costs	20,761	-	-	20,761	-
Sub total	37,019	-	-	37,019	16,680
A4 Asset and investment purchases, (see table)					
Laptops	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	37,019	-	-	37,019	16,680
Net of receipts/(payments)	4,753	-	-	4,753	9,893
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	60,987	-	-	60,987	51,094
Cash funds this year end	56,234	-	-	56,234	60,987

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 Current Account	2,729	-	-
	HSBC Deposit Account	53,505	-	-
		-	-	-
	Total cash funds	56,234	-	-
(agree balances with receipts and payments account(s))		OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
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 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
	<i>V. Clark</i>		29/04/2024



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 2023

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 24/07/2022.

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:

18/07/2023

Name:

Michael Letch & Partners LLP

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

Association of Chartered Certified Accountants

Address:

146 High Street

Billerica

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).

