CHARITY COMMISSION
FOR ENGLAND AND WALES

## Trustees' Annual Report for the period

**From 01/01/24** **Period start date** **To**
**Period end date 31/12/24**

**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<br>**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<br>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.<br><br>We have worked alongside many organisations throughout 2024 to raise the profile of the charity and of the condition.<br><br>Beacon For Rare Diseases<br>Rare Revolution Magazine<br>Epilepsy Research UK<br>Matthew's Friends<br>Epilepsy Sparks/ Torie Robinson<br>RDNN Rare Disease Nurse Network<br>Genetic Alliance<br>Eurodis<br>Metabolic Support UK<br>The Journal of Inherited Metabolic Disease<br>M4RD Medics for Rare Diseases<br>Wales Gene Park Genomics Partnership Wales |

| | | |
|---|---|---|
| | | During the year we have:<br><br>Attended the BPNA Annual Conference in Edinburgh<br>Exhibited at Mathew's Friends Ketogenic Dietary Therapies event<br>Attended the 4th European Glut 1 Deficiency Conference in Germany<br>Attended the International Epilepsy Congress in Dublin, Ireland<br>Attended an All Parliamentary Group meeting for rare, genetic and undiagnosed diseases |

**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 for the year of £1,833 |
| 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 | £17,531 |
| 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 | | | |
| 2 | Stefanie Plomer | | | |
| 3 | Sheena Cunniffe | | | |
| 4 | | | | |
| 5 | | | | |
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| 16 | | | | |
| 17 | | | | |
| 18 | | | | |
| 19 | | | | |
| 20 | | | | |

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)** | | |
| **Full name(s)** | Sheena Cunniffe | |
| **Position (eg Secretary, Chair, etc)** | Trustee | |
| **Date** | 31/10/2025 | |

CHARITY COMMISSION FOR ENGLAND AND WALES

| Glut 1 Deficiency UK | 1192599 |
|---|---|

# Receipts and payments accounts

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| For the period from | 01/01/2024 | To | 31/12/2024 |
|---|---|---|---|

## 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 | 4,825 | - | - | 4,825 | 3,378 |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| ***Sub total*** *(Gross income for AR)* | 4,825 | - | - | 4,825 | 3,378 |
| **A2 Asset and investment sales, (see table).** | | | | | |
| | - | - | - | - | |
| | - | - | - | - | - |
| ***Sub total*** | - | - | - | - | - |
| ***Total receipts*** | 4,825 | - | - | 4,825 | 3,378 |
| **A3 Payments** | | | | | |
| Sundry | 208 | - | - | 208 | 1,137 |
| Postage, stationery & advertising | 550 | - | - | 550 | 1,262 |
| Travel expenses | 2,234 | - | - | 2,234 | 1,247 |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| ***Sub total*** | 2,992 | - | - | 2,992 | 3,646 |
| **A4 Asset and investment purchases. (see table)** | | | | | |
| | - | - | - | - | |
| | - | - | - | - | |
| ***Sub total*** | - | - | - | - | - |
| ***Total payments*** | 2,992 | - | - | 2,992 | 3,646 |
| ***Net of receipts/(payments)*** | 1,833 | - | - | 1,833 | - 268 |
| **A5 Transfers between funds** | | - | - | - | |
| **A6 Cash funds last year end** | 15,698 | - | - | 15,698 | 15,966 |
| ***Cash funds this year end*** | 17,531 | - | - | 17,531 | 15,698 |

## 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 | 17,531 | - | |
| | | - | - | - |
| | | - | - | - |
| | ***Total cash funds*** | 17,531 | - | - |
| | (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) |
|---|---|---|---|
| | | - | - |
| | | - | - |
| | | - | - |
| | | - | - |
| | | - | - |

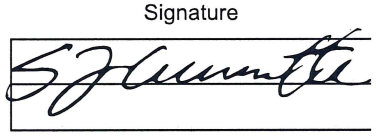
## B4 Assets retained for the charity's own use

| 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 | 17/10/2025 |
| | | |