



Trustees' Annual Report for the period

Period start date		Period end date	
From	25 July 2019	To	24 July 2020

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, Kent 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		
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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 a DBS check, and to take an active role in the administration and activities of the CIO.

Section C Objectives and activities

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

1. To advance the education of the public in the subject of the diagnosis, progression and treatment for all forms of Metachromatic Leukodystrophy (MLD)
2. To relieve the mental and physical sickness of persons resident in the United Kingdom, suffering from bereavement or loss of a family member through MLD by the provision of counselling and support for such persons.
3. To promote and protect the physical and mental health of sufferers of MLD in the United Kingdom through the provision of support, education and practical advice to their families and through the provision of financial assistance to bona fide clinicians and research bodies who are seeking therapeutic treatment for this condition.

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 CIO has continued to spread awareness of MLD through the distribution of explanatory leaflets to health professionals and families.

A Registry of sufferers of MLD in the UK is being produced which will be available to scientists and clinicians. This work was delayed by the Pandemic but will be progressed in the coming year.

Trustees have represented the CIO at various meetings and conferences so that we can inform clinicians and researchers of our presence and to network with other organisations relating to similar disorders.

Jackie Imrie and Vivienne Clark have been involved in meetings with Orchard Therapeutics and NICE to get Gene Therapy brought to the UK, following successful clinical trials in Milan, Italy. Submissions from MLD Support Association UK will be prepared and submitted to NICE in late 2020, in preparation of their Committee Meeting in 2021.

Additional details of objectives and activities (Optional information)

The CIO has had continuing support by way of donations from volunteer fund raisers who are generally friends and family of people affected by MLD.

Wickstead Park was the venue for a family fun day on 7 September 2019. All families with MLD sufferers were invited for a free day out. We received a grant from the Community Fund of the National Lottery for a to cover the cost. The day was a huge success and all families had a wonderful time. We plan to repeat this Fun Day in future years.

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

Summary of the main achievements of the charity during the year

The website has again been extensively updated to offer advice to families during the Coronavirus Pandemic.

On 25 June we offered advice on shielding of MLD sufferers who were deemed Clinically Extremely Vulnerable.

On 10 July we held a Family Zoom meeting where all affected families were able to meet up online and have a "coffee morning" chat.

Unfortunately, our Family and Scientific Conference planned for June 2020 had to be cancelled because of the Pandemic. We are planning on organising this Conference again, hopefully in late 2021.

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)	<i>V. Clark</i>	<i>D. F. Lawson</i>
Full name(s)	Vivienne Clark	David Lawson
Position (eg Secretary, Chair, etc)	Chair and Trustee	
Date	21 April 2021	



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

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For the period from	Period start date 25.07.2019	To	Period end date 24.07.2020
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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	8,068	-	-	8,068	14,548
HMRC Gift Aid	-	-	-	-	129
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	8,068	-	-	8,068	14,677
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	8,068	-	-	8,068	14,677
A3 Payments					
Charitable Donations		-	-	-	
Bank Charges		-	-	-	
Administration Expenses	702	-	-	702	523
Website Costs	5,856	-	-	5,856	9,159
Marketing Expenses	328	-	-	328	6,705
Office Expenses	401	-	-	401	230
Travel Expenses	391	-	-	391	2,145
Subscription Fees	316	-	-	316	438
Accountancy Fees	240			240	240
Registry of sufferer	4,000			4,000	2,930
Event costs	2,306	-	-	2,306	1,193
Sub total	14,540	-	-	14,540	23,563
A4 Asset and investment purchases, (see table)					
Laptops	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	14,540	-	-	14,540	23,563
Net of receipts/(payments)	- 6,472	-	-	- 6,472	- 8,886
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	61,717	-	-	61,717	70,603
Cash funds this year end	55,245	-	-	55,245	61,717

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	1,395	-	-
	HSBC Deposit Account	53,850	-	-
		-	-	-
	Total cash funds	55,245	-	-

(agree balances with receipts and payments account(s))


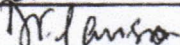
	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	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
	VIVIENNE CLARK	19/4/2021
	DAVID LAWSON	19/4/2021