



**CHARITY COMMISSION**  
FOR ENGLAND AND WALES

## Trustees' Annual Report for the period

From Period start date 1 April 2023 to Period end date 31 March 2024

Charity name: DC Action

Charity registration number: 1167150

## Objectives and Activities

|  | SORP reference     |  |
|--|--------------------|--|
| Summary of the purposes of the charity as set out in its governing document  | Para 1.17          | <ul style="list-style-type: none"><li>• To preserve and protect the health of patients with Dyskeratosis Congenita and other Telomere Disorders, by providing and assisting in the provision of facilities, support services and educational materials not normally provided by the statutory authorities.</li><li>• To advance the education of the public by the publication of a website, newsletters, information sheets and other materials.</li><li>• To promote and protect the physical and mental health of those affected by Dyskeratosis Congenita through the provision of advocacy, support, education and practical advice.</li><li>• To advance the education of the general public, medical and scientific professionals in all areas relating to Dyskeratosis Congenita and other telomere disorders.</li></ul> |
| 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 | <ul style="list-style-type: none"><li>• Principal Patient and Public Involvement organisation for DEMISTFI, a large UKRI funded study into multimorbidity.</li><li>• Participation in regular Better Together for Healthy Bone Marrow consortium meetings and joint projects.</li><li>• Dissemination of Mental Wellbeing and other Better Together courses to the DC Action community.</li><li>• Convenor of quarterly Community Support Meetings in conjunction with the Gary Woodward Dyskeratosis Congenita Trust.</li><li>• Attendance at the British Thoracic Society Meeting to raise awareness of Telomere Biology Disorders with respiratory physicians.</li></ul>  |

|  |           |  |
|--|-----------|--|
|  |           | <ul style="list-style-type: none"> <li>• Participation in Familial Pulmonary Fibrosis NHSE pathway development workshop.</li> <li>• Ongoing patient and family support.</li> <li>• Contributor to the Aplastic Anaemia Trust's Rare Voices Report.</li> <li>• Contributor to "Accessibility of Medical Products for Rare Diseases in the UK" (Dr. Eva Hilberg, University of Sheffield qualitative study)</li> <li>• Contributor to Medics for Rare Diseases medical student prize essay competition</li> <li>• Contributed to several other surveys re rare diseases</li> </ul> |
| 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 acted in accordance with the guidance issued by the Charity 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      | DC Action does not intend to disburse grants. However, the trustees will consider any request for a grant on a case-by-case basis, with due regard to the charity's aim and objectives.  |
| Policy on social investment including program related investment | Para 1.38      |  |
| Contribution made by volunteers                                  | Para 1.38      | <ul style="list-style-type: none"> <li>• Advocacy.</li> <li>• Governance.</li> <li>• Fundraising.</li> <li>• Provision of medical and scientific advice.</li> <li>• Providing a community reference.</li> <li>• Support to patients and their families.</li> <li>• Participation in conferences and meetings.</li> </ul> |
| 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      | <p>DC Action supported over 50 patients over the past year and new patients are contacting us on a regular basis. Raising awareness of Telomere Biology Disorders is one of DC Action's primary aims and we have done this by attendance at conferences and meetings and through exchanges with healthcare professionals and other organisations such as The Specialised Health Care Alliance and Medics for Rare Diseases.</p> <p>Through our work promoting genetic diagnosis,</p> <ul style="list-style-type: none"> <li>- there are now (limited) telomere biology disorder panels available to NHS respiratory physicians and haematologists.</li> <li>- uptake of telomere length testing is increasing (STELA method)</li> <li>- This has increased diagnosis rates and therefore allowed avoidance of ineffective/damaging treatments, while improving access to appropriate care.</li> </ul> <p>Through the Better Together Consortium (National Lottery Community Fund supported) we have offered mental wellbeing support, advice on financial support and hosted well attended, quarterly Community Meetings via Zoom which give patients living with these rare disorders the opportunity to come together to ask questions and discuss the most pressing issues they face.</p> |

### 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 | Although DC Action's funds of £9,170 at year end are modest, income of £4,307 exceeded expenditure of £1,854: the charity's financial situation is robust. Funds are being built up in anticipation of holding one or more major advocacy events in FY24-25. |
| Statement explaining the policy for holding reserves stating why they are held   | Para 1.22 | The trustees consider that there is currently no requirement for specific reserves to be set aside.  |
| Amount of reserves held  | Para 1.22 | Zero.  |
| Reasons for holding zero reserves  | Para 1.22 | The trustees consider that as funds are currently at a low level, there is no requirement for reserves. The trustees will review this policy annually.   |
| Details of fund materially in deficit  | Para 1.24 | Not applicable.  |
| Explanation of any uncertainties about the charity continuing as a going concern | Para 1.23 | DC Action's finances, though limited, are sound and set to build. Income streams are reliable and expenditure is limited.  |

### 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 | Grants from the National Lottery Community Fund via The Aplastic Anaemia Trust (principal applicant) and small individual private donations via JustGiving & The GivingMachine.  |
| Investment policy and objectives including any social investment policy adopted | Para 1.46 | The trustees consider that there are currently insufficient funds for investment. The trustees will review this policy annually.   |
| A description of the principal risks facing the charity                         | Para 1.46 | As DC Action's outputs are essentially advocacy, support and education, the principal risk is to our reputation. This is mitigated by having a mix of trustees, with backgrounds ranging from medical expertise to lay people.<br>DC Action is actively seeking to expand the number and range of expertise of its trustees. |
| Other   |           |  |

## Structure, Governance and Management

|   |           |   |
|---|-----------|---|
| Description of charity's trusts:  |           |   |
| Type of governing document (trust deed, royal charter)  | Para 1.25 | 'Foundation' model constitution.  |
| How is the charity constituted? (e.g unincorporated association, CIO)   | Para 1.25 | DC Action has a constitution of a Charitable Incorporated Organisation (CIO). |
| 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 | DC Action's only voting members are its charity trustees.                     |

### 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 | Trustees are referred to The Charity Commission's guidance on charity governance.   |
| The charity's organisational structure and any wider network with which the charity works | Para 1.51 | DC Action works closely with: <ul style="list-style-type: none"> <li>• Aplastic Anaemia Trust</li> <li>• Better Together for Healthy Marrow Alliance</li> <li>• British Thoracic Society</li> <li>• DEMISTIFI, NIHR</li> <li>• Gary Woodward Dyskeratosis Congenita Trust</li> <li>• Genetic Alliance</li> <li>• M4RD</li> <li>• Rare Beacon (medical student prize essay)</li> <li>• US charity Team Telomere</li> </ul> |
| Relationship with any related parties   | Para 1.51 |   |
| Other   |           |   |

**Reference and Administrative details**

|                             |  |
|-----------------------------|--|
| Charity name                | DC Action                                  |
| Other name the charity uses | (None).                                    |
| Registered charity number   | 1167150                                    |
| Charity's principal address | 83 Digby Crescent, London, England, N4 2HS |
|                             |  |

## 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  | Alice Buckley    | IT support               |                                   | Fellow trustees   |
| 2  | Willem Buckley   | Treasurer;<br>governance | From October 2023                 | Fellow trustees   |
| 3  | Hilary Longhurst | Medical Advisor          |                                   | Fellow trustees   |
| 4  | Jane Paxton      | Scientific Advisor       |                                   | Fellow trustees   |
| 5  |                  |                          |                                   |   |
| 6  |                  |                          |                                   |   |
| 7  |                  |                          |                                   |   |
| 8  |                  |                          |                                   |   |
| 9  |                  |                          |                                   |   |
| 10 |                  |                          |                                   |   |
| 11 |                  |                          |                                   |   |
| 12 |                  |                          |                                   |   |
| 13 |                  |                          |                                   |   |
| 14 |                  |                          |                                   |   |
| 15 |                  |                          |                                   |   |
| 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)                        | <i>Will Buckley</i> | <i>Jane K Paxton</i> |
| Full name(s)                        | Willem Buckley      | Jane Paxton          |
| Position (eg Secretary, Chair, etc) | Treasurer           | Scientific Adviser   |
| Date                                | 23 December 2024    |                      |



CHARITY COMMISSION  
FOR ENGLAND AND WALES

|                           |                        |
|---------------------------|------------------------|
| Charity Name<br>DC Action | No (if any)<br>1167150 |
|---------------------------|------------------------|

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## Receipts and payments accounts

|                        |                                |    |                              |
|------------------------|--------------------------------|----|------------------------------|
| For the period<br>from | Period start date<br>01-Apr-23 | To | Period end date<br>31-Mar-24 |
|------------------------|--------------------------------|----|------------------------------|

### Section A Receipts and payments

|  | Unrestricted<br>funds<br>to the nearest<br>£ | Restricted<br>funds<br>to the nearest £ | Endowment<br>funds<br>to the nearest £ | Total funds<br>to the nearest £ | Last year<br>to the nearest £ |
|--|--|---|--|---------------------------------|-------------------------------|
| <b>A1 Receipts</b>   |  |   |  |                                 |                               |
| Amazon Europe  | 23   | -                                       | -                                      | 23                              | 22                            |
| Justgiving & Givingmachine   | 876  | -                                       | -                                      | 876                             | 268                           |
| National Lottery Community Fund, via the<br>Aplastic Anaemia Trust | 3,408  | -                                       | -                                      | 3,408                           | 1,680                         |
|  | -  | -                                       | -                                      | -                               | -                             |
|  | -  | -                                       | -                                      | -                               | -                             |
|  | -  | -                                       | -                                      | -                               | -                             |
|  | -  | -                                       | -                                      | -                               | -                             |
| <b>Sub total (Gross income for<br/>AR)</b>                         | <b>4,307</b>                                 | <b>-</b>                                | <b>-</b>                               | <b>4,307</b>                    | <b>1,970</b>                  |
| <b>A2 Asset and investment sales,<br/>(see table).</b>             |  |   |  |                                 |                               |
|  | -  | -                                       | -                                      | -                               | -                             |
|  | -  | -                                       | -                                      | -                               | -                             |
| <b>Sub total</b>   | <b>-</b>                                     | <b>-</b>                                | <b>-</b>                               | <b>-</b>                        | <b>-</b>                      |
| <b>Total receipts</b>  | <b>4,307</b>                                 | <b>-</b>                                | <b>-</b>                               | <b>4,307</b>                    | <b>1,970</b>                  |
| <b>A3 Payments</b>   |  |   |  |                                 |                               |
| DSJ Partners   | 1,080  | -                                       | -                                      | 1,080                           | -                             |
| British Thoracic Society - conference<br>registration              | 480  | -                                       | -                                      | 480                             | -                             |
| Refund of personal expenses  | 220  | -                                       | -                                      | 220                             | -                             |
| Minuteman Press  | 74   | -                                       | -                                      | 74                              | -                             |
|  | -  | -                                       | -                                      | -                               | -                             |
|  | -  | -                                       | -                                      | -                               | -                             |
|  | -  | -                                       | -                                      | -                               | -                             |
|  | -  | -                                       | -                                      | -                               | -                             |
| <b>Sub total</b>   | <b>1,854</b>                                 | <b>-</b>                                | <b>-</b>                               | <b>1,854</b>                    | <b>-</b>                      |
| <b>A4 Asset and investment<br/>purchases, (see table)</b>          |  |   |  |                                 |                               |
|  | -  | -                                       | -                                      | -                               | -                             |
|  | -  | -                                       | -                                      | -                               | -                             |
| <b>Sub total</b>   | <b>-</b>                                     | <b>-</b>                                | <b>-</b>                               | <b>-</b>                        | <b>-</b>                      |
| <b>Total payments</b>  | <b>1,854</b>                                 | <b>-</b>                                | <b>-</b>                               | <b>1,854</b>                    | <b>-</b>                      |
| <b>Net of receipts/(payments)</b>                                  | <b>2,453</b>                                 | <b>-</b>                                | <b>-</b>                               | <b>2,453</b>                    | <b>1,970</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>6,717</b>                                 | <b>-</b>                                | <b>-</b>                               | <b>6,717</b>                    | <b>4,747</b>                  |
| <b>Cash funds this year end</b>                                    | <b>9,170</b>                                 | <b>-</b>                                | <b>-</b>                               | <b>9,170</b>                    | <b>6,717</b>                  |

## Section B Statement of assets and liabilities at the end of the period

| Categories  | Details   | Unrestricted funds<br>to nearest £ | Restricted funds<br>to nearest £ | Endowment funds<br>to nearest £ |
|---|---|------------------------------------|----------------------------------|---------------------------------|
| <b>B1 Cash funds</b>  |   | 9,244                              | -                                | -                               |
|   |   | -                                  | -                                | -                               |
|   |   | -                                  | -                                | -                               |
|   | <b>Total cash funds</b><br>(agree balances with receipts and payments account(s)) | 9,170                              | -                                | -                               |
|   |   | OK                                 | OK                               | OK                              |
|   |   | Unrestricted funds<br>to nearest £ | Restricted funds<br>to nearest £ | Endowment funds<br>to nearest £ |
| <b>B2 Other monetary assets</b>                             | Details   |                                    |                                  |                                 |
|   |   | -                                  | -                                | -                               |
|   |   | -                                  | -                                | -                               |
|   |   | -                                  | -                                | -                               |
|   |   | -                                  | -                                | -                               |
|   |   | -                                  | -                                | -                               |
| <b>B3 Investment assets</b>                                 | Details   |                                    |                                  |                                 |
|   |   |                                    | -                                | -                               |
|   |   |                                    | -                                | -                               |
|   |   |                                    | -                                | -                               |
|   |   |                                    | -                                | -                               |
| <b>B4 Assets retained for the charity's own use</b>         | Details   |                                    |                                  |                                 |
|   |   |                                    | -                                | -                               |
|   |   |                                    | -                                | -                               |
|   |   |                                    | -                                | -                               |
|   |   |                                    | -                                | -                               |
|   |   |                                    | -                                | -                               |
|   |   |                                    | -                                | -                               |
|   |   |                                    | -                                | -                               |
| <b>B5 Liabilities</b>                                       | Details   |                                    |                                  |                                 |
|   |   |                                    | -                                |                                 |
|   |   |                                    | -                                |                                 |
|   |   |                                    | -                                |                                 |
|   |   |                                    | -                                |                                 |
| Signed by one or two trustees on behalf of all the trustees | Signature   | Print Name                         | Date of approval                 |                                 |
|   |   |                                    |                                  |                                 |