

# DC ACTION

England & Wales · Charity number 1167150

## Details

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**Status** Registered

**Legal form** CIO

**Registered** 2016-05-17

**Register** [View on the Charity Commission register](#)

## Contact

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**Address** 83 Digby Crescent  
London  
N4 2HS

**Phone** 02088000027

**Email** [info@dcaction.org](mailto:info@dcaction.org)

**Website** <http://dcaction.org>

## Activities

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**Objects:** THE OBJECTS OF THE CIO ARE:1. 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. TO ADVANCE THE EDUCATION OF THE PUBLIC BY THE PUBLICATION OF A WEBSITE, NEWSLETTERS, INFORMATION SHEETS AND OTHER MATERIALS.2. 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.3. TO ADVANCE THE EDUCATION OF THE GENERAL PUBLIC, MEDICAL AND SCIENTIFIC PROFESSIONALS IN ALL AREAS RELATING TO DYSKERATOSIS CONGENITA AND OTHER TELOMERE DISORDERS.

**Activities:** 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. To advance the education of the general public, medical and scientific professionals in all areas relating to Dyskeratosis Congenita and other telomere disorders.

## Classification

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- **How:** Provides Advocacy/advice/information
- **What:** General Charitable Purposes, The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, Elderly/old People, Other Defined Groups

## Geography

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- Throughout England And Wales

## Finances

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Period end	Income	Expenditure	Assets	Employees
2025-03-31	£12,109	£11,629	-	-
2024-03-31	£4,307	£1,780	-	-
2023-03-31	£2,092	£1,716	-	-
2022-03-31	£1,219	£273	-	-
2021-03-31	£1,647	£276	-	-

## Trustees

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Name	Role	Appointed
Alice Mary Buckley		2017-01-20
Dr Hilary Jane Longhurst		2016-12-03
Dr JANE PAXTON		2016-12-03
Jill Yvonne Whitehouse		2024-05-18
Willem Buckley		2021-09-03

**DC ACTION**

England & Wales - Charity number 1167150

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# Accounts

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**DC Action Trustee Annual Report for the year ended 31 March 2025**

**Reg no:** 1167510

**Address:** 83 Digby Crescent, London N4 2HS

**Trustees:**

Dr Hilary Longhurst

Dr Jane Paxton

Alice Buckley

Willem Buckley

Jill Whitehouse

DC Action is a charitable incorporated organisation, managed by its trustees on a voluntary basis. It has no employees. Trustees have to date been recruited to meet skill requirements from people known to the founders and current trustees.

**Activities and objectives in the year**

As a charity, DC Action is focused on improving the understanding and treatment of Dyskeratosis Congenita (DC) and Telomere Biology Disorders (TBDs) in the UK.

Dyskeratosis Congenita (DC) and other Telomere Biology Disorders (TBDs) are inherited conditions causing premature ageing of cells due to telomere repair abnormalities. Telomeres protect the ends of our chromosomes and have been likened to the protective caps on the ends of shoelaces. Symptoms can include abnormalities of skin and nails, and in some cases, bone marrow failure (anaemia, low white blood count and platelet-blood clotting problems), or fibrosis (scarring) of lungs and liver cirrhosis.

TBDs are rare and have a wide spectrum. Diagnosis and management are complex and there is a need for greater awareness including among the medical profession and for increased research.

We aim to raise awareness of the condition within the medical community, and for patients and their families. Our efforts are focused on three core areas:

- **Support** - We provide support and advice for people affected by Dyskeratosis Congenita.
- **Education** - We aim to raise awareness of DC amongst medical professionals, patients and the public.
- **Advocacy** - Our advocacy work focuses on research and expert care and treatments.

DC Action is part of an alliance of charities called Better Together for Healthy Marrow (Better Together).

## **Support**

A diagnosis of Dyskeratosis Congenita is frightening to receive and the need for support for both the patient and their family/caregivers is great. Through its support for those people, DC Action provides an important public benefit.

Throughout the year, we held quarterly Community Support Meetings for the DC Action community, covering various topics of interest to patients. These meetings enable patients to ask questions and discuss aspects of their condition.

We also supported numerous individual patients who made contact with us via our website.

Support is also provided to help patients and their families and carers access practical and financial support to help with such things as transport to medical appointments, applying for grants and get the best out of the NHS and other health support services.

As part of Better Together, we provide a podcast discussing what it's like to live with a rare condition day-to-day, from home life, work, going out, dealing with the healthcare system, how to deal with anxiety as parents of a child living with a serious rare condition, how to connect with others facing similar diagnosis, and how to navigate the healthcare system.

Listen now: <https://super-rare.org/podcast>

Thanks to National Lottery funding, we are able, as part of Better Together, to provide our community with emotional wellbeing support. Our emotional wellbeing support includes access to webinars and courses, available to both patients (and their families/carers) completely free of charge.

During the year, the Better Together Alliance commissioned and convened mental health support sessions, benefits advice for patients and resilience training.

Through all these measures, DC Action has provided public benefit by

## **Education**

Via our website we provide not only patients and their families and caregivers with education on DC and TBDs, but also medical professionals. DC Action and other TBDs are complex disorders and information can be confusing or hard to access. DC Action provides significant public benefit by making information readily available and working to increase awareness of Dyskeratosis Congenita across a wide range of medical specialities where it may be encountered.

During the year, our Scientific Advisor Dr Jane Paxton and Medical Advisor Dr Hilary Longhurst (both of whom are trustees) attended a number of meetings and conferences.

These included the following:

Dr Jane Paxton and Dr Hilary Longhurst convened and organised the first DC Action TeloNet meeting at the Francis Crick Institute, which brought together more than 60 patients, clinicians and scientists to review management of Telomere Biology Disorders and develop improved diagnostics and management services.

Dr Jane Paxton attended a DEMISTIFI meeting. DEMISTIFI is a Medical Research Council funded multicentre study to investigate multiorgan fibrosis with DC Action as the lead Patient and Public Involvement partner.

Throughout this period HL served as the patient & public- involvement and engagement representative for the DEMISTIFI MRC-funded study, investigating multisystem fibrosis. Fibrosis is the major cause of death for patients with telomere biology disorders. This involved online meetings with other interested charities and 2 public online seminars on the subject.

Throughout this period, 3 DC Action community members with lived experience participated in regular meetings in the Better Together Alliance clinical reference group- representing DC Action

Monthly meetings of Genetic Alliance

Quarterly Specialised Healthcare Alliance meetings to keep up to date with developments in NHS Specialised Services and to lobby for better services for Telomere Biology Disorders.

Monthly meetings of the Better Together Steering Group and larger meetings of the Better Together Alliance.

Regular TeloNet meetings

Dr Jane Paxton attended the British Society for Haematology Meeting in Liverpool to raise awareness of DC with haematology professionals.

Dr Hilary Longhurst attended the European Allergy and Immunology Congress to raise awareness of DC with immunology healthcare professionals.

They both attended the Research and Clinical Advisory Panel conference organised by The Aplastic Anaemia Trust to learn about the latest research in Aplastic Anaemia and TBDs from clinical experts.

Dr Jane Paxton attended the British Respiratory Society Meeting in London to raise awareness of TBDs with respiratory healthcare professionals.

Dr Paxton and Dr Longhurst both attended a meeting with the UK Cancer Genetics Group to plan an update to genomic diagnostic services for TBDs.

Dr Paxton also attended a CCCTAA meeting to discuss a Skeletal and Bone Health study.

Dr Longhurst has been invited to join the Multidisciplinary Management Team run by the Exeter Hospital Interstitial Lung Disease Team.

## **Advocacy**

Dyskeratosis Congenita is a rare condition, diagnosed in 1 in a million people. Through our advocacy activities, we aim to achieve better services for people suffering from it, thus benefitting the public.

Dr Jane Paxton attended a parliamentary round table convened to discuss NHS services for Paroxysmal Nocturnal Haemoglobinuria and how other rare disease services could be modelled on this service.

Throughout the year, we liaised with other members of the Better Together Alliance concerning oral health services, disease registers and lobbying for better services for DC and TBDs.

## **Financial Review**

During the year, DC Action received a total of £12,108.74. This was comprised of £3,851.50 by way of voluntary donations, £3,750 by way of grants and £4,507.24 as Better Together alliance funding.

Expenditure totalled £11,629.46 and comprised expenses of attending meetings and conferences, updating the website and IT costs.

Fundraising:


- DC Action participated in the SuperRare fundraising initiative in Feb-March 2024, with several community members and supporters raising funds for DC Action. Activities included an Alpaca Walk in Milton Keynes.

- Alice Buckley, one of our trustees, ran the Belfast marathon in May 2024 to raise funds for DC Action.

DC Action does not hold significant funds or incur significant expenditure as everyone involved in it is a volunteer. There is therefore currently no reserves policy, but the trustees are always prudent and only incur expenditure when funds are available.

No funds are held as a custodian trustee.



		Unrestricted funds	Restricted funds	Endowment funds
	Details	to nearest £	to nearest £	to nearest £
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<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 liability relates	Amount due (optional)	When due (optional)
<b>B5 Liabilities</b>			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name		Date of approval
		JILL WHITEHOUSE		21/1/26

**DC ACTION**

England & Wales - Charity number 1167150

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# Accounts

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## 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. 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**

	<b>Trustee name</b>	<b>Office (if any)</b>	<b>Dates acted if not for whole year</b>	<b>Name of person (or body) entitled to appoint trustee (if any)</b>
1	Alice Buckley	IT support		Fellow trustees
2	Willem Buckley	Treasurer; 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**

<b>Director name</b>		

**Name of trustees holding title to property belonging to the charity**

<b>Trustee name</b>	<b>Dates acted if not for whole year</b>	

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

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## Exemptions from disclosure

Reason for non-disclosure of key personnel details

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## Other optional information

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## Declarations

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

Signed on behalf of the charity's trustees

<b>Signature(s)</b>	<i>Will Buckley</i>	<i>Jane K Paxton</i>
<b>Full name(s)</b>	Willem Buckley	Jane Paxton
<b>Position (eg Secretary, Chair, etc)</b>	Treasurer	Scientific Adviser
<b>Date</b>	23 December 2024	



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name DC Action	No (if any) 1167150
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## Receipts and payments accounts

For the period from	Period start date 01-Apr-23	To	Period end date 31-Mar-24
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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>					
Amazon Europe	23	-	-	23	22
Justgiving & Givingmachine	876	-	-	876	268
National Lottery Community Fund, via the Aplastic Anaemia Trust	3,408	-	-	3,408	1,680
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>4,307</b>	<b>-</b>	<b>-</b>	<b>4,307</b>	<b>1,970</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>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 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 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>
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	6,717	-	-	6,717	4,747
<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 to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B1 Cash funds</b>		9,244	-	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>9,170</b>	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
<b>B2 Other monetary assets</b>	<b>Details</b>	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>	<b>Details</b>	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>	<b>Details</b>	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>	<b>Details</b>	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	

**DC ACTION**

England & Wales - Charity number 1167150

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# Accounts

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## DC Action Trustees Annual Report 2023

### Trustees:

Willem Buckley: Trustee and Governance lead, additionally appointed as treasurer 2023

Hilary Longhurst: Trustee and Medical Advisor

Jane Paxton: Trustee and Scientific Advisor

Alice Buckley: Trustee, Website support.

### Volunteers:

Inderjeet Dokal, Graeme Alexander, Tom Vulliamy: Medical/scientific advisors

Shah Riaz & Paula Mason: Community reference group

Wendy Adams: Parent advisor

Mieke Buckley: assistant treasurer

### Finances:

1. Willem Buckley appointed as treasurer Oct 2023
  - a. HL, JP and MB (treasurer) signed up as signatories for bank account.
  - b. E-banking- working well.
  - c. Tax returns up to date
  - d. Barclays anti-money-laundering audit successfully completed
2. Amazon smile has closed but [www.thegivingmachine.co.uk](http://www.thegivingmachine.co.uk) still active – small receipts. TheGivingMachine Team  
[Contact us 0845 2960028](mailto:08452960028)
3. **The Giving Machine and website donations not being correctly credited to Barclays account Possible PayPal update issue. WB to investigate.**
4. Just giving page functional
  - a. Hilary, Jane, Will are administrators
5. February 2023 Better together for healthy marrow (BTFHM) “SuperRare” campaign raised £388.58
6. Regular small income from Lottery Grant
7. Accounts prepared by Willem Buckley
8. Grant application to Jeans 4 Genes submitted re updating of website (see below)

### Governance:

1. Charities annual return due Jan 2024
2. Will Buckley has updated DC Action constitution
3. Tax return due Jan 2024- Will to check if still need to submit these.

### Projects:

1. **Better together for healthy marrow alliance, lottery grant**
  - Access to administrative and logistic infrastructure
  - First foray into fundraising (see above)
  - Emotional support online one to one (via Maggie's psychologist)

Emotional support online courses (resilience, aimed at those with bone marrow failure, via Maggies)

Resilience assessment undertaken

Main actions required: Update website (esp. security, better prominence of educational materials)

Improve engagement with members

(DC Action very

active in community reference group. Regular online meetings planned 2024)

Appoint additional trustees (WB appointed, open to further trustees)

Annual meeting of stakeholders: JP and HL attended. Very useful for finding common ground with other aplastic anaemia charities and for understanding how best to use the Better Together team funded by the lottery grant.

Test and learn projects selected for 2024

Informed by results of community survey (see below)

1. Benefits advice
  - a. Includes web-based tools (to be developed) and individual access to advice (now available: currently funded to end 2024)
2. Information resources creation
  - a. Community survey (BTFHM project, funded by pharma via Aplastic anaemia trust):  
Completed 2023- report published  
<https://super-rare.org/homepage/report/>  
2 launch meetings- 1 open to pharma, 1 patients/caregivers only. Both attended by HL, JP and DC Action community members.  
Need for better information (including on scientific trials), benefits support, multidisciplinary care\* and emotional support.

## **2. DEMISTIFI, NIHR grant**

Multidisciplinary 5 year project to investigate diagnosis and prevalence of fibrosis (the main cause of death in dyskeratosis congenita/telomere biology disorders) via big data, MRI scanning (to develop a "fibrosis score") and volunteer patient cohorts and data/tissue banks.

- a. Hilary is Public/ patient involvement and engagement (PPIE) grantholder and represents PPI interests on monthly executive board
- b. PPIE committee meetings attended by DEMISTIFI scientists to discuss progress and receive PPIE feedback/advice
- c. Stakeholders meeting. London, February 2023
  - i. DC Action members WA (speaker), JP and AD attended and contributed to debate
- d. Public (PPIE engagement) online meeting "Big data" December 2023
- e. 6 peer-reviewed academic publications
- f. Letter of support for DEFOG- aiming to discover functional abnormalities underlying fibrosis (grant not MRC funded but will be resubmitted elsewhere)

### **3. Interventional trials: REMAP-ILD**

Project to set up platform trial (to test multiple /repurposed medications for treatment of pulmonary fibrosis) but Imperial/ Action for pulmonary fibrosis. DC Action have been pressing for such a trial.

Letter of support from DC Action and DEMISTIFI support charities, urging

- i. consideration of inclusion of those with preclinical abnormalities and healthy people with high genetic risk of pulmonary fibrosis.
- j. Consideration of extension to other fibrotic disorders, especially multisystem fibrosis.

Consideration of novel trial design to enable local inclusion of underserved communities, including those too unwell/ financially unable to travel to research centre

### **4. Student voice prize**

HL interviewed by a medical student (Holly Richards, Queen Mary, London) who wrote an essay on dyskeratosis congenita for the student prize. Winner to be announced early 2023. (Essay to be published on DC Action website, if suitable and more widely if a winner)

### **Meetings:**

Feb 2023: DEMISTIFI biennial stakeholders meeting (see above)

Oct 2023: TFHM annual in-person meeting (see above)

Nov 2023: British Thoracic Society winter scientific meeting, London.

Attended by JP, WA and AD

DC Action stand

Multiple contacts and fruitful medical/scientific feedback. Need for second DCAAction telomere interest clinical/scientific group meeting highlighted.

Nov & Dec 2023 Online community survey report launch public/ community meetings (see above)

CCCTAA meetings (bimonthly): attended by HL and/or JP. Mainly focussed on patient registry

### **Members:**

**1.** 3 new families in 2023

**2.** Increased engagement with existing DC Action members, principally from BTFHM/DEMISTIFI projects.

### **Publications:**

1. As per DEMISTIFI

2. Case report WPL Joe Wheeler (UEA medical student, Dr ASad Luqmani , Hammersmith Hospital, Dr H Steve Jenkins, Broomfield Hospital, HJL) submitted to BMJ Case reports. Rejected after review by BMJ case reports. On hold

**Specialist clinic:** Importance/ unmet need highlighted by BTFHM survey. NHSE has new service specification. Letter submitted (see BTFHM, above). BTFHM to submit applicant for haematology/infection/immunology specialised services committee.

### **New medications trials:**

1. (See REMAP-ILD-above) HL & JP to continue promoting to professional contacts: 1. adaptive drug/other intervention trials. 2. Bayesian randomisation in trial drug allocation 3. Trial governance enabling local (not centralised) participation
2. HL & JP have been in discussion with Cincinnati US centre/ biotech company re UK patients being funded for travel to participate in trial of gene editing ex-vivo blood cell telomere elongation treatment.
  - a. US health care model unsuitable for UK patients- further discussion needed on safeguarding of access to non-trial-related healthcare

### **Collaborators.**

- 1. Gary Woodward Dyskeratosis Congenita Trust**
  - a. Ongoing contact. Collaboration for Jan 2024 online patients' meeting. Further quarterly meetings planned if successful.
- 2. Team Telomere (TT)-** DC Action have reached out and JP/ WA represented DC Action at an online meeting with Katie Stevens, TT Chief executive, to discuss working together. Team Telomere subsequently invited to co-participate in BLF scientific meeting but no response. Channels of communication to be kept open.
- 3. M4RD**  
Continued informal contact and introduction to medical student prize essay
- 4. Rare beacon**
  - a. Medical student prize essay (see above)
- 5. Genetic alliance** membership to continue

### **Website**

Minor updates complete.

Professional assistance required for security/accessibility upgrades

Adam Faulkner will assist with visuals/design

### **Information resources**

#### **1. "Cheatsheets"**

All updated 2023

#### **2. Poster for academic meetings**

Created

#### **3. Patient pamphlet (generic, introduction to DC - new member)**

Under development

## DC Action Interim Management Accounts, FY 23-24, as at 19 Dec 23

<b>Name</b>	<b>Date</b>	<b>Payment in, £</b>
Balance carried forward	31-Mar-23	6716.9
Amazon Europe	24-Apr-23	5
Just Giving	2-May-23	63.36
Amazon Europe	19-May-23	18.38
Just Giving	30-May-23	175.55
Aplastic Anaemia Trust	1-Jun-23	840
Just Giving	6-Jun-23	68.27
Just Giving	12-Jun-23	52.37
DSJ Partners	20-Jun-23	
British Thoracic Society	24-Aug-23	
Aplastic Anaemia Trust	1-Sep-23	840
Etsy	18-Sep-23	
Just Giving	2-Oct-23	29.03
Cashier's Office	4-Oct-23	
Jane Paxton	11-Oct-23	
Minuteman Press	27-Oct-23	
		<hr/>
		8808.86
Balance carried forward		7092.67

**Payment  
out, £**

**Purpose, item, activity or service**

	As per Barclays bank statement 3 May 23
	Donation(s)
	Donation(s)
	Donation(s)
	Donation(s)
	Income from 'Better Together' charity
	Donation(s)
	Donation(s)
1080	Accountancy services
480	Conference fee - charity stand
	Income from 'Better Together' charity
12	Display stand
	Donation(s)
37.5	Refund of expenses - display stands
32.69	Refund of expenses - British Thoracic Society meeting
74	Printing - DC Action educational posters

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1716.19

Reconciled with Barclays bank statement 2 Nov 23

<b>Repayment required?</b>	<b>Repaid</b>	<b>Date repaid</b>	<b>Remarks</b>
No			
No			
No			
No			
No			
No			UK National Lottery Grant
No			
No			
No			
No			
No			UK National Lottery Grant
No			
No			
No			
No			

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**DC ACTION**

England & Wales - Charity number 1167150

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# Accounts

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## **DC (Dyskeratosis Congenita) Action Annual Report 2021- 22**

UK Charity no. 1167150  
83 Digby Crescent, London N4 2HS

Trustees 2021-22:  
Hilary Longhurst  
Alice Buckley  
Jane Paxton  
Willem Buckley

Treasurer : Mieke Buckley  
Charities Commission/ Annual Return: William Longhurst

### **General:**

Willem Henk Buckley was appointed as a trustee with special responsibility for information governance and to assist the treasurer.

The charity is managed by committee, with decisions being made by discussion and consensus.

Trustees are appointed by the committee, based on their expertise and commitment to the charity's objectives.

### **2021-22 Objectives:**

1. To continue support for families and individuals affected by telomere biology disorders
2. To lobby for improved health care services and treatments with a focus on the UK
3. To continue and strengthen collaborations with other charities, research organisations and healthcare services to facilitate 2.
4. To update governance and procedures to maintain or exceed compliance with required UK charity standards

### **Achievements 2021-22**

**1. MRC grant for DEMISTIFI consortium** (sarcoidosis UK, Action for Pulmonary Fibrosis (APF), Scleroderma UK, Kidney research UK, Diabetes UK, EPIC/ Exeter Patients in Collaboration for Pulmonary Fibrosis & others)

Establishment of patient advisory group, including integral roles for patient advisors in each work package.

Expectation that this project will be a model for greater patient involvement in future research.

NZ family- DCO- geneticist (Alexa Kidd)

## **2. Together for Healthy Marrow consortium (TFHM)**

**Lottery grant:** first round application invited to progress: second round proposal in development. If successful, money will allow development for charity governance, outreach & communications skills with dedicated support person (administered via Aplastic Anaemia Trust/AAT)

TFHM: MarrowKidz programme 2020-1 ended: Website. Age-specific advice sheets, posters and website for patients, siblings and parents affected by aplastic anaemia. Overwhelmingly positive feedback from patients/ families and professionals. (Funding via National Lottery, managed by AAT on behalf of TFHM)

**3. Exeter Patients in Collaboration for Pulmonary Fibrosis EPIC group:** continued close collaboration on research initiatives, early diagnosis/ intervention and patient empowerment.

4. Development and implementation of information governance policy  
Child/ vulnerable adult protection policies currently in development.

## **Communication/ Outreach**

- Contact /individual support with 4 additional families J&TD, establishment of Coats plus interest group.
- E- meetings with Professor Yanick Crow- DC Action (Nov 2021) and Coats plus interest group families meeting (15 Dec 2021)
- Together for Healthy Marrow (TFHM) consortium (Aplastic anaemia trust, Fanconi Hope, PNH support, DBA UK, Sickle cell UK, SDS UK, DBS UK): Support for governance issues

## **Research**

DEMISTIFI . MRC grant (£2.8M) awarded to UK academic consortium (lead Prof G. Jenkins, Imperial College) for work packages for imaging/ quantifying & monitoring multiorgan fibrosis/fibrotic multimorbidity (FMM) via MRI  
assessing extent of UK problem via research and NHS databases

reaching out to affected communities and embedding patient's priorities in the research  
DC Action (Dr Hilary Longhurst) is an (unfunded/volunteer) coapplicant with special focus on patient public involvement.

*This is an essential prerequisite for developing appropriate NHS services and enabling inclusive trials of repurposed and new treatments.*

NCARDRS, patient experience, telomere length monitoring project proposal: No further progress re NCARDRS, however, aims of using large UK databanks for determining scale of TBD will in large part be achieved via MRC DEMISTIFI (fibrotic multimorbidity) grant:

Exeter Patients for Pulmonary Fibrosis research group. (Main contact Dr Anna Duckworth)

Published: Duckworth A, Longhurst HJ, Paxton JK, Scotton CJ. The Role of Herpes Viruses in Pulmonary Fibrosis. Front Med (Lausanne). 2021 Jul 22;8:704222.

Plans to collaborate on further research re risk factors/ early diagnosis of PF

*Early diagnosis will enable treatments to be tested at a potentially more reversible stage of the fibrosis process.*

## **Clinic**

Multidisciplinary clinic: Plans on hold due to COVID until 2022. Now working with Addenbrookes Haematology and SDS UK to include dyskeratosis congenita in business case. Future virtual clinics/expansion of home monitoring likely be helpful in addressing barriers to specialist care experienced by TBD patients.

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<b>Name</b>	<b>Payment in</b>	<b>Payment out</b>
Kathryn Scheduling Longhurst	£276.00	£276.00
Amazon Europe	£5.00	
Amazon Europe	£5.40	
Amazon Europe	£6.70	
Global Asthma	£819.00	
Amazon Europe	£5.82	
The Giving Machine	£80.86	
The Giving Machine	£19.85	
<b>Total</b>	<b>£1,218.63</b>	<b>£276.00</b>

**Purpose****Repaym€Repaid? Date paid**

Google hosting services

No

No

24/05/21

17/08/21

13/12/21

01/17/2022

23/02/22

24/07/20

08/12/20

## Repaid date

Donation Monthly payments of £23 Apr-Mar

Retail charity cash-back payments

Retail charity cash-back payments

Retail charity cash-back payments

Charitable donation

Retail charity cash-back payments

Retail charity cash-back payments

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**DC ACTION**

England & Wales - Charity number 1167150

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<b>Name</b>	<b>Payment</b>	<b>Payment</b>
Hilary Longhurst	£126.00	£126.00
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Amazon Europe	£8.40	
Amazon Europe	£8.40	
Amazon Europe	£9.90	
Amazon Europe	£11.00	
Amazon Europe	£9.26	
The Canadian Society for Allergy & Clinical Immunology	£1,097.46	
The Giving Machine	£80.86	
The Giving Machine	£19.85	
<b>Total</b>	<b>£1,647.13</b>	<b>£276.00</b>

<b>Purpose</b>	<b>Repayment</b>		<b>Repaid? Date paid</b>
Meeting with Dr James Turner (Bath University), Dr Anna Duckworth (Exeter University), Dr Jane Paxton (DC Action Scientific Advisor)	No	No	10/07/20
Google hosting services	No	No	21/05/20
			02/06/20
			13/08/20
			16/11/20
			11/02/21
			19/11/20
			24/07/20
			08/12/20

## Repaid date

Donation London to Bath return (car mileage)

Donation Monthly payments of £23 Apr-Mar

Retail charity cash-back payments

Retail charity cash-back payments

Retail charity cash-back payments

Retail charity cash-back payments

Retail charity cash-back payments

Retail charity cash-back payments

Retail charity cash-back payments

Retail charity cash-back payments