



Trustees' Annual Report for the period

Period start date			Period end date		
From	25	07	To	24	07
			2021		
			2022		

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

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:	
1 November 2021	Great News! We will be holding a virtual Christmas Party on Saturday 11th December 1pm-2pm for our MLD children and their siblings. We will also be distributing Festive Family packages in the lead up to Christmas to UK MLD families.
9 December 2021	A formal application to add Metachromatic Leukodystrophy to the UK Newborn Bloodspot (NBS) programme has now been made to the National Screening Committee (NSC). This is an important milestone for the MLD community and one which could not have been possible without the important support and ongoing collaboration of many brilliant scientists and heroic clinicians.
26 January 2022	Thanks to National Lottery funding the MLD Support Association UK Funday will take place on Sunday 10th April at Drayton Manor (Tamworth, Staffordshire, B78 3TW).
4 February 2022	We are delighted to announce that Atidarsagene autotemcel (Libmeldy®) has been recommended as an option by NICE (The National Institute for Health and Care Excellence) for treating metachromatic leukodystrophy (MLD) in England and Wales for eligible children.
22 February 2022	Following the wonderful news that Gene Therapy was approved for use in England by the NHS for pre-symptomatic Late-Infantile and pre-symptomatic and mildly-symptomatic Early Juvenile MLD, we now have more exciting news! A clinical study for sufferers of pre-symptomatic and early-symptomatic sufferers of Late Juvenile MLD is now recruiting. The study is being conducted at Ospedale San Raffaele – Telethon Institute for Gene Therapy (OSR-TIGET) in Milan, Italy.
22 July 2022	MLD Support Association UK is a small charity with limited resources, so we value working with The MPS Society, who offer specialist support for families affected by MLD. The rarity of MLD means that affected individuals and their families often experience difficulties accessing local support services.

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.

Section D

Achievements and performance

Section D	Achievements and performance
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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:

Providing a comprehensive survey report to NICE on sufferers of MLD to support the application for Gene Therapy, which was successful.

Complete updating of the website and information literature following the NICE decision to provide Gene Therapy for MLD on the NHS in England.

Continuing to provide support, both by Zoom meetings and Fun Days for all families affected by MLD.

Continuing to support ArchAngel MLD Foundation with their application to get MLD put onto the Newborn Screening testing for the UK

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

09/04/2023



Charity Name	MLD Support Association UK	No. (if any)	1150542
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Receipts and payments accounts

For the period from	Period start date	To	Period end date
	25.07.2021		24.07.2022

CC16a

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	8,680	-	-	8,680	9,254
Donation	1,191	-	-	1,191	-
Fundraising	16,702	-	-	16,702	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	26,573	-	-	26,573	9,254
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	26,573	-	-	26,573	9,254
A3 Payments					
Charitable Donations	-	-	-	-	-
Bank Charges	71	-	-	71	-
Administration Expenses	507	-	-	507	487
Website Costs	8,373	-	-	8,373	3,337
Marketing Expenses	1,080	-	-	1,080	1,375
Office Expenses	802	-	-	802	570
Travel Expenses	375	-	-	375	-
Subscription Fees	356	-	-	356	256
Accountancy Fees	240	-	-	240	240
Registry of sufferer	-	-	-	-	3,038
Event costs	4,877	-	-	4,877	4,103
Sub total	16,680	-	-	16,680	13,405
A4 Asset and investment purchases, (see table)					
Laptops	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	16,680	-	-	16,680	13,405
Net of receipts/(payments)	9,893	-	-	9,893	- 4,151
A5 Transfers between funds					
A6 Cash funds last year end	51,094	-	-	51,094	55,245
Cash funds this year end	60,987	-	-	60,987	51,094

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	1,422	-	-
	HSBC Deposit Account	59,565	-	-
		-	-	-
	Total cash funds	60,987	-	-
	(agree balances with receipts and payments account(s))			
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets				
B4 Assets retained for the charity's own use				
B5 Liabilities				
Signed by one or two trustees on behalf of all the trustees				
Signature		Print Name	Date of approval	
Clark		VIVIANNE CLARK	05/04/23	



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 2022

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:

Michael Letch & Partners LLP

Date:

4/04/2023

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 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 2022

**Charity no
(if any)**

1150542

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**Independent
examiner's statement**

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- 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:

4/04/2023

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

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.