



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	Day	Month	Year		Day	Month	Year
	01	APRIL	2024		31	MARCH	2025

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	Anna Cole	Chair		
2	Carol Field			
3	Clare Millington			
4	Paul Bates			
5	Amy Clarkson			
6	Geoff Kermode			
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. 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 third year a family meetup day was held at Thomley in Buckinghamshire in May 2024. This was a great success, with 9 families attending, for some it was the first time they had met another person with DDX3X.

Hanna Munro (OT) continues to work with DDX3X families. 2 OT students spoke with DDX3X families, working towards providing a more tailored service to help 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 highlights included a charity run which raised over £1k, Anna Cole (our Chair of Trustees) completed the Swim 22 Challenge and raised £1300, plus £500 from her employer LV. In April 2024 an additional £6000 donation was received for the 3000km Bike Ride across New Zealand carried out in Jan 2024. £5591 donation was received in Jan 2025, for a Sail Across the Atlantic. £511 in donations were also received from Much Loved.

We continue to receive 2 regular monthly direct debits.

Our families have started to sign up with Easyfundraising and we received our first donation in Feb of £31.19

Once again we entered into the Beacon for Rare Diseases patient group pairing for the annual student voice competition. A medical student from Oxford University interviewed 2 of our trustees/DDX3X parents (Anna and Clare), 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 5th year we have entered the competition.

The Charity Chair continues working with the Rare Beacon Patient Group Mentoring Programme 2024-25. This 12-month programme incorporates (1) Mentor 'Empowerment Training' (Mental Health & Resilience, Project Management, Strategy), (2) Mentor Pairing with 4 goals to support the patient support group, (3) In-Person & Virtual Events & Networking, (4) Access to a Resource Hub.

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.

CamRARE have produced a 'this is me passport', it is branded to each charity, so the DDX3X Support UK logo would be on the passport. The link was posted to our families so they could download and print this off at home. This important information about your child can then be passed on to medical and care staff.

Rarefest, which took place in October had on display a set of tapestries with a representation of the DDX3X Gene, designed by Lizzie Radford. This once again helped raise awareness of DDX3X.

Trustees held a strategy day in January to plan for the year ahead and look at how to grow the charity.

To mark Rare Disease Day in February 2025, Genetic Alliance asked for families to write a story, poem, artwork that bring to life the experiences of individuals within the genetic, rare and undiagnosed communities. Two pieces from DDX3X families were included in the 'More than you can imagine' anthology, which was then displayed in the English, Welsh and Scottish parliaments.

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)	Anna Cole	Carol Field
Position (eg Secretary, Chair, etc)	Chair	Treasurer
Date	03.07.2025	03.07.2025



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 2024	To	Period end date 31 March 2025
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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	16,137	-	-	16,137	12,798
Family contribution to Charity Events	-	-	-	-	36
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	16,137	-	-	16,137	12,834
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	16,137	-	-	16,137	12,834
A3 Payments					
Enthuse	384	-	-	384	336
Zoom	96	-	-	96	-
Charity Events inc Weekend Meetups	192	-	-	192	155
Merchandise	437	-	-	437	67
Insurance	96	-	-	96	-
Other	159	-	-	159	737
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	1,364	-	-	1,364	1,295
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	1,364	-	-	1,364	1,295
Net of receipts/(payments)	14,773	-	-	14,773	11,539
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	29,956	-	-	29,956	18,417
Cash funds this year end	44,729	-	-	44,729	29,956

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	44,729	-	-
		-	-	-
		-	-	-
		-	-	-
	Total cash funds	44,729	-	-
	(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 Anna Cole	03.07.2025 03.07.2025	