



# Trustees' Annual Report for the period

Period start date		Period end date	
25	July	24	July
2018		2019	
From		To	

## Section A Reference and administration details

<b>Charity name</b>	MLD Support Association UK		
<b>Other names charity is known by</b>	MLD Support Association UK 1 MLD Support UK		
<b>Registered charity number (if any)</b>	1150542		
<b>Charity's principal address</b>	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	Christine Longmire	Secretary	Resigned 26/09/2018	
3	Nicola Daly	Secretary	Commenced 24/10/2018	
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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	Commenced 15/08/2018

**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 will be produced which would be available to scientists and clinicians. This work will be continued in the forthcoming 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.

**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 suggested for a family fun day in September. All families with MLD suffers will be invited for a free day out. We have applied to the Community Fund of the National Lottery for a grant to cover the cost.

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**

Three new information leaflets were produced, one each for health professionals, families and fundraising. These are being actively sent out to relevant parties.

The new website has been extensively modernised and was successfully launched. The new website allows us to log all upcoming events and also allows for the download of information on MLD.



**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)**

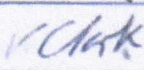
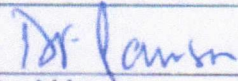
You **may choose** to include additional information, where relevant about:

- 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**

<b>Signature(s)</b>		
<b>Full name(s)</b>	Vivienne Clark	David Lawson
<b>Position (eg Secretary, Chair, etc)</b>	Chair and Trustee	TRUSTEE
<b>Date</b>	08 April 2020	





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 25.07.18	To	Period end date 24.07.2019
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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 £
<b>A1 Receipts</b>					
Donations	14,548	-	-	14,548	13,098
HMRC Gift Aid	129	-	-	129	343
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>14,677</b>	<b>-</b>	<b>-</b>	<b>14,677</b>	<b>13,441</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>14,677</b>	<b>-</b>	<b>-</b>	<b>14,677</b>	<b>13,441</b>
<b>A3 Payments</b>					
Charitable Donations		-	-	-	
Bank Charges		-	-	-	
Administration Expenses	523	-	-	523	1,335
Website Costs	9,159	-	-	9,159	480
Marketing Expenses	6,705	-	-	6,705	1,560
Office Expenses	230	-	-	230	450
Travel Expenses	2,145	-	-	2,145	1,288
Subscription Fees	438	-	-	438	333
Accountancy Fees	240			240	240
Registry of sufferer	2,930			2,930	-
Event costs	1,193	-	-	1,193	8,442
<b>Sub total</b>	<b>23,563</b>	<b>-</b>	<b>-</b>	<b>23,563</b>	<b>14,128</b>
<b>A4 Asset and investment purchases, (see table)</b>					
Laptops	-	-	-	-	1,374
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>1,374</b>
<b>Total payments</b>	<b>23,563</b>	<b>-</b>	<b>-</b>	<b>23,563</b>	<b>15,502</b>
<b>Net of receipts/(payments)</b>	<b>- 8,886</b>	<b>-</b>	<b>-</b>	<b>- 8,886</b>	<b>- 2,061</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>70,603</b>	<b>-</b>	<b>-</b>	<b>70,603</b>	<b>72,664</b>
<b>Cash funds this year end</b>	<b>61,717</b>	<b>-</b>	<b>-</b>	<b>61,717</b>	<b>70,603</b>

# 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	1,867	-	-
	HSBC Deposit Account	59,850	-	-
		-	-	-
	<b>Total cash funds</b>	<b>61,717</b>	<b>-</b>	<b>-</b>

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

OK

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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

*V. Clark*  
*D. Lawson*

VIVIANNE CLARK  
DAVID LAWSON

19/02/2020  
19/02/2020