



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	Day 01	Month APRIL	Year 2021		Day 31	Month MARCH	Year 2022

Section A Reference and administration details

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)
1	Clare Millington	Chair		
2	Carol Field			
3	Alicia Makinson			
4	Paul Bates			
5	Amy Clarkson			
6				
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

A family weekend meetup at Bendrigg was organised for older DDX3X diagnoses.

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 was registered with HMRC to be able to claim back gift aid.

The charity was registered with SmileAmazon and easyfundraising, to help with raising funds when making a purchase with no cost to the buyer.

Contact from families diagnosed continues to grow and we now have 190 supporter and we have 86 families identified as having a diagnosis of DDX3X Syndrome - that have joined our facebook group

We had a May Fundraising event where Fundraising events were held by the DDX3X community – Clare's held a plant fundraising event, Carol held a cake bake at work and Amber had a birthday fundraiser – all of these helped to raise awareness of DDX3X.

In May we received our first regular monthly donation by direct debit followed in June by our second regular monthly donation.

Foot against the Floor a book of poems and short stories about living with complex needs was published by the Clare and her husband Gary and all proceeds went to the charity.

A royal ascot ladies day charity lunch was held on 17th June at Luciano's in Bolton with DDX3X being one of the charities being supported - £1400 was donated to the charity.

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

The charity chair joined the DDX3X day of learning run by the ICAHN school of medicine in New York. Part of the 3 hour presentation was a study of mice that showed when given the DDX3X gene they did have a normal life expectancy.

The chair entered into the Beacon for Rare Diseases patient group pairing for the annual student voice competition. A medical student from the university of Buckingham 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 an opportunity to raise awareness of DDX3X.

Paul Bates trustee completed Clinical guidelines – a list of different conditions associated with DDX3X.

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	17.12.2022	17.12.2022



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name
DDX3X SUPPORT UK

No (if any)
1187846

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Receipts and payments accounts

For the period from	01 April 2021	To	Period end date 31 March 2022
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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 £
A1 Receipts					
Donations	5,875	-	-	5,875	4,566
Family contribution to Charity Events	870	-	-	870	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	6,745	-	-	6,745	4,566
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	6,745	-	-	6,745	4,566
A3 Payments					
Enthuse	312	-	-	312	168
Zoom	144	-	-	144	115
Charity Events inc Weekend Meetups	2,294	-	-	2,294	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	2,749	-	-	2,749	283
A4 Asset and investment purchases. (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	2,749	-	-	2,749	283
Net of receipts/(payments)	3,996	-	-	3,996	4,283
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	11,081	-	-	11,081	6,798
Cash funds this year end	15,077	-	-	15,077	11,081

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	15,077	-	-
		-	-	-
		-	-	-
	Total cash funds	15,077	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
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	
		Carol Field	17.12.2022	
		Clare Millington	17.12.2022	