



# Trustees' Annual Report for the period

Period start date		Period end date	
25	July	24	July
2017		2018	
<b>From</b>		<b>To</b>	

## 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		
<b>Postcode</b>	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		
3				
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9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				

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

Name	Dates acted if not for whole year
Bob Stott	25 July 2017 – 17 June 2018
Twila D'Cruz	
David Lawson	
Jackie Imrie	

**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.

It was decided that new leaflets should be produced to bring the information up to date, so this will be pursued in the coming year.

It was also decided to update the website and, again, this will be extensively modernised in the forthcoming year.

A Registry of sufferers of MLD in the UK will be produced which would be available to scientists and clinicians. This work had just begun at the end of this financial year, and will be continued in the forthcoming year.

A Conference for scientists and families was held at Wyboston Lakes on 8<sup>th</sup> June for Scientists and 9<sup>th</sup> June for families. The conference provided an opportunity for scientists and clinicians to meet up and discuss MLD and future advance in treatment. Families learned about coping with children and adults with MLD and also about future research to find a cure.

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)**

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

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

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.

**Summary of the main achievements of the charity during the year**

In June 2018 MLD Support Association UK held a scientific and family Conference at Wyboston Lakes, bringing together top clinicians and scientists in the field of MLD and Leukodystrophies. The family conference provided the opportunity to learn about coping with MLD and also information on new research. It was a great success and another Conference will be held in 2020

## 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*

*D. Lawson*

**Full name(s)**

Vivienne Clark

David Lawson

**Position (eg Secretary, Chair, etc)**

Chair and Trustee

TRUSTEE

**Date**

26 March 2018





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 25.07.17	To	Period end date 24.07.2018
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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	13,098	-	-	13,098	5,698
HMRC Gift Aid	343	-	-	343	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>13,442</b>	<b>-</b>	<b>-</b>	<b>13,442</b>	<b>5,698</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>13,442</b>	<b>-</b>	<b>-</b>	<b>13,442</b>	<b>5,698</b>
<b>A3 Payments</b>					
Charitable Donations		-	-	-	
Bank Charges		-	-	-	
Administration Expenses	1,335	-	-	1,335	481
Website Costs	480	-	-	480	872
Marketing Expenses	1,560	-	-	1,560	422
Office Expenses	450	-	-	450	370
Travel Expenses	1,288	-	-	1,288	1,700
Subscription Fees	333	-	-	333	-
Accountancy Fees	240	-	-	240	240
Event costs	8,442	-	-	8,442	1,533
<b>Sub total</b>	<b>14,128</b>	<b>-</b>	<b>-</b>	<b>14,128</b>	<b>5,618</b>
<b>A4 Asset and investment purchases, (see table)</b>					
Laptops	1,374	-	-	1,374	
	-	-	-	-	
<b>Sub total</b>	<b>1,374</b>	<b>-</b>	<b>-</b>	<b>1,374.47</b>	<b>-</b>
<b>Total payments</b>	<b>15,502</b>	<b>-</b>	<b>-</b>	<b>15,502</b>	<b>5,618</b>
<b>Net of receipts/(payments)</b>	<b>- 2,061</b>	<b>-</b>	<b>-</b>	<b>- 2,061</b>	<b>80</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>72,664</b>	<b>-</b>	<b>-</b>	<b>72,664</b>	<b>72,584</b>
<b>Cash funds this year end</b>	<b>70,603</b>	<b>-</b>	<b>-</b>	<b>70,603</b>	<b>72,664</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	4,603	-	-
HSBC Deposit Account	66,000	-	-
	-	-	-
<b>Total cash funds</b>	<b>70,603</b>	<b>-</b>	<b>-</b>
(agree balances with receipts and payments account(s))	OK	OK	OK

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

## B2 Other monetary assets

	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-

## 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

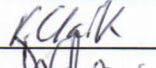
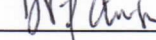
Details	Fund to which liability relates	Amount due (optional)	When due (optional)
		-	
		-	
		-	
		-	
		-	

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

Signature

Print Name

Date of approval

	VIVienne CLARK	20/2/2019
	DAVID LAWSON	20/2/2019