

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 still active – small receipts. TheGivingMachine Team
Contact us 0845 2960028
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 DCAction 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

Name	Date	Payment in, £
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 Sociey	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

Repayment required?	Repaid	Date repaid	Remarks
No			
No			
No			
No			
No			
No			UK National Lottery Grant
No			
No			
No			
No			
No			UK National Lottery Grant
No			
No			
No			
No			
