

UP – The Adult Cerebral Palsy Movement

Charity Number: 1179458

Trustees' Annual Report & Financial Statements for the Period 7 April 2022 to 6 April 2023

January 2024

UP - The Adult Cerebral Palsy Movement

Trustees' Annual Report & Financial Statements for the Financial Period from 07-Apr-2022 to 06-Apr-2023

Reference & Administration Details

Charity Details:

Name:	UP – The Adult Cerebral Palsy Movement
Charity Number:	1179458
Company Number:	CE014808
Registered 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-Law, appointed 1st October 2020
Dr Valerie Stevenson, appointed 1st October 2020
Dr Jennifer Ryan, appointed 21st December 2020

Independent Examiner

Peter Taylor, Taylor Associates, Gallery Court, 28 Arcadia Avenue, London, N3 2FG

Bankers

Metro Bank PLC, One Southampton Row, London WC1B 5HA

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:

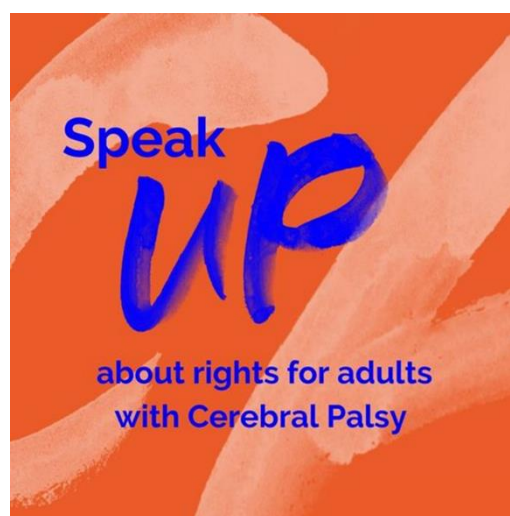
Raise awareness

- 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

Much progress was made in advancing the aims of the charity during the year.

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.



On October 6th, World CP Day, we launched our **42p campaign**, calling on the Government to provide proper healthcare for adults with CP. We sent a card with 42p stuck on it, to all 650 Members of Parliament to push for each of the UK's 130,000 adults with CP to receive the minimum care required and highlighting the inequalities the community face and the compelling economic and moral case to address this.

With the publication of NICE Guidelines in 2019, as well as the 2023 report from the All-Party Parliamentary Group (APPG) on Cerebral Palsy, commissioned by the charity, there is a now clarity on the minimum requirements for proper coordinated healthcare for adults with cerebral palsy. The headline changes are:

- the creation of a specialist multi-disciplinary clinic for adults with Cerebral Palsy.
- the opportunity for all adults to have an annual review; and
- the requirement for a named health professional to be responsible for a clear and detailed care pathway for adults with Cerebral Palsy in each health authority.

Right now, none of this happens as care drops off a cliff face for people with CP when they turn 18.

It costs the NHS far more to neglect this preventive treatment, and these efficient care pathways. The result of that neglect is that degeneration is accelerated, causing untold, unnecessary, pain and suffering, and landing each individual on the NHS at a point when they need much more expensive treatment.

Investing in specialist support services will reduce demand on these 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.

Through our Health Economic Study, we estimate that investing in specialist CP services would cost only an estimated £20m per annum. Using the Government's 1 to 4 ratio of

investment to economic benefit, this could be achieved if only 4,000 or 3% of the adult population are helped to gain or stay in employment. However, we think in reality, this could benefit over 20,000 adults to enter or stay in employment, providing a gross economic benefit to the economy of £422m.

That £20m amounts to 42p a day for each of the 130,000 adults with CP in the UK. 42p is the difference between a life of pain and discomfort and disability, rather than a life of physical and mental wellbeing. 42p is the difference between a life of frustration living on benefits, instead of having a productive life in work.

Emma took the message to the House of Lords in November 2022 where she was invited to speak at an event hosted by the Lord Speaker, Baron McFall of Alcluith.

And in March 2023, we sent the same card to more than 800 members of the House of Lords, again highlighting that for just 42p for every adult with CP in the UK, we could achieve proper health provision for our community.

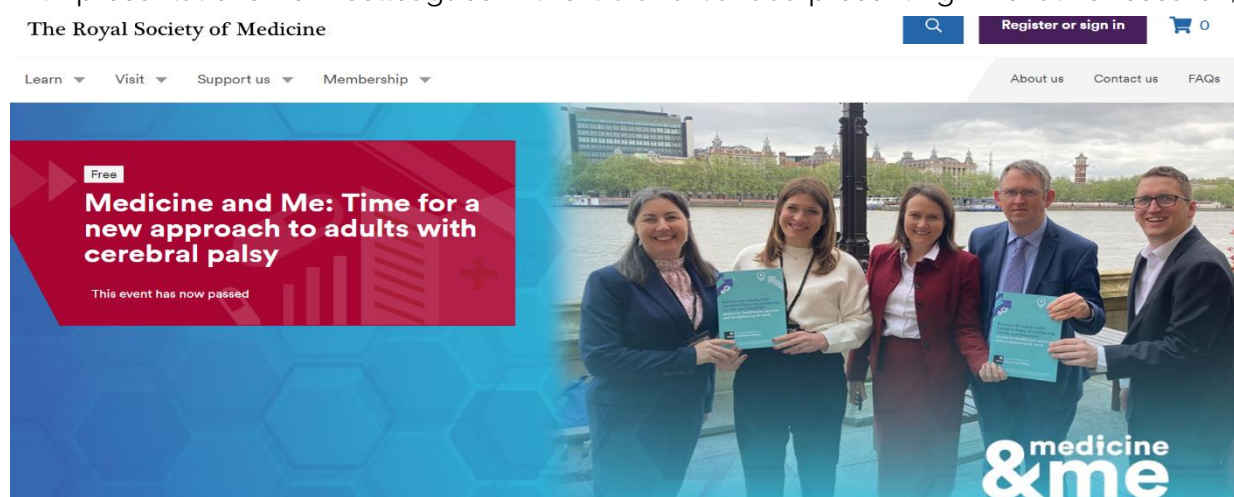


Launch of Working Group

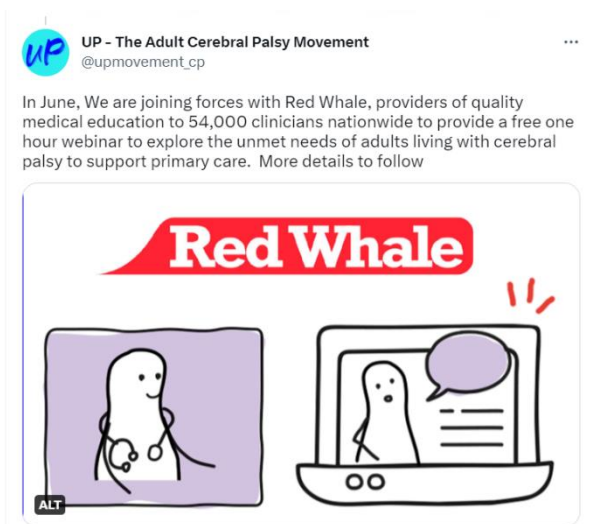
We established a working Group of clinicians, NHS representatives, MPs and other CP charities to progress the recommendations pertaining to adults of the All Party Parliamentary Group on Cerebral Palsy. The inaugural meeting was held in November 2022 and has continued to meet and push for change throughout 2023.

Educating professionals

In July 2022, we held a ground-breaking conference at the [Royal Society of Medicine](#), "Time for a new approach to adults with cerebral palsy". The event had over 250 participants including leading experts from around the world, politicians, representatives from NHS England and adults living with CP. In this unique event the community and clinicians shared an equal platform, the focus was very much looking towards solutions for our community, with presentations from colleagues in the US and Canada presenting innovative research,



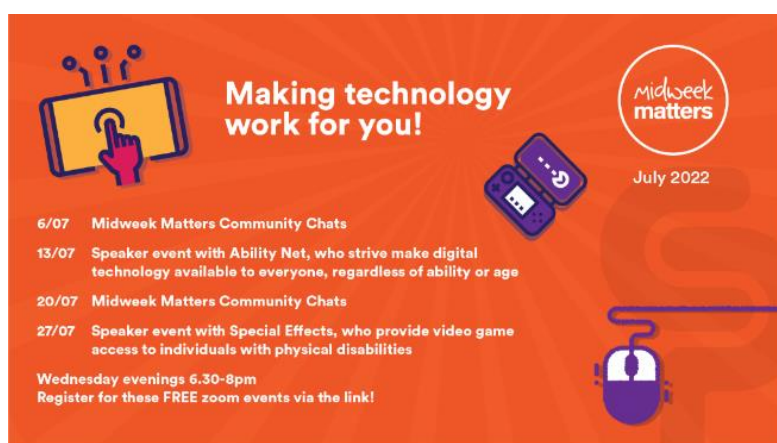
powerful exemplars of good practice from Sweden and clinicians from here in the UK who are trying to change things from the ground up.



This year we also teamed up with Red Whale, the leading education provider for primary care, to facilitate a free one-hour webinar, aimed at GPs, exploring the unmet health needs of adults living with cerebral palsy. This is vital as co-ordinated services stop on transition to adulthood and the responsibility for managing care falls to the GP, whose knowledge and resources are sadly insufficient. This is a significant step in facilitating the realisation of the All Party Parliamentary Group on CP recommendations around medical training, education and the knowledge to support their patient's better.

Educating and supporting the community

Our weekly community support programme, **'Midweek Matters'** continues to flourish and deliver on our goals 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 over 40 sessions this year and been able to connect with other organisations and many external 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 "Parenting", "Independent Living", "Work", "Advocacy", "Poetry", "Accessible Fashion",



"Technology" & "Supporting Positive Mental Health".

The response from the community to Midweek Matters has been highly positive, with over 600 attendees during 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)

Independent Examiner's Report to the Trustees on the Accounts

I report to the trustees on my examination of the accounts of UP – The Adult Cerebral Palsy Movement ("the Charity") for the year ended 06 April 2023.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Basis of Independent Examiner's Report

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all of the evidence that would be required in an audit, and consequently we do not express an audit opinion on the accounts.

Independent examiner's statement

I confirm I am qualified to undertake the examination by being a qualified member of The Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

1. the accounting records were not kept in accordance with section 130 of the Charities Act; or
2. the accounts did not accord with the accounting records; or
3. the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed

Full name Peter Taylor FCA FCCA
Address: Taylor Associates LLP
 Gallery Court, 28 Arcadia Avenue, London, N3 2FG

Date 19 January 2024

Statement of Financial Activity

Receipts and payments accounts for the period 7th April 2022 to 6th April 2023

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	43,675	-	-	43,675	4,239
Sponsorship	-	-	-	-	-
Event Income	-	-	-	-	-
Gift Aid	1,257	-	-	1,257	-
Other Income	128	-	-	128	14,692
Sub total (Gross income for AR)	45,060	-	-	45,060	18,931
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	45,060	-	-	45,060	18,931
A3 Payments					
Event Costs	2,522	-	-	2,522	-
Design & Printing	1,395	-	-	1,395	1,146
Promotion	-	-	-	-	1,986
IT Spend	372	-	-	372	527
Professional Services	39,522	-	-	39,522	6,405
Other Expense	2,788	-	-	2,788	2,228
Sub total	46,600	-	-	46,600	12,293
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	46,600	-	-	46,600	12,293
Net of receipts/(payments)	- 1,540	-	-	- 1,540	6,638
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	13,091	-	-	13,091	-
Cash funds this year end	11,551	-	-	11,551	13,091

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	11,551	-	-
		-	-	-
		-	-	-
	Total cash funds	11,551	-	-
	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

26 January 2024