

UP – The Adult Cerebral Palsy Movement

**A working name for Adult Cerebral Palsy Hub,
Charity Number: 1179458**

Trustees' Annual Report & Financial Statements for the Period 7 April 2021 to 6 April 2022

January 2023

UP - The Adult Cerebral Palsy Movement

Trustees' Annual Report & Financial Statements for the Financial Period from 07-Apr-2021 to 06-Apr-2022

Reference & Administration Details

Charity Details:

Name:	Adult Cerebral Palsy Hub
Working Name:	UP – The Adult Cerebral Palsy Movement
Charity Number:	1179458
Company Number:	CE014808
Address:	Taylor Associates, Gallery Court, 28 Arcadia Avenue, London, N3 2FG
e-mail:	hello@upmovement.org.uk
website:	https://upmovement.org.uk/

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.

UP – the Adult Cerebral Palsy Movement 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.

We aim to:

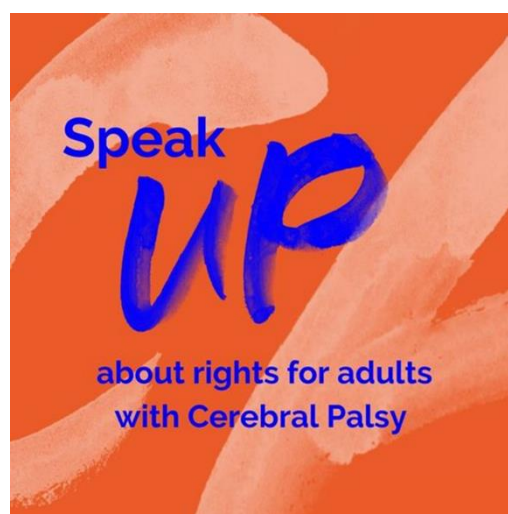
Raise awareness

- among adults with Cerebral Palsy, and their families, about the options they have, and what we all need to do to get the support we need to live our best lives.
- among politicians and policy-makers about the injustices that people with Cerebral Palsy face, and what they can do about it.
- among the general public, about what life is like for people with Cerebral Palsy, and how they can help.

Educate the medical profession so they can give informed advice, and also be aware of where they can draw on additional resources of information.

Build community so that we adults with Cerebral Palsy can support each other, learn from each other, gain hope from each other, and add strength to each other so that our voices are heard.

Campaign to bring real force to the arguments we make, and to insist on change. We are no longer going to take no for an answer.



Achievements & Performance

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

Campaigning

We continue to campaign for the services that the adult Cerebral Palsy community need and deserve but which fall unacceptably way short of those recommended in the NICE Guidelines.

Our campaign for better services for adults with CP is not just based on it being the right thing to do (which it is), but is also based on sound economics. Our economic report, published in 2020, highlights that the lack of support results in worse health outcomes and, lower education and employment participation for individuals and a substantial economic loss to the country. 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.



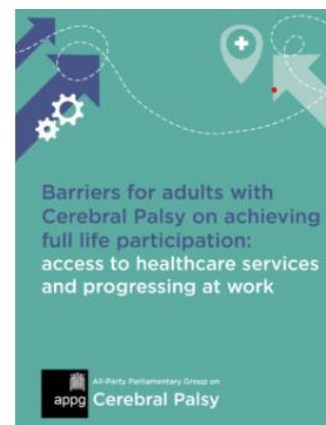
In October 2021, to coincide with World CP Day and ahead of the Paralympics in Japan, we launched our next round of 'Second Class Citizens' stamps for our award winning [#StampOutTheGap](#) campaign. Our campaign aimed to stamp out the gap in healthcare provision for adults with CP vs those with other life-long conditions. Using mock second class stamps featuring six successful Paralympians - athlete Georgina Hermitage, athlete Kare Adenegan, Boccia player David Smith MBE, Boccia player Beth Moulam, swimmer Tully

Kearney and wheelchair basketball player, Siobhan Fitzpatrick, all of whom live with CP - to remind people you shouldn't have to be a world class athlete to have best in class healthcare, whilst continuing to highlight how adults with CP are treated like 'Second Class Citizens'. Our campaign received good coverage across the media in print, radio and pleasingly on Sky News.

During the year we were also delighted to jointly sponsor, in partnership with Scope, two sessions of the All Party Parliamentary Group on Cerebral Palsy. The APPG looked at the health inequalities and the barriers for adults with Cerebral Palsy on achieving full life participation. The volume and passion of expert testimony from clinicians, academic experts, and, crucially members of the adult Cerebral Palsy community sharing their lived experience, demonstrated how pressing the needs of the community are.

Commenting on the launch of their report in March 2022, co-chairs, Mary Kelly Foy MP and Paul Maynard MP said:

'Cerebral Palsy is a lifelong condition, and we hope that this report emphasises the crucial need to refocus attention on barriers to achieving full life participation for those living with it... we also must not let the pandemic distract from long-standing problems that need to be addressed.'



The report highlights that the problems faced by the community are multifaceted and that collaboration between health, social care and employment is essential.

Among the recommendations, Parliamentarians called on NHS England, social care, education, and employment specialists to commission dedicated specialist services across the new 42 Integrated Care Systems (ICSs) in England and the devolved governments should put in similar measures in their respective health systems.

Other proposals contained in report include:

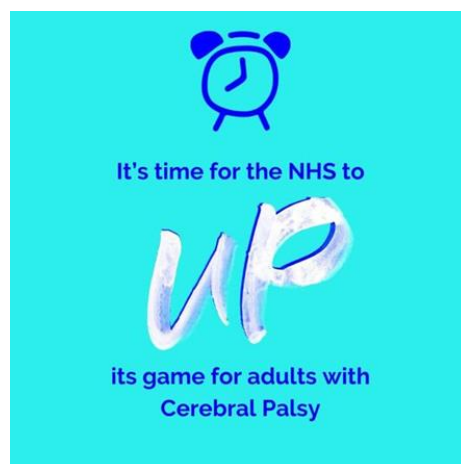
- Guaranteeing adults living with Cerebral Palsy annual medical reviews to better assess their evolving health and care needs.
- Ringfencing funding for the ICSs to develop specialist services.
- Enhancing employment rights for adults with Cerebral Palsy to better reflect the varied, fluctuating, and complex nature of their conditions.
- Creating a new online information hub for employers to better understand the needs of member of the adult Cerebral Palsy community in their workforces.

We see this All-Party Parliamentary Group report as a watershed moment, recording the range of challenges faced by adults with CP and, importantly, setting out an agenda for removing these. However, we do not want this to be yet another report that sits on the shelf and gathers dust.

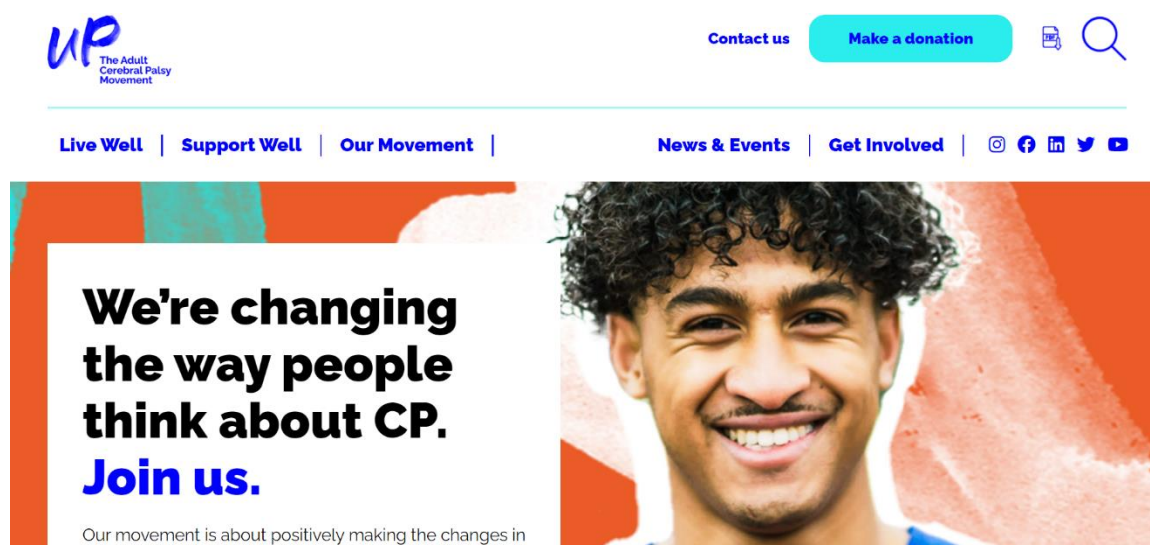
For us this is a clear mandate for change.

We know what needs to happen. Now we have to make it happen.

To do this, we realise that we need a louder, stronger, more forceful voice to get the healthcare we need and deserve. And we need to be a larger, more engaged community to give each other the support we need to live our best lives. So, in July 2022, we were delighted to change our name to **UP – The Adult Cerebral Palsy Movement** to better reflect our aims to be a movement for change.



So today, as **UP – The Adult Cerebral Palsy Movement**, we are continuing to build our community so that adults with CP can support each other, learn from each other, gain hope from each other, and add strength to each other so that our voices are heard.



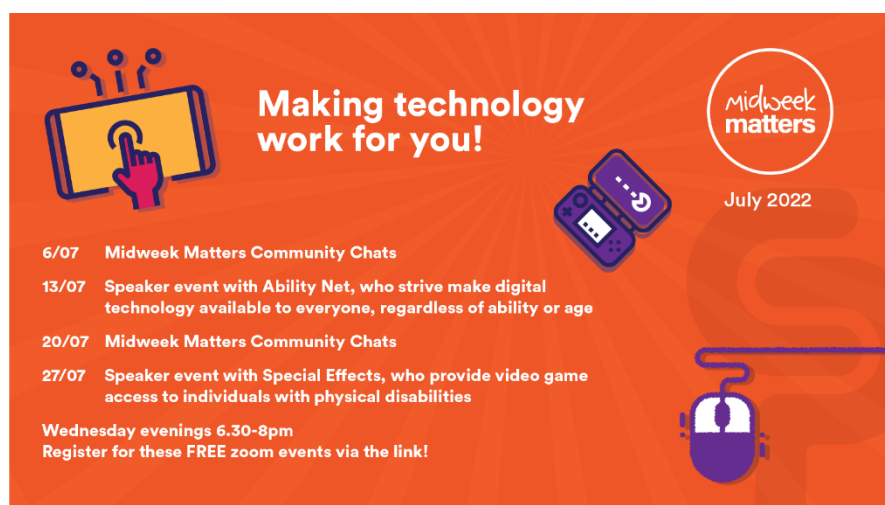
And together with the wider community alongside us, we will campaign to bring real force to the arguments we make, and to insist on change. We are no longer going to take no for an answer.

We are demanding the change that adults with CP need and deserve. To live their best life.

Educating and supporting the community

Staying as active as possible is one of the best ways for adults with CP to stay healthy and maintain their skills. In April 2021, we ran "Spring into Action", in partnership with CP Sport, to continue to encourage our community to get moving. This 12-week programme was developed to support the community to become more active and recover from de-conditioning caused by lockdown. The 15 participants were provided with expert guidance and support from neuro-physiotherapists, CP sports coaches and CP mentors and fully supported with weekly virtual meet-ups and an programme of motivational speakers.

In January 2022, we launched our new weekly community support programme, '**Midweek Matters**'. For the prior 18 months we hosted twice weekly zoom chats to support the community throughout the pandemic. In response to what we learnt and to answer the questions that interest the community most; we launched this new programme to **educate, support and connect** with the CP community. Every Wednesday, between 6.30pm and 8pm we meet on Zoom to explore topics that matter to the community. We have had 48 sessions and been able to connect with 16 other organisations and 14 speakers with Cerebral Palsy. Every month we cover a different topic, supported by inspirational speakers and experts from all walks of life. We have covered diverse range of topics including "Relationships, Sexuality, Desirability and Disability", "Travel", "Fitness for All", "Parenting", "Accessible Fashion", "Technology" & "Supporting Positive Mental Health". The response from the community to Midweek Matters has been really positive, with over 600 attendees over the year.



Financial Review

Principal Sources of Funding and Outgoings

The principal source of funding has been public donations.

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

Statement of the Charity's Policy on Reserves

The Reserves at present are sufficient to support ongoing expenditure of the charity.

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

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 2021 to 6th April 2022

Section A Receipts and payments					
	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Donation	4,239	-	-	4,239	6,758
Sponsorship	-	-	-	-	-
Event Income	-	-	-	-	-
Gift Aid	-	-	-	-	-
Other Income	14,692	-	-	14,692	207
Sub total (Gross income for AR)	18,931	-	-	18,931	6,965
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	18,931	-	-	18,931	6,965
A3 Payments					
Event Costs	-	-	-	-	203
Design & Printing	1,146	-	-	1,146	706
Promotion	1,986	-	-	1,986	241
IT Spend	527	-	-	527	571
Professional Services	6,405	-	-	6,405	12,240
Other Expense	2,228	-	-	2,228	701
Sub total	12,293	-	-	12,293	14,663
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	12,293	-	-	12,293	14,663
Net of receipts/(payments)	6,638	-	-	6,638	- 7,698
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	6,453	-	-	6,453	-
Cash funds this year end	13,091	-	-	13,091	6,453

Section B Statement of assets and liabilities at the end of the period

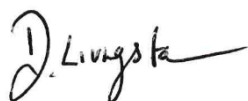
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Bank	13,091	-	-
		-	-	-
		-	-	-
	Total cash funds	13,091	-	-
	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary 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			-	
			-	
			-	
			-	
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, appearing to read 'D. Livingstone', with a stylized flourish at the end.

Full name

Derek Livingstone

Date

30th January 2023