



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.

[illegible]

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