

Dyskeratosis Congenita Action Annual Report 2021- DRAFT
UK Charity no. 1167150
83 Digby Crescent, London N4 2HS

Trustees 2021:
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 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

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
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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.*

NCARDS, patient experience, telomere length monitoring project
proposal: No further progress re NCARDS, 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.

Name	Payment	Payment
Hilary Longhurst	£126.00	£126.00
Kathryn Scheduling Longhurst	£276.00	£276.00
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	
Total	£1,647.13	£276.00

Purpose	Repayment	Repaid?	Date paid
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

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