CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From 01/01/22 Period start date To
Period end date 31/12/22

Charity name: GLUT1 DEFICIENCY UK

Charity registration number: 1192599

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	Glut1 Deficiency UK aims to support carers and patients impacted by Glut1DS in the UK and Ireland. Increasing awareness of Glut1 Deficiency Syndrome (Glut1DS) Improved education for families and health professionals in relation to Glut1DS. Advocacy for families and patients impacted by Glut1DS. Support and funding for Glut1DS research
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	Providing Advocacy/advice/information **The main activities include raising awareness of the condition amongst professionals, caregivers via event attendance, social media and building networks and partnerships.**
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	**The trustees have had regard to the guidance issues by the Commission on public benefit**

Additional information (optional)
You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	

Policy on social investment including program related investment	Para 1.38	
Contribution made by volunteers	Para 1.38	
Other		

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	We are steadily building our networks and partnerships with UKRET (Rare Epilepsies Together), Neurological Alliance, Rare Disease UK, Genetic Alliance, Gene People, Eurodis, and Beacon while raising awareness of Glut1DS throughout the wider community and medical field We have also been building on our connections with the Cross Party parliamentary Group members across the UK by highlighting our specific needs as a Rare Disease, through the UK Rare Diseases Framework and its commitment from all four health ministers across the UK to improve the lives of people affected by rare diseases; we hope to raise the profile of Glut1 Deficiency and the needs of our community. Hosting regular super carer's zoom sessions for patients and carers of loved ones with Glut1 DS. Engaging the wider community. Attended and presented at Mathews Friends Keto Education Day. Participated and celebrated International Glut1 Awareness Day Collocating with Epilepsy Sparks participating in a video raising

		awareness a Networking and participating under the Rare Epilepsies together umbrella. Presented at the Young Epilepsy Professional Event in London Attended the Keto family day – engaging with families and sharing experiences of te Ketogenic diet. Presented at the Glut1 Deficiency European Conference in Aschaffenburg Germany. Participated in the Patient Pairing Scheme for The Student Voice Prize Attended the ILA Conference in Dublin – actively engaged in discussions, connecting with neurologists. Sharing crucial information about Glut1 Deficiency. We raised awareness of Glut1DS throughout our Social Media Platforms for Rare Disease Day, International Epilepsy Day, Brain Awareness Week, Purple Day, National Epilepsy Week, World Brain Day, World Mental Health Day and National Epilepsy Week through our project's including Find Someone With Glut1 targeting the undiagnosed and misdiagnosed patients with Glut1DS.

Additional information (optional)
You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	
Performance of fundraising activities against objectives set	Para 1.41	
Investment performance against objectives	Para 1.41	

Other		

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	Income surplus of £5,942
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	Reserves are intended to be held at an appropriate level to cover operational expenditure and commitments.
Amount of reserves held	Para 1.22	£15,966
Reasons for holding zero reserves	Para 1.22	N/a
Details of fund materially in deficit	Para 1.24	N/a
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	N/a

Additional information (optional)
You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	
Investment policy and objectives including any social investment policy adopted	Para 1.46	
A description of the principal risks facing the charity	Para 1.46	
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document (trust deed, royal charter)	Para 1.25	Trust deed
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	CIO - Association Registered 01 Dec 2020
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Minimum of 3 trustees appointed on a rotational basis

Additional information (optional)
You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	
The charity's organisational structure and any wider network with which the charity works	Para 1.51	
Relationship with any related parties	Para 1.51	
Other		

Reference and Administrative details

Charity name	GLUT1 DEFICIENCY UK
Other name the charity uses	
Registered charity number	1192599
Charity's principal address	2 East Grimsby, Arbroath, DD11 1PA

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	Trudy Jane Morgan		27 Nov 2020 – current	
2	Stefanie Plomer		27 Nov 2020 – current	
3	Sheena Cunniffe		27 Nov 2020 – current	
4				
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Corporate trustees – names of the directors at the date the report was approved

Director name		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

Exemptions from disclosure

Reason for non-disclosure of key personnel details

Other optional information

Declarations

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

Signed on behalf of the charity's trustees

Signature(s)	Stefanie Plomer	
Full name(s)	Stefanie Plomer	
Position (eg Secretary, Chair, etc)	Secretary	
Date	17/10/2023	

CHARITY COMMISSION FOR ENGLAND AND WALES

Glut 1 Deficiency UK	1192599

Receipts and payments accounts

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For the period from	01/01/2022	To	31/12/2022

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	8,524	-	-	8,524	11,104
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
***Sub total** (Gross income for AR)*	8,524	-	-	8,524	11,104
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	8,524	-	-	8,524	11,104
A3 Payments					
Professional fees	-	-	-	-	900
Sundry	282	-	-	282	180
Postage, stationery & advertising	1,938	-	-	1,938	-
Travel expenses	362	-	-	362	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	2,582	-	-	2,582	1,080
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	2,582	-	-	2,582	1,080
Net of receipts/(payments)	5,942	-	-	5,942	10,024
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	10,024	-	-	10,024	-
Cash funds this year end	15,966	-	-	15,966	10,024

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	Bank account	15,966	-	
		-	-	-
		-	-	-
	Total cash funds	15,966	-	-

(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
	Sheena Cunniffe	17/10/2023