

## **Communication/ Outreach**

- Contact /individual support with 3 additional families
- DC Action- COVID information posted on website with links to NHS resource following March lockdown
- Gary Woodward meeting May 2020 (DC Action to contribute) postponed because of COVID
- Camp Sunshine international meeting April 2020 postponed because of COVID.
- Together for Healthy Marrow (TFHM) (e-)resources: see below

## **Research**

NCARDRS, patient experience, telomere length monitoring project proposal. Collaboration with Exeter University for student pilot project. Co-funded by DC Action/ Exeter University. *Deferred because of COVID and pending future of NCARDRS/NHS England. This or a similar project is an essential prerequisite for developing appropriate NHS services and enabling trials of repurposed and new treatments.*

British Lung Foundation grant co-applicant (with Exeter University)- early diagnosis of pulmonary fibrosis. Application deferred and ultimately unsuccessful at final round. *Continued close contact with research team and with Exeter Patients for Pulmonary Fibrosis research group. Early diagnosis will enable treatments to be tested at a potentially more reversible stage of the fibrosis process.*

DC Action members contributed to research surveys: Rare 2030 foresight study Rare.2030.eu.

UK rare diseases framework published, taking into account input from rare disease charities, including DC Action.

European Respiratory Society (ERS): small grant application for e-exercise project with Bath University (Dr James Turner), Exeter University (Dr Anna Duckworth & Exeter Patients for Pulmonary Fibrosis Research; EPIC PF) – no finance but offer to share resources. Similar project launched by ERS. e-meeting 19 Nov- project will go ahead- ongoing.

DEMISTIFI . First meeting 10th September 2020. Agreed to be a PPI partner. Ongoing contribution to work packages 2 & 5. Full grant application due March 2021

University of East London- see below

## **Other collaborations:**

Together for Healthy Marrow (TFHM) consortium (Aplastic anaemia trust, Fanconi Hope, PNH support, DBA UK, Sickle cell UK)

MarrowKidz published

E-resources aimed mainly at bone marrow failure patients, but also e-support for mental health in a crisis helpful generally to DC Action members.

Approached regarding PhD projects for University of East London student-contributed ideas.

Role of herpes viruses in pulmonary fibrosis. Meta-analysis and review written (with Drs Anna Duckworth, Chris Scotton, Exeter University & JP/HL DCAction). Awaiting submission.

Professor Mary Bythell: continues to provide valuable advice and support regarding NCARDRS project

## **Clinic**

Multidisciplinary clinic: No further progress. Future virtual clinics/expansion of home monitoring may be helpful.

## **Meetings**

Drs Denise Bonney and Stefan Meyer, Consultants in Paediatric Haematology (Transplant), Manchester on 3rd Feb 2020 in Manchester to discuss TBD in general and the proposed NCARDRS project

Prof James Chalmers , Dundee University, to discuss multifactorial Trial design 27th Aug 2020 (Remote meeting)

Dr Adrian Maunder, Cardiff University, to discuss detailed potential multifactorial trial designs, with Baysean Allocation. 30 Sept 2020 (Remote meeting)

Prof Kasaini Myers to discuss stem cell study for bone marrow failure (Cincinnati 2nd Sept 2020)- will include UK patients but self- funded transport to USA required.

Prof Mary Bythell (NCARDRS), Drs Scotton, Duckworth (Exeter University), JP, HL to discuss NCARDRS collaboration; 24 July 2020

Dr Hilary Longhurst attended virtual Team Telomere (Australasia) meeting Oct 2020

Internal DC Action Trustees meetings Feb, March, July 2020

---



<b>Name</b>	<b>Payment</b>
Jane Paxton	£23.35
Jane Paxton	£67.00
Hilary Longhurst and Mieke Buckley	£220.00
Hilary Longhurst	£127.03
Jane Paxton	£23.35
Jane Paxton	£67.00
Hilary Longhurst	£25.30
Hilary Longhurst	£40.00
Hilary Longhurst	£78.65
Total Expenditure	£671.68

**Purpose**

Kings College Hospital meeting  
Kings College Hospital meeting  
Team Telomere Family Day (Preston)  
Team Telomere Family Day (Preston)  
Aplastic anaemia Trust meeting  
Aplastic anaemia Trust meeting  
Dr. Helen Parfrey visit (Papworth Hospital)  
DC Action meeting  
Networking dinner expenses

**Repayme Repaid?**

No -  
No -  
No -  
No -  
No -  
No -  
No -  
No -  
No -

Date paid	Repaid date	
10/07/19		Train fare Bath to London terminals (GWR)
10/07/19		Train fare London Paddington to Bath single
12-14/07/19		Garstang (Preston) meeting. Zipcar expense
12-14/07/19		Garstang (Preston) meeting. AirBnB expense
18/07/19		Train fare Bath Spa to London terminals sing
18/07/19		Train fare London Paddington to Bath Spa si
16/08/19		Pulmonary fibrosis specialist. Train fare Lon
02/11/19		Mileage London- Bath return (280 miles)
01/02/20		Dishoom, Manchester

;

s.

es.

gle

ingle

idon- Royston day return (off-peak)