

# **UP – The Adult Cerebral Palsy Movement**

**Charity Number: 1179458**

## **Trustees' Annual Report & Financial Statements for the Period 7 April 2023 to 6 April 2024**

January 2025

# UP - The Adult Cerebral Palsy Movement

## Trustees' Annual Report & Financial Statements for the Financial Period from 07-Apr-2023 to 06-Apr-2024

### Reference & Administration Details

#### Charity Details:

|                            |  |
|----------------------------|--|
| <b>Name:</b>               | <b>UP – The Adult Cerebral Palsy Movement</b>                                  |
| <b>Charity Number:</b>     | <b>1179458</b>   |
| <b>Company Number:</b>     | <b>CE014808</b>  |
| <b>Registered Address:</b> | <b>Taylor Associates, Gallery Court, 28 Arcadia Avenue,<br/>London, N3 2FG</b> |
| <b>e-mail:</b>             | <b>hello@upmovement.org.uk</b>   |
| <b>website:</b>            | <b><a href="https://upmovement.org.uk/">https://upmovement.org.uk/</a></b>     |

#### Names of the Charity Trustees

Emma Livingstone, appointed 6<sup>th</sup> August 2018  
Derek Livingstone, appointed 6<sup>th</sup> August 2018  
Miriam Creeger, appointed 6<sup>th</sup> August 2018  
Stephen Jacobs OBE, appointed 1<sup>st</sup> October 2020  
Natalie South-Law, appointed 1<sup>st</sup> October 2020, resigned 12<sup>th</sup> September 2024  
Dr Valerie Stevenson, appointed 1<sup>st</sup> October 2020  
Dr Jennifer Ryan, appointed 21<sup>st</sup> December 2020  
Prof Siva Nair, appointed 1<sup>st</sup> August 2024

#### 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:

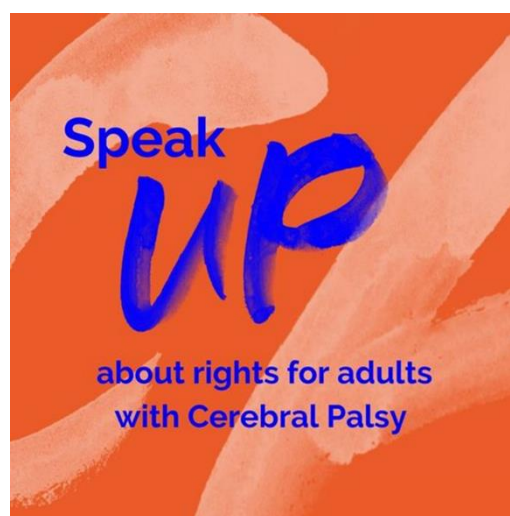
#### Raise awareness

- 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.

We launched our [The Cerebral Palsy Charter](#) to help move Cerebral Palsy up the political agenda. We have assembled a coalition of disability charities and clinicians, calling on the Government and all political parties to recognise cerebral palsy as a lifelong condition. We are also asking for a pledge to ensure all adults with cerebral palsy get enhanced health and social care support, including an annual medical review.

## THE UK'S 130,000 ADULTS WITH CEREBRAL PALSY ARE INVISIBLE TO THE NHS

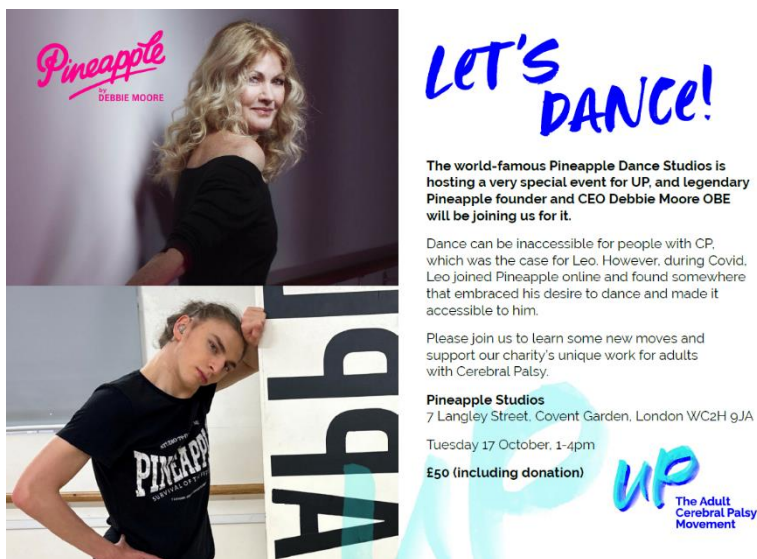
### Recognising Cerebral Palsy as a lifelong condition and therefore...

1. Enabling access to the framework used by GPs to identify individuals with long term conditions, and offering annual medical reviews.
2. Implementing systematic reviews leading to specialist neuro rehabilitation pathways for health interventions and for accessing and staying in work.
3. Funding dedicated key professionals to advocate, coordinate and support individuals with CP to live and age well.
4. Investing in recruitment and training to increase specialist knowledge of Cerebral Palsy across health and social care.

In February 2024, we took a major step towards developing an action plan for improving care for adults with cerebral palsy across London with a meeting chaired by the Regional Medical Director for NHS London. Attendees included representatives from all five ICBs in London and representatives of NHS England, London Rehabilitation Medicine and The Royal Society of Speech and Language Therapists. We continue to actively support this initiative.

For World CP Day in October 2023, we partnered with the world-famous [Pineapple Dance Studios](#) in London for a unique afternoon of dance, led by Pineapple's founder and CEO, Debbie Moore OBE and member of our community Leo. We had 50 people with Cerebral Palsy in the studio and many more online, having a wonderful experience.

Too often, dance can be inaccessible for people with CP, which was the case for Leo. Thankfully, At Pineapple, Leo found somewhere that embraced his desire to dance and made it accessible to him. Pineapple welcomed Leo to their online dance classes during lockdown and continue to adapt and integrate Leo into their classes. Debbie and all at Pineapple understand the power of movement on our mind, body and soul and that it should be accessible for all.



**LET'S DANCE!**

The world-famous Pineapple Dance Studios is hosting a very special event for UP, and legendary Pineapple founder and CEO Debbie Moore OBE will be joining us for it.

Dance can be inaccessible for people with CP, which was the case for Leo. However, during Covid, Leo joined Pineapple online and found somewhere that embraced his desire to dance and made it accessible to him.

Please join us to learn some new moves and support our charity's unique work for adults with Cerebral Palsy.

**Pineapple Studios**  
7 Langley Street, Covent Garden, London WC2H 9JA  
Tuesday 17 October, 1-4pm  
£50 (including donation)

**UP**  
The Adult Cerebral Palsy Movement

Leo's story is a testament to the power of opportunity and the importance of accessible healthcare provisions for all. When we give people with CP the support they need, they can achieve anything they set their minds to.

That's why UP is calling on the government and the NHS to do more to support adults with CP. Specifically, that they acknowledge that CP is a lifelong condition and as such offer the annual reviews and pathways of care we know are needed.

## The Adult Cerebral Palsy 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 in late 2022. The Working Group meets four times year and enables the charity to ensure that its plans for enhancing the health and social care support for adults with Cerebral Palsy are always guided by expert advisers.

## Educating and Supporting professionals

We've initiated practical interventions like GP training programs and web-based tools to improve healthcare access and empower individuals with CP. In January 2024, we launched our new web-based tool for GPs which enables them to find their local Community Neuro Team, to whom they can refer patients with Cerebral Palsy in need of specialist support.

Our co-founder, Emma, has emerged as a prominent voice on the issues faced by adults with CP, in the UK and internationally, advocating for policy changes and representing the disability community. Emma was the keynote speaker at the European Academy of Childhood Diseases in Slovenia in May 2023. She was also invited to give the keynote speech in Norway at a conference held to launch their CP guidelines in March 2024. Emma was also invited to Downing Street to participate in a roundtable on Menopause in the Workplace, chaired by Mims Davies, the then Minister of State for Disabled People, Health and Work and Helen Tomlinson, the Government's Menopause Employment Champion.

### Support Well

## Find Your Community Neuro Team

This is a tool for doctors to be able to look up the details of the relevant Community Health Team for their patient with Cerebral Palsy, and then to make a referral. Patients may wish to direct their GP to this page.

The charity continues to actively support the research community to increase the knowledgebase around Cerebral Palsy. In 2023, Emma was a co-author of a research paper in the Journal of Developmental Medicine & Child Neurology titled "Prevalence and incidence of chronic conditions among adults with cerebral palsy: A systematic review and meta-analysis".

## 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 "Pain Management", "Women's Health", "Cooking", "Self-Love", "Mindfulness" & "Employment".

### Midweek Matters – #lifelong



### Midweek Matters – Cooking Up a Storm



At the end of each month, we summarise the information and resources discussed during the programme and make them available on our website as a reference for the community, making our [website the most authoritative source of information for adults with CP](#).

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 2024.

## 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                22<sup>nd</sup> January 2025

# Statement of Financial Activity

Receipts and payments accounts for the period 7<sup>th</sup> April 2023 to 6<sup>th</sup> April 2024

| Section A Receipts and payments                       |   |                                      |                                     |                                 |                               |
|---|---|--------------------------------------|-------------------------------------|---------------------------------|-------------------------------|
|   | Unrestricted funds<br>to the nearest<br>£ | Restricted funds<br>to the nearest £ | Endowment funds<br>to the nearest £ | Total funds<br>to the nearest £ | Last year<br>to the nearest £ |
| <b>A1 Receipts</b>                                    |   |                                      |                                     |                                 |                               |
| Donation  | 45,371                                    | -                                    | -                                   | 45,371                          | 43,675                        |
| Sponsorship   | -   | -                                    | -                                   | -                               | -                             |
| Event Income  | 19  | -                                    | -                                   | 19                              | -                             |
| Gift Aid  | 252                                       | -                                    | -                                   | 252                             | 1,257                         |
| Other Income  | 8,057                                     | -                                    | -                                   | 8,057                           | 128                           |
| <b>Sub total (Gross income for AR)</b>                | <b>53,698</b>                             | <b>-</b>                             | <b>-</b>                            | <b>53,698</b>                   | <b>45,060</b>                 |
| <b>A2 Asset and investment sales, (see table).</b>    |   |                                      |                                     |                                 |                               |
|   | -   | -                                    | -                                   | -                               | -                             |
|   | -   | -                                    | -                                   | -                               | -                             |
| <b>Sub total</b>                                      | <b>-</b>                                  | <b>-</b>                             | <b>-</b>                            | <b>-</b>                        | <b>-</b>                      |
| <b>Total receipts</b>                                 | <b>53,698</b>                             | <b>-</b>                             | <b>-</b>                            | <b>53,698</b>                   | <b>45,060</b>                 |
| <b>A3 Payments</b>                                    |   |                                      |                                     |                                 |                               |
| Event Costs   | 13,352                                    | -                                    | -                                   | 13,352                          | 2,522                         |
| Design & Printing                                     | 1,126                                     | -                                    | -                                   | 1,126                           | 1,395                         |
| Promotion   | -   | -                                    | -                                   | -                               | -                             |
| IT Spend  | 414                                       | -                                    | -                                   | 414                             | 372                           |
| Professional Services                                 | 42,679                                    | -                                    | -                                   | 42,679                          | 39,522                        |
| Other Expense   | 199                                       | -                                    | -                                   | 199                             | 2,788                         |
| <b>Sub total</b>                                      | <b>57,770</b>                             | <b>-</b>                             | <b>-</b>                            | <b>57,770</b>                   | <b>46,600</b>                 |
| <b>A4 Asset and investment purchases, (see table)</b> |   |                                      |                                     |                                 |                               |
|   | -   | -                                    | -                                   | -                               | -                             |
|   | -   | -                                    | -                                   | -                               | -                             |
| <b>Sub total</b>                                      | <b>-</b>                                  | <b>-</b>                             | <b>-</b>                            | <b>-</b>                        | <b>-</b>                      |
| <b>Total payments</b>                                 | <b>57,770</b>                             | <b>-</b>                             | <b>-</b>                            | <b>57,770</b>                   | <b>46,600</b>                 |
| <b>Net of receipts/(payments)</b>                     | <b>- 4,072</b>                            | <b>-</b>                             | <b>-</b>                            | <b>- 4,072</b>                  | <b>- 1,540</b>                |
| <b>A5 Transfers between funds</b>                     | <b>-</b>                                  | <b>-</b>                             | <b>-</b>                            | <b>-</b>                        | <b>-</b>                      |
| <b>A6 Cash funds last year end</b>                    | <b>11,551</b>                             | <b>-</b>                             | <b>-</b>                            | <b>11,551</b>                   | <b>-</b>                      |
| <b>Cash funds this year end</b>                       | <b>7,479</b>                              | <b>-</b>                             | <b>-</b>                            | <b>7,479</b>                    | <b>11,551</b>                 |

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

| Categories                                   | Details                 | Unrestricted funds<br>to nearest £ | Restricted funds<br>to nearest £ | Endowment funds<br>to nearest £ |
|--|-------------------------|------------------------------------|----------------------------------|---------------------------------|
| B1 Cash funds                                | Bank                    | 7,479                              | -                                | -                               |
|  |                         | -                                  | -                                | -                               |
|  |                         | -                                  | -                                | -                               |
|  | <b>Total cash funds</b> | <b>7,479</b>                       | <b>-</b>                         | <b>-</b>                        |
|  | Details                 | Unrestricted funds<br>to nearest £ | Restricted funds<br>to nearest £ | Endowment funds<br>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                               |                         |                                    | -                                |                                 |
|  |                         |                                    | -                                |                                 |
|  |                         |                                    | -                                |                                 |
|  |                         |                                    | -                                |                                 |

## 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, cursive script.

Full name

Derek Livingstone

Date

27<sup>th</sup> January 2025