



Trustees' Annual Report for the period

From		Period start date			To		Period end date		
		Day	Month	Year			Day	Month	Year
		01	APRIL	2022			31	MARCH	2023

Section A Reference and administration details

Charity name

Other names charity is known by

Registered charity number (if any)

Charity's principal address

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	Clare Millington	Chair		
2	Carol Field			
3	Alicia Makinson			
4	Paul Bates			
5	Amy Clarkson			
6	Anna Cole		From 09.12.2022	Voted in by all trustees
7				
8				
9				
10				
11				
12				
13				
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

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)	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.

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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.

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

Registered with HMRC to claim gift aid tax back on donations using charities online.

We are registered with Enthuse and they manage our donations and claim gift aid back on the charities behalf.

Our first newsletter was published available for families to access a copy on our facebook page.

A family meetup day was held at Thomley in Buckinghamshire in July 2022. This was a great success and 9 families attended, for many it was the first time they had met another person with DDX3X.

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.

Summary of the main achievements of the charity during the year

The charity is registered with HMRC and gift aid is claimed back by Enthuse on the charities behalf.

The charity is registered with SmileAmazon and continued to receive donations with SmileAmazon up until the 20 February 2023 when the scheme sadly ended.

A donate button was added to our website <https://ddx3xsupport.co.uk>

Contact from families identified as having a diagnosis to join our closed facebook group continues to grow steadily, the first diagnoses in Wales joined the group, whilst diagnosis from Scotland and Ireland are low.

Fundraising events were held by the DDX3X community including a 3 legged walk, a 5k walk and a half marathon - all of these helped to raise awareness of DDX3X.

We continue to receive 2 regular monthly direct debits.

£1800 was received from the DDX3X Foundation this subsidised DDX3X Support UK meetups - a weekend for families at Bendrigg and a family day held at Thomley.

£1150 grant was received from the Yorkshire Dales for activities to take place in the local area, where a caving experience was enjoyed

It was agreed by all trustees that Nigel Over (retired chair of Smith-McGeniss – a similar condition as DDX3X) would be paid on an ad-hoc basis to help manage internships over the summer.

The charity chair attended an online public speaking course with the Beacon and also attended the DDX3X scientific conference online.

The charity chair entered into the Beacon for Rare Diseases patient group pairing for the annual student voice competition. A medical student from the Cambridge university interviewed Clare and the essay they wrote about DDX3X was entered into the competition. Even though the student did not win a prize this is once again an opportunity to raise awareness of DDX3X and is the 3rd year we have entered the competition.

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 continued to research 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.

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.

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 F

Other optional information

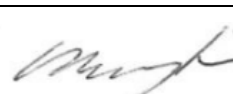
Section G

Declaration

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

Signed on behalf of the charity's trustees

Signature(s)



Full name(s)

Clare Millington

Carol Field

Position (eg Secretary, Chair, etc)

Chair

Treasurer

Date

18.01.2024

18.01.2024



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name
DDX3X SUPPORT UK

No (if any)
1187846

Receipts and payments accounts

CC16a

For the period
from

01 April 2022

To



Period end date

31 March 2023

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	5,204	-	-	5,204	5,875
Family contribution to Charity Events	52	-	-	52	870
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	5,256	-	-	5,256	6,745
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	5,256	-	-	5,256	6,745
A3 Payments					
Enthuse	288	-	-	288	312
Zoom	144	-	-	144	144
Charity Events inc Weekend Meetups	1,300	-	-	1,300	2,294
Merchandise	57	-	-	57	-
Insurance	128	-	-	128	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	1,916	-	-	1,916	2,749
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	1,916	-	-	1,916	2,749
Net of receipts/(payments)	3,340	-	-	3,340	3,996
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	15,077	-	-	15,077	11,081
Cash funds this year end	18,417	-	-	18,417	15,077

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	Cash in Bank	18,417	-	-
		-	-	-
		-	-	-
	Total cash funds	18,417	-	-
	(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	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
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	
		C Field	18.01.2024	
		C Millington	18.01.2024	