



## Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	Day	Month	Year		Day	Month	Year
	01	APRIL	2023		31	MARCH	2024

### 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 to Jan 2024		
2	Carol Field			
3	Alicia Makinson		Resigned 18.01.2024	
4	Paul Bates			
5	Amy Clarkson			
6	Anna Cole	Chair from Jan 2024		Voted in by all trustees
7	Geoff Kermod		From 15.02.2024	Voted in by all trustees
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.

## 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. The website has a donate button for visitors / families to donate towards the Charity.

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.

Newsletters continue to be published on an annual and ad-hoc basis these are available for families to access a copy on our facebook page.

For the second year a family meetup day was held at Thomley in Buckinghamshire in June 2023. This was a great success, with 5 families attending, for some it was the first time they had met another person with DDX3X.

An online sensory workshop was provided by Hanna Munro (OT) to DDX3X families, this was really beneficial providing much needed practical advice. Trustees agreed to fund working further with Hanna to provide a more tailored service would enhance lives for DDX3X families. This work continues.

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.

Contact from families identified as having a diagnosis to join our closed facebook group does continue, although this seems to have slowed down this year. Diagnoses in Ireland, Scotland and Wales still remain low.

Fundraising events were held by the DDX3X community including money donated instead of Wedding presents, a donation received from LV, money donated from participating in the London Marathon and a sail across the Atlantic where DDX3X Support UK were one of the Charities that received fundraising money raised. £6k was also raised from a 3000km bike ride across New Zealand, further donations were also received into the next tax year - all of these helped to raise awareness of DDX3X.

We continue to receive 2 regular monthly direct debits.

Over the summer, the charity chair worked with 2 interns on several projects, one to produce new resources including a patient passport and the other a data collection project. We are now looking at producing these in a suitable format to benefit our families.

The charity chair entered into the Beacon for Rare Diseases patient group pairing for the annual student voice competition. A medical student from 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 4<sup>th</sup> year we have entered the competition.

The Rare resilience program run by a counsellor bringing together small charities, discussing similar concerns regarding various rare conditions, continues to be a beneficial resource for the charity.

The new charity chair signed up with Rare Beacon Patient Group Mentoring Programme 2024-25 and has been matched with a mentor for a year. The programme helps patient support groups get established, build their capacity and streamline their work in order to improve patient support services, implement new projects and/or increase their involvement in research.

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.

The Bingo project once again continues to reach out to DDX3X families, Bingo is a great flag bearer for DDX3X and helps towards the research.

DDX3X Speech and Language Murdoch Children's research institute (Australia) produced a report that was shared with DDX3X families.

## 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

<b>Signature(s)</b>		
<b>Full name(s)</b>	Anna Cole	Carol Field
<b>Position (eg Secretary, Chair, etc)</b>	Chair	Treasurer
<b>Date</b>	18.01.2025	18.01.2025



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 2023	To	Period end date 31 March 2024
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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	12,798	-	-	12,798	5,204
Family contribution to Charity Events	36	-	-	36	52
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>12,834</b>	<b>-</b>	<b>-</b>	<b>12,834</b>	<b>5,256</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>12,834</b>	<b>-</b>	<b>-</b>	<b>12,834</b>	<b>5,256</b>
<b>A3 Payments</b>					
Enthuse	336	-	-	336	288
Zoom	-	-	-	-	144
Charity Events inc Weekend Meetups	155	-	-	155	1,300
Merchandise	67	-	-	67	57
Insurance	-	-	-	-	128
Other	737	-	-	737	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>1,294</b>	<b>-</b>	<b>-</b>	<b>1,294</b>	<b>1,916</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>1,294</b>	<b>-</b>	<b>-</b>	<b>1,294</b>	<b>1,916</b>
<b>Net of receipts/(payments)</b>	<b>11,539</b>	<b>-</b>	<b>-</b>	<b>11,539</b>	<b>3,340</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>18,417</b>	<b>-</b>	<b>-</b>	<b>18,417</b>	<b>15,077</b>
<b>Cash funds this year end</b>	<b>29,956</b>	<b>-</b>	<b>-</b>	<b>29,956</b>	<b>18,417</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 £
<b>B1 Cash funds</b>	Cash in Bank	29,956	-	-
		-	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	29,956	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
<b>B2 Other monetary assets</b>	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>	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	18.01.2025	
		Anna Cole	18.01.2025	