



Adult Cerebral Palsy Hub

Charity Number: 1179458

Trustees' Annual Report & Financial Statements for the Period 7 April 2020 to 6 April 2021

February 2022

Adult Cerebral Palsy Hub

Trustees' Annual Report & Financial Statements

for the Financial Period from 07-Apr-2020 to 06-Apr-2021

Reference & Administration Details

Charity Details:

Name(s):	Adult Cerebral Palsy Hub
Charity Number:	1179458
Company Number:	CE014808
Address:	Taylor Associates, Gallery Court, 28 Arcadia Avenue, London N3 2FG
e-mail:	info@adultcphub.org
website:	http://adultcphub.org

Names of the Charity Trustees

Emma Livingstone, appointed 6th August 2018
Derek Livingstone, appointed 6th August 2018
Miriam Creeger, appointed 6th August 2018
Stephen Jacobs OBE, appointed 1st October 2020
Natalie South, appointed 1st October 2020
Dr Valerie Stevenson, appointed 1st October 2020
Dr Jennifer Ryan, appointed 21st December 2020

Names & Addresses of Advisors

None

Names of Senior Staff with Delegated Responsibilities

None

Structure, Governance & Management

Type of Governing Document:

Constitution – based on the Charity Commission’s model governing document for Foundation Charitable Incorporated Organisations, ie: where the Trustees are the only Members of the charity. Registered 06 Aug 2018

How the Charity is Constituted:

Charitable Incorporated Organisation

Trustee Selection Methods:

There must be at least three charity trustees. The maximum number of trustees is 12. In accordance with the Constitution, apart from the first charity trustees, Trustees are appointed or re-appointed for a term of three years by a resolution passed at a properly convened meeting of the charity trustees. In appointing Trustees due consideration is given to ensuring that the Trustees have, between them, the skills and experience necessary to manage the charity effectively and in accordance with charity law.

Charitable Objects

The objects of the CIO are:

- to promote and protect the physical and mental health of adult sufferers of cerebral palsy through the provision of assistance, support, education and practical advice;
- to advance the education of the general public, relevant medical and educational professionals and related and relevant disciplines in all areas relating to cerebral palsy by working with medical and research communities to promote best practice in the treatment, care, education and support of adults with cerebral palsy;
- to encourage adults affected by cerebral palsy to attain their full life potential as members of society by improving their conditions of life;
- to promote research into cerebral palsy in adults and allied conditions and to promote the publication of the results; and
- to promote any other charitable purpose for the benefit of adults with cerebral palsy and / or their families, dependents, friends and carers and other persons affected by cerebral palsy, in each case for the public benefit.

Activities

Statutory Declaration on Public Benefit

The trustees declare that they have complied with their duty to have due regard to the guidance on public benefit published by the Charity Commission in exercising their powers or duties.

The activities we carry out to further our charitable objects (purposes) are for the public benefit.

Adult Cerebral Palsy Hub is the charity for Adults with Cerebral Palsy, informing, educating, and supporting them to live their best lives.

Cerebral Palsy is a lifelong condition that affects 130,000 adults in the UK. It is a condition which develops associated co-morbidities during adulthood and demands a specialist care pathway to achieve positive and long-lasting results. However, co-ordinated and specialist services do not universally exist today for adults with Cerebral Palsy, unlike most other neurological conditions.

After the age of the 18 adults with CP report feeling a “cliff edge loss of support” and the journey to services is problematic and feels like being “lost at sea”.

We believe no adult should be told “their CP is getting worse.” Rather, they are entitled to knowledge about the process of ageing with CP as well as coordinated care that improves wellness, participation, and quality of life.

We aim to provide adults with the help and information on how to better manage their condition and campaign for improved services.

Our activities are focused on the following areas:

1. **Knowledge:** We provide adults with help, information and practical guidance on how to better manage their condition based on the latest research and practice.
2. **Support:** We are developing a support structure for the community to provide practical strategies, emotional support and help to navigate their care.
3. **Coordinated Care:** Coordinated care does not universally exist today for adults living with CP. We raise awareness and educate stakeholders about Cerebral Palsy as a lifelong condition. We lobby for clear care pathways and specialist services and to stamp out the gap in health inequality experienced by our community.

Achievements & Performance

Despite this year being dominated by the Covid-19 pandemic, which hit the UK in March 2020, much progress was made in advancing the aims of the charity.

The impact of the pandemic was and remains highly stressful for the adult Cerebral Palsy community, compounding the physical and mental health challenges already faced. Adult CP Hub prides itself as being a community-based organisation and during these unprecedented and uncertain times we have tried to respond quickly to the needs of our community.

"I'M IN MY EARLY 30S AND LIVING WITH CP, DEPRESSION AND ANXIETY/PHOBIAS. MY FAMILY HAVE BEEN SHIELDING SINCE THE BEGINNING OF MARCH AS WE ARE ALL 'AT RISK' OR 'EXTREMELY VULNERABLE' TO COVID, AND LIFE...WELL, YOU ALL KNOW HOW TOUGH THINGS ARE I EXPECT! IT'S REALLY GOOD TO KNOW ALL OF YOU ARE OUT THERE, AND I REALLY HOPE I CAN GET TO KNOW YOU"

We quickly launched a Facebook support group for the community to share tips and advice on how to survive during lockdown. We also started running twice weekly virtual support groups providing an opportunity to meet others with the condition, share ideas, ask questions, and provide mutual support as well as make new friends. These proved very successful during these troubled times, reaching people across the age range and spectrum of need, with many of the regular participants reporting that these became anchors in their week.

Staying as active as possible is one of the best ways for adults with CP to stay healthy and maintain their skills. We ran a pilot 12-week Community Movement Challenge to help our community to better understand their condition and have practical tips and exercises to help develop healthy habits. Led by a physiotherapist and an expert disability trainer, participants set their own specific personal goals and were fully supported throughout the challenge. Support included access to an online support group, sharing of daily tips and advice on how to keep moving and motivated, weekly video-chat group sessions and advice and support from fellow participants. These had huge benefit for all participant both physically and psychologically.

"I HAVE BEEN MOVING A LOT MORE OVER THE LAST FEW WEEKS, WITH DOING HOUSEWORK, USING MY CRUTCHES MORE AROUND THE FLAT, AND STANDING AT MY WINDOW WAITING FOR DELIVERIES. IT REALLY HAS MADE A HUGE DIFFERENCE TO MY PERSONAL WELLBEING. I HAVEN'T BEEN THIS HAPPY FOR YEARS"

Adults with CP face difficulties finding up to date information about their condition and struggle to access advice and support. Many adults with CP have also told us they experience low self-esteem, low mood, and little aspiration for the future. We launched our **"chatting with"** series, a virtual programme of regular talks and events designed to bring the community together and showcase role models within our community. Topics addressed issues that impact greatly on the community including "how to stay active", "pain management", "sleep" and "The Equality Act and your rights" as well as "ask a professional" sessions with physio and occupational therapists.

"THANK YOU SO MUCH FOR ARRANGING THE TALK TONIGHT ON PAIN, REALLY INFORMATIVE..... I THINK I KNOW NOW WHERE I NEED TO BE SEEN AND WILL FORWARD THE NICE GUIDELINES TO GP. THANKS AGAIN"

"YOU HAVE INSPIRED ME TO ACCEPT MY CP AND SPREAD AWARENESS ON MY DISABILITY AND CHRONIC ILLNESS ON MY BLOG. I WOULD LIKE TO TAKE THIS OPPORTUNITY TO SAY THANK YOU."

In October 2020, to mark [World CP Day](#), we released a short film showcasing that there are many members of our community who are already making their mark. The film included comedians, actors, writers, medical professionals, politicians, and athletes all of whom live with Cerebral Palsy.

We also produced another film for [World Mental Health Day](#). We know that adults with Cerebral Palsy are 40% more affected by mental health issues than the general population and are affected by issues of loneliness and social isolation which unsurprisingly have been intensified by the pandemic. In the film, members of our community describe how mental health issues impact them and the need for better recognition for the community around mental health.

We would like to thank all those that contributed to the film, Director Ruth Sewell and Alan Walsh at the charity [HelpFilm.org](#) who made this happen.

Sharing personal stories has always been a powerful way to connect with others and provide personal testimony about living with Cerebral Palsy as an adult. We had a very positive response and reached many new members of the CP community when our founder Emma Livingstone was interviewed by Lou Hamilton on her podcast Brave new Girl which seeks to celebrate the success of woman. Pleasingly she shared with us that it was her most popular podcast to date and exceeded all expectations with the number of times it was listened to and shared.

"I JUST THINK IT'S WONDERFUL HOW SUPPORTIVE @ADULTCPHUB ARE FOR A COMMUNITY THAT OFTEN FEELS LEFT IN THE DARK, THEY ARE A LIFELINE. I HONESTLY WOULDN'T HAVE EVEN BEGUN MY JOURNEY BACK INTO PHYSIO AND HEALTHCARE SUPPORT WITHOUT THEIR GUIDANCE."

During the year, Emma Livingstone spoke at several professional conferences, raising the profile of the needs of the adult CP community with medics and researchers.

One of the aims of the charity is to develop better understanding of Cerebral Palsy in Adults through research. The Charity has continued to support the research community, providing the patient voice.

Adult Cerebral Palsy Hub became a member of the "Community Rehabilitation Alliance", a coalition of organisations and charitable bodies that have come together to demand access to improved rehabilitation services. The alliance has participated in NHSE's Ageing Well programme and the Long Covid taskforce, ensuring that rehabilitation is a key consideration for both initiatives.

Ahead of Cerebral Palsy Awareness month in March 2021, the charity launched its **#StampOutTheGap** campaign, aiming to stamp out the gap in healthcare provision for adults with CP vs those with other life-long conditions. To make the point, we created a set of six mock second class stamps featuring six well-known personalities - comedian Rosie Jones, comedian Francesca Martinez, actor James Moore, Britain's Got Talent winner 'Lost Voice Guy' Lee Ridley, Paralympian David Smith MBE and para-Dressage rider Tegan Vincent-Cooke - all of whom have Cerebral Palsy, to highlight how adults

with CP are treated like 'Second Class Citizens'. Through the campaign, the charity is asking the Government to 'stamp out' this inequality and insisting the NICE (National Institute for Health & Care Excellence) guidelines are adopted, to improve life for the 130,000 adults in the UK living with CP.

Before lockdown, we commissioned an **economic report to make the case for specialist services** and this was completed and published this year. This comprehensive report was based on latest research and interviews with wide range of practitioners and patients. This report served to give us a better understanding of our population. There are now thought to be 130,000 adults in the UK who have cerebral palsy. This is 50% more than previously publicised. Interestingly also that 70% are in GMFCS Levels 1 to 3 who are those people with higher mobility.

The report also looked at patient experience finding that, adults with CP have less specialist support services than people with almost any other long-term condition resulting in significant unmet patient need and health inequalities. In addition, adults with CP often have sub-optimal experiences and outcomes from services due to lack of understanding of CP and its effects, combined with lack of appropriate clinical pathways. This lack of support results in worse health outcomes and, lower education and employment participation for individuals and a substantial economic loss to the country.

The report made the case for the development of specialist services and clear clinical pathways into local services. It found there to be three broad reasons we must deliver better services for adults with CP

1. **A quality of life case for action:** society has made significant medical advances in life-preserving treatments. We now need to give as much focus on quality of life.
2. **An economic case:** investing in specialist support services will reduce demand on expensive "downstream" health and care services, and by supporting people with cerebral palsy into education and employment, the payback in wider economic benefits to the country will easily offset the costs of investment.
3. **A parity and equity case:** people with cerebral palsy have a right to support, but they currently suffer significant health inequalities in part because the services that do exist are under resourced compared to those available for almost any other long-term condition

The economic benefits largely arise from increased employment / retention of employment. The new specialist adult cerebral palsy service cost is estimated at £20m per annum. The Government's required 1 to 4 ratio of investment to economic benefit means £80m of benefit is needed to justify spend. This would be achieved if only 4,000 people (3% of the adult CP community) gain or are helped to stay in employment.

The reports key recommendation was that all NHS, social care, education and employment support commissioners work together to commission a dedicated specialist adult CP service for their local population based on the hub and spoke model.

It has been very important to maintain strong links with the community and furthermore to use every opportunity to have the voice of the community heard. For this

reason and the continuing need to raise awareness with the wider public we used March – CP awareness month - to work with the community to do this using a series of home-made videos and / or photographs and quotes in a month-long social media campaign. Every day in March one member of our community was able to tell us what having Cerebral Palsy meant to them. We then shared this in daily posts across our social media platforms.

Financial Review

Principal Sources of Funding and Outgoings

The principle source of funding has been public donations.

The charity has not engaged in any specific applications for grants or fundraising activities in the current year.

Gift Aid is reclaimed on donations where the donor indicates that is their wish.

Statement of the Charity's Policy on Reserves

Given the early stage of the Charity, the Charity does not have a policy on reserves.

Details of Any Funds Materially in Deficit

The Trustees declare that the charity had no funds which were materially in deficit at the date of the statement of assets & liabilities.

Remuneration of Trustees

All Trustees act in a voluntary capacity and receive no remuneration or other material benefits from their services to the Charity.

Out-of-pocket expenses necessarily and reasonably incurred by Trustees in promoting the purposes of the Charity are reimbursed at cost.

State of the Charity's Finances

Though modest, the charity's current resources are sufficient to meet its outgoings for at least next year. All the indications are that this will remain the case for the foreseeable future.

Particulars of Any Outstanding Guarantee Given by the Charity

The Trustees declare that the charity has given no guarantee where potential liability is outstanding at the date of the statement of assets & liabilities.

Particulars of Any Outstanding Debt

The Trustees declare that the charity has no outstanding debts which are secured by an express charge on any of the assets of the charity at the date of the statement of assets & liabilities.

Statutory Statements on Liabilities

The Trustees declare that:

- The charity has given no guarantees where potential liability under the guarantee is outstanding at the date of this statement (eg: any outstanding/ongoing contract or legal undertaking to buy or provide specific services)
- The charity has no debt outstanding at the date of this statement which is owed by the CIO and which is secured by an express charge on any assets of the CIO (eg: a mortgage on property owned by the charity)

Statement of Financial Activity

Receipts and payments accounts for the period 7th April 2020 to 6th April 2021

Section A Receipts and payments					
	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donation	6,758	-	-	6,758	8,980
Sponsorship	-	-	-	-	-
Event Income	-	-	-	-	1,559
Gift Aid	-	-	-	-	1,246
Other Income	207	-	-	207	18
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	6,965	-	-	6,965	11,804
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	6,965	-	-	6,965	11,804
A3 Payments					
Event Costs	203	-	-	203	1,402
Design & Printing	706	-	-	706	558
Promotion	241	-	-	241	-
IT Spend	571	-	-	571	7,191
Professional Services	12,240	-	-	12,240	-
Other Expense	701	-	-	701	637
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	14,663	-	-	14,663	9,789
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	14,663	-	-	14,663	9,789
Net of receipts/(payments)	- 7,698	-	-	- 7,698	2,015
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	14,151	-	-	14,151	-
Cash funds this year end	6,453	-	-	6,453	14,151

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 £
B1 Cash funds	Bank	6,453	-	-
		-	-	-
		-	-	-
	Total cash funds	6,453	-	-
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	Details			
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			-	
			-	
			-	
			-	
At the date of this statement of assets and liabilities, no guarantees have been given and no debt is outstanding				

Declaration

The Trustees declare that they have approved the above Annual Report & Statement of Financial Activity.

Signed on behalf of the charity's trustees

Signature

A handwritten signature in black ink that reads "Derek Livingstone". The script is cursive and fluid.

Full name

Derek Livingstone

Date

07 / 02 / 2022