



Trustees' Annual Report for the period

| | | |
|------|-------------------|-----------------|
| | Period start date | Period end date |
| From | 25 July 2020 | To 24 July 2021 |

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 | | |
| 3 | | | | |
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| 18 | | | | |
| 19 | | | | |

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)

Section B

Structure, governance and management

Description of the charity's trusts

| | |
|--|--|
| Type of governing document <small>(eg. trust deed, constitution)</small> | Charitable Incorporated Organisation Constitution |
| How the charity is constituted <small>(eg. trust, association, company)</small> | Trust |
| Trustee selection methods <small>(eg. appointed by, elected by)</small> | 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)

| | |
|--|--|
| <p>You may choose to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> • 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. | <p>We require all Trustees to undertake a DBS check, and to take an active role in the administration and activities of the CIO.</p> |
|--|--|

Section C

Objectives and activities

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. The website has also been updated regularly to reflect information available and events.

The following announcements were made on our website:

28 August 2020
We announced a Survey to understand the MLD patient and care-giver experience. This research is extremely important for us to gather, so we can ensure that regulatory bodies such as NICE and the NHS fully understand the effects of MLD on patients and families, and that we do our best to secure access to therapies and support future access to Newborn Screening

15 September 2020
Exciting news! Funding from the Coronavirus Community Support Fund, distributed by The National Lottery Community Fund, means that MLD Support Association UK are able to offer Covid Care Packages to our UK superheroes.

22 Jan 2021
We announced that for people with MLD, the British Inherited Metabolic Disease Group (BIMDG), has stated that either of the COVID-19 vaccinations offered is considered safe for all inherited metabolic disorders.

12 July 2021
Following long discussions around the current worldwide status of Registries for MLD and because of the unforeseen delays in getting the UK registry up and running, it has been decided to change our plans. It is extremely important to have a National Database of all known families in order to keep them updated on developments, and to be able to contact them. We have, therefore, decided to create the National MLD Families Database which will be held by MLD Support Association UK, strictly adhering to GCP guidelines. It will be safe and secure

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

Summary of the main achievements of the charity during the year

The CIO has continued to spread awareness of MLD through the distribution of explanatory leaflets to health professionals and families. The website has also been updated regularly to reflect information available and events

The achievements have included:

Providing up-to-date information on the Coronavirus epidemic, including advice on vaccinations for those with MLD.

Introducing a National Database which would show all sufferers of MLD in the UK

The introduction of a comprehensive survey for MLD patients and care-givers.

Continued updating of website.

Further details of all these achievements 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

5 May 2022



Charity Name
MLD Support Association UK

No (if any)
1150542

Receipts and payments accounts

CC16a

| For the period from | Period start date | To | Period end date |
|---------------------|-------------------|----|-----------------|
| | 25.07.2020 | | 24.07.2021 |

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 | | | | | |
| Donations | 9,254 | - | - | 9,254 | 8,068 |
| HMRC Gift Aid | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| Sub total (Gross income for AR) | 9,254 | - | - | 9,254 | 8,068 |
| A2 Asset and investment sales, (see table). | | | | | |
| | - | - | - | - | - |
| | - | - | - | - | - |
| Sub total | - | - | - | - | - |
| Total receipts | 9,254 | - | - | 9,254 | 8,068 |
| A3 Payments | | | | | |
| Administration Expenses | 487 | - | - | 487 | 702 |
| Website Costs | 3,337 | - | - | 3,337 | 5,856 |
| Marketing Expenses | 1,375 | - | - | 1,375 | 328 |
| Office Expenses | 570 | - | - | 570 | 401 |
| Travel Expenses | - | - | - | - | 391 |
| Subscription Fees | 256 | - | - | 256 | 316 |
| Accountancy Fees | 240 | - | - | 240 | 240 |
| Registry of sufferer | 3,038 | - | - | 3,038 | 4,000 |
| Event costs | 4,103 | - | - | 4,103 | 2,306 |
| Sub total | 13,405 | - | - | 13,405 | 14,540 |
| A4 Asset and investment purchases, (see table) | | | | | |
| Laptops | - | - | - | - | - |
| | - | - | - | - | - |
| Sub total | - | - | - | - | - |
| Total payments | 13,405 | - | - | 13,405 | 14,540 |
| Net of receipts/(payments) | - 4,152 | - | - | - 4,152 | - 6,472 |
| A5 Transfers between funds | - | - | - | - | - |
| A6 Cash funds last year end | 55,245 | - | - | 55,245 | 61,717 |
| Cash funds this year end | 51,093 | - | - | 51,093 | 55,245 |

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 | 5,243 | - | - |
| | HSBC Deposit Account | 45,850 | - | - |
| | | - | - | - |
| | Total cash funds | 51,093 | - | - |
| | (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 |
| | V. CLARK | VIVIANNE CLARK | 5/5/2022 |