



Trustees' Annual Report for the period

Period start date

From

Period end date

To

Day
10
Month
FEBRUARY
Year
2020

Day
31
Month
MARCH
Year
2021

Charity name

DDX3X SUPPORT UK

Other names charity is known by

Registered charity number (if any)

1187846

Charity's principal address

Biggins Lodge Farmhouse

High Biggins

Carnforth

Postcode LA6 2NP

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)

Clare Millington
Chair

1

Carol Field

2

Alicia Makinson

3

Paul Bates

4

Amy Clarkson

June 2020

5

6

7

8

14

15

16

17

18

19

20

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

Name
Dates acted if not for whole year
TAR

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
(eg. trust deed, constitution)

Constitution

How the charity is constituted
(eg. trust, association, company)

Charitable Incorporated Organisation

Trustee selection methods
(eg. appointed by, elected by)

Appointment by existing trustees

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.

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 general public and medical profession in all areas relating to the conditions caused by mutations of the DDX3X gene.
2. The relief of sickness and preservation and protection of good health by sharing information on the DDX3X condition.
3. To promote and protect the physical and good mental health of sufferers of DDX3X in the UK, their families and carers through the provision of opportunities to meet together for mutual support.

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 Charity has a website that provides a valuable source of information for DDX3X Syndrome benefitting those affected or concerned by the condition.

We have a Facebook Group providing information for the general public, we also have a closed Facebook group to provide support to members.

Zoom meets were held inviting the DDX3X community to join us for a supportive group chat. As F2F suspended

Promotes the charity and raises awareness through media, organised events and networking.

Registered with Enthuse to enable donations and gift aid (once registered) to be managed by them

19 DDX3X families joined the Bingo (Brain and Behaviour in Intellectual Disability of known Genetic Origin) research study held by the University of Cambridge and feedback was received from the study. DDX3X was the largest cohort in the study and anxiety was a much more marked in DDX3X than any other condition.

All activities have been undertaken with due regard to the guidance issued to trustees by the Charity Commission on public benefit

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.
- Application submitted to HMRC for gift aid

Section D

Achievements and performance

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

The charity was recently registered as a CIO in February 2020

Contact from families diagnosed continues to grow and we now have 160 supporter and we have 83 families identified as having a diagnosis of DDX3X Syndrome - that have joined our facebook group

Fundraising events were held – Pip’s Canoe Challenge, a daily blog reached out to over 14000 people helping to raise awareness of DDX3X and over £3000 was raised.

The charity chair attended Concord co-ordinated care for rare conditions webinar.

The charity chair joined meetings organised by the Rare resilience program run by a counsellor bringing together small charities, discussing similar concerns regarding various rare conditions.

Trustees have researched and reached out to other rare chromosome groups with similar conditions to gain knowledge on support they offer to members and specialist clinics they hold.

The chair has had a meeting with Lauren Roberts from Genetic Alliance UK for help and guidance of a job description / job specification for a person to possibly be recruited by the charity.

The idea of information packs for families with a recent diagnosis were discussed.

Section E

Financial review

Brief statement of the charity's policy on reserves

Because we have minimal fixed outgoings there is no reason at present that we need to have a reserve. However, in the future we are considering having a £1k in reserve.

Details of any funds materially in deficit

N/A

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 G

Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)

Full name(s)

Clare Millington
Carol Field

Position (eg Secretary, Chair, etc)

Chair

Date

25/11/2021



Receipts and payments account

For the period from	###	To
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Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £
A1 Receipts			
Donations Direct (2)	1,182	-	-
Just Giving	701	-	-
Enthuse	2,683	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-
Sub total (Gross income for AR)	4,566	-	-
A2 Asset and investment sales, (see table).			
	-	-	-
	-	-	-
Sub total	-	-	-
Total receipts	4,566	-	-
A3 Payments			
Enthuse	168	-	-
Zoom	115	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-
Sub total	283	-	-
A4 Asset and investment purchases, (see table)			
	-	-	-
	-	-	-
Sub total	-	-	-
Total payments	283	-	-
Net of receipts/(payments)	4,283	-	-
A5 Transfers between funds	-	-	-
A6 Cash funds last year end	6,798	-	-

<i>Cash funds this year end</i>	11,081	-	-
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Section B Statement of assets and liabilities at the end of

Categories	Details	Unrestricted funds to nearest £
B1 Cash funds	Cash in Bank	11,081
		-
		-
	Total cash funds	11,081
	(agree balances with receipts and payments account(s))	OK
B2 Other monetary assets	Details	
		-
		-
		-
		-
		-
		-
B3 Investment assets	Details	Fund to which asset belongs
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs
B5 Liabilities	Details	Fund to which liability relates

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

Signature

Print N

Clare Mil
Carol I



Total funds	Last year
to the nearest £	to the nearest £
1,182	-
701	-
2,683	-
-	-
-	-
-	-
-	-
-	-
4,566	-
-	-
-	-
-	-
4,566	-
168	-
115	-
-	-
-	-
-	-
-	-
-	-
-	-
-	-
283	-
-	-
-	-
-	-
283	-
4,283	-
-	-
6,798	-

11,081	-
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the period

Restricted funds to nearest £	Endowment funds to nearest £
-	-
-	-
-	-
-	-
OK	OK

Restricted funds to nearest £	Endowment funds to nearest £
-	-
-	-
-	-
-	-
-	-
-	-

Cost (optional)	Current value (optional)
-	-
-	-
-	-
-	-
-	-

Cost (optional)	Current value (optional)
-	-
-	-
-	-
-	-
-	-
-	-
-	-
-	-
-	-

Amount due (optional)	When due (optional)
-	
-	

-	
-	
-	

lame	Date of approval
lington	11/25/2021
Field	11/25/2021

Accounts for 10 February 2020 - 31 March 2021

Cash

02/10/2020 Opening Cash Balance	6798.40
Closing Cash Balance	11081.27

Receipts

07/27/2020 Donation - Cheque Received	1000.00
09/21/2020 Enthuse	1026.67
10/15/2020 Just Giving	452.33
10/20/2020 Enthuse	1646.54
10/21/2020 Just Giving	132.12
10/27/2020 Just Giving	116.72
11/19/2020 Enthuse	9.75
12/09/2020 Credit	181.77

Total Receipts	4565.90
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Payments

06/11/2020 Zoom	-115.10
09/08/2020 Enthuse	-23.99
10/01/2020 Enthuse	-23.99
10/30/2020 Enthuse	-23.99
12/02/2020 Enthuse	-23.99
01/04/2020 Enthuse	-23.99
02/01/2020 Enthuse	-23.99
03/04/2020 Enthuse	-23.99

Total Payment	-283.03
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Enthuse	2682.96
Just Giving	701.17

Enthuse	-167.93
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