

# Chris Westwood Charity for Children with Physical Disabilities.

## Update Report - First Quarter 2024

### Background:

Activity in 2023 was again down a little on the previous year, and we completed 76 grants totalling £81,337.24. We had expected to see a return to the previous pre-COVID level of applications in 2023 as the early part of the year was particularly busy which raised concerns about possible funding limitations arising towards the year end. We usually find that Q4 activity is very high, often approaching 40% of the total for the year but, surprisingly, December was unexpectedly quiet and as a result of the lower activity at the year end we had an opportunity to build a small reserve going into 2024 for the first time in a number of years.

### Progress in Q1 2024:

From the start of January this year we experienced a sharp change in activity with a large number of grant applications arriving in the first week, suggesting that the apparent slowdown at the end of 2023 was probably just a result of a slight change in the timing of submissions to us. Thankfully with the higher level of reserves we had accumulated, we were able to respond and keep up with this dramatic increase and by the end of Q1 we reached 28 grants completed totalling £33,731.24. We also have a number of enquiries likely to proceed to full applications, and we expect to receive these shortly for our consideration.

The level of Q1 activity has had a big effect on our reserves but with some fundraising from events and other supporters coming in, we have managed to complete all the work we wished to approve during the quarter.

As a result, we face Q2 with much lower reserves but with the application for Gift Aid due to be submitted on or after the 06.04.24, and usually paid within 8 working days, it will at least be some help towards facing the next surge in applications.

### Grants Made in Q1 2024:

Age Yrs	Grant £	Details
18	1310.00	She has a diagnosis of Spinal Muscular Atrophy Type 2 and uses a wheelchair. Due to her mobility problems she requires full time care, particularly at night. She had outgrown her special bed supplied by Children's Services and now having moved to Adult Services it was found that they do not supply beds for home use. Due to the cost of a suitable profile bed (approx £4,300), the family had contacted several other charities for help. Initially (late 2023) we were asked separately if we could fund an airflow mattress to help with comfort and relieve pressure points with the new bed, and we agreed to fully fund that item. With the family having raised some funding from two other charities for the bed, we agreed to provide a further grant of £1,310.00 to fund the balance needed to complete a co-fund purchase of the bed as well.
4	934.81	Born prematurely at 29 weeks he has a diagnosis of cerebral palsy affecting his head and trunk control and all four limbs. The Charity funded a Ppod Bean seat for him in 2023, but following a change to being tube fed he had put on a growth spurt and needs a customised liner to hold him in the correct position when in the Ppod seat, which we agreed to fund.
14	1370.00	She suffered a stroke prior to birth and has a diagnosis of cerebral palsy, epilepsy, visual impairment and needs orthotics on both feet, as well as other medical problems. She can walk a very short distance but mainly uses a manual wheelchair. She has outgrown her current chair and the NHS chair would now be adult size. Having assessed the folding wheelchair, it was too heavy for her mother to lift into a car, and also too heavy for the young person to easily move around manually. A suitable very strong and lightweight wheelchair was assessed and found to be ideal for her needs. While the cost was quoted at £1,860.00, the NHS agreed to grant a voucher of £490.00 towards a private purchase as the adult option had been declined. This resulted in the need for £1,370.00 to complete the purchase which we agreed to fund.

2.5	282.00	She has a diagnosis of X Linked Pyruvate dehydrogenase deficiency, an inherited genetic condition. She exhibits with global delay, is not yet walking and has low muscle tone. She has been supplied with a special buggy by Wheelchair Services, but as usual, without any of the much needed accessories (sun and rain covers, and basket) making it unsuitable for use in all weathers. We agreed to fully fund to enable the buggy to be used in all weather conditions.
14	1900.79	He has a diagnosis of quadriplegic cerebral palsy and severe learning disability. He needs adult care for all daily living and uses a wheelchair practically all the time as he has no other comfortable and secure seating system at home. He requires a system which can hold him securely as he also suffers with seizures and can fall from a chair or sofa. A suitable seating system was assessed, and with the family having raised a significant contribution towards the cost we agreed to approve the balance required.
17	399.00	She has a diagnosis of Cerebral palsy and epilepsy. She is also a full time wheelchair user. She attends Dudley College but needed help with a laptop and additional software to enable her to be able to keep up with her classwork. We had helped her some years previously and she is continuing to try hard to adapt and remain in mainstream education. We agreed to fund the laptop with the family funding the accessories.
12	2061.00	She has a diagnosis of Jouberts Syndrome (a genetic brain disorder) and sight impairment. She attends secondary school but uses a wheelchair as she can only walk very short distances. With weak muscles she finds use of a manual wheelchair is becoming an increasing problem and a powered wheelchair was proposed. This was quoted at £11,178.00 due to the various accessories required for her. After approaching a number of other charities, £9,117.00 was raised and we agreed to fund the balance of £2,061.00 so that the purchase could proceed.
7.5	1228.37	He has a diagnosis of cerebral palsy and a range of other medical problems. He had outgrown his Ppod bean seat and needed it to be built into a larger frame, but his NHS Trust would not fund the additional cost as they had already funded an Xpanda Chair to hold him securely in the correct posture. He still needed a comfortable seat to rest from the Xpanda chair which also had a secure harness system, so we agreed to fund the work required to renew the Ppod seat.
14	1528.98	He has complex epilepsy coupled with sight problems, initially diagnosed as Best Eye Disease, and recently requiring emergency surgery after developing a further retinal condition called CNV. No other known cases of both occurring together having been reported has raised problems with his treatment programme. The condition results in a form of macular degeneration and in order to continue his studies with a longer term option of University, a large screen laptop computer and special software, as recommended by the Vision Impairment experts, was required, which we agreed to fully fund.
8.5	1459.10	Born prematurely, has a rare immune system deficiency, has had problems with chronic lung disease, and has frequent joint pain. She needs leg braces to walk and a special exercise trike was proposed to help to develop her leg muscles to improve her mobility and to help to improve her co-ordination.
5	2058.89	She has a diagnosis of Canavan disease, a degenerative brain condition, for which there is no cure. She suffers with Dystonia (involuntary muscle movement) and has recently started suffering fits. The long term prognosis is poor with a life expectancy unlikely to exceed the age of 10 years. She has a special Ppod bean seat at home to hold her safely and in comfort. She now attends a Special School and originally transferred with another Ppod seat that she had used at her pre-school. She is unable to tolerate her posture control seating at school and having now outgrown the Ppod seat, urgently needs a replacement. With no funding available due to Local Authority administration problems we were asked to help. The cost was reduced by reusing some parts of the existing seat and we agreed to fund the amount required to build a replacement seat.
10.5	3539.00	She has a diagnosis of Down's Syndrome and Hypothyroidism. She exhibits with low muscle tone and, although she had access to a bike with stabilisers, as she has grown she has found balance more difficult and is unstable when trying to use it. A trike was proposed, the aim being to help to develop her low muscle tone to improve her mobility and her co-ordination. She was assessed with a number of trikes and the model proposed was the only trike she was able to pedal herself. As part of a single parent family with a younger sister, help with the cost was needed and we agreed to fully fund the purchase.
3.25	899.00	He has a diagnosis of mosaic Down's Syndrome, and exhibits with global delay, speech and communication difficulties, and mobility problems. He has no sense of danger and urgently needed a special buggy, but with his Local Authority in administration, no progress was being made and with three other siblings (one also with special needs) the family needed help, so we agreed to fund.
12.25	981.00	He has a diagnosis of autism and learning disabilities, with other medical complications. He exhibits with challenging behaviour, and no sense of danger, which has recently worsened, and heavyweight secure furniture is now required as he has recently broken two TV units, exposing himself to electrical hazards. A secure cabinet was proposed to protect both the equipment and him from further danger, and we agreed to fully fund it due to family circumstances.
1.5	680.00	He has a diagnosis of Congenital muscular dystrophy – FKR related dystrocanopathy, global development delay and is fully reliant on adult care for all his needs. Life expectancy is limited to probably no more than the age of 20 years. He was assessed by Wheelchair Services for a special buggy, but as usual, they do not provide the canopy, rain cover, basket and tray needed for regular use. We agreed to fund the items required (this is a typical problem we are regularly requested to fund).
17.5	735.00	She has a diagnosis of Leber's Congenital Amaurosis, other sight problems and is registered Blind. She is about to start using a laptop computer which she will then also use at a College of Further Education when she moves there in September, but needs a special screen reader to match the software being used by both her current school (for students with visual impairment), and the College of Further Education. We agreed to fully fund this item.

1.5	220.47	He has a diagnosis of cerebral palsy and has complex and enduring health needs, requiring constant supervision. He has been allocated a special pushchair but (as usual) the sun hood and rain cover were not included which limits its use. With his single parent mother acting as a full time carer, funding help was needed and we agreed to fund the items required.
4.75	829.80	He has a diagnosis of cerebral palsy, and developed sepsis shortly after birth. He exhibits with global delay compared to his twin brother and uses a wheelchair due to his mobility problems, only being able to crawl at present. He has recently had an operation for hip dislocation and a special trike was proposed to help to develop his leg muscles and improve his mobility. With another charity contributing £800.00, we agreed to fund the balance required after our discount structure with the supplier.
7	819.90	He has a diagnosis of autism, never crawled and was unable to walk until 2 years old. He had a recent further diagnosis of Duchenne Muscular Dystrophy, and a special trike was proposed to help to retain some mobility for as long as possible with this degenerative condition. With the family having already obtained some funding from another charity, we agreed to fund the balance required.
5	1612.10	He has a diagnosis of cerebral palsy together with a range of associated medical complications. He uses a walker indoors and a wheelchair when outdoors, and has been assessed as having a low muscle tone. A special exercise trike was proposed to help to develop his leg and core strength, help with his stretching exercises, and to improve his mobility. We agreed to fund the purchase cost, reduced by our discount agreement with the supplier.
9	1637.30	He has a diagnosis of cerebral palsy quadriplegia and recently had hip surgery to try to improve his mobility. A special exercise trike was proposed to help to develop his leg and trunk muscle strength, and to help with the stretching exercises needed to retain some mobility in his legs. We agreed to fully fund the purchase cost, after deducting the discount we receive from the supplier selected by the Healthcare Professional.
10.5	2265.00	He has a diagnosis of Angelman Syndrome with additional problems including global delay, incontinence, feeding problems, mobility limitations such that he uses a wheelchair for other than short distances, and severely disturbed sleep. He needs constant care, sleeps in his parents bedroom so that they can attend to his needs in the night and currently sleeps on the floor due to the danger of him falling from his bed. He wakes regularly, and moves about, and a UrZone Safety Sleeper was proposed which would provide a safe, secure and comfortable sleeping space. This was trialled and found to be a great help. With the family unable to raise any funds and one parent acting as a full time carer, £3,690 was raised from two other charities. We agreed to fund the balance required.
1.5	453.07 + 453.07	Twin girls, born prematurely and both exhibiting with a range of medical problems including global development delay and very poor postural and head control due to weak muscles. Both have outgrown their original baby car seats and new seating required with suitable support and a tilt/turn function. With the family needing help, we agreed to fully fund both seats.
11.75	2126.50	He has a diagnosis of Cerebral Palsy, and has limited mobility. He has outgrown his existing wheelchair but having some limited mobility he has now been re-classified as ineligible for further funding, despite the fact that he still needs a wheelchair when out and when at school. With £1,000.00 already confirmed from another local charity we agreed to fund the balance required.
5.5	439.00	She has a diagnosis of cerebral palsy, is non mobile and relies on her parents for all aspects of her care. We funded a special secure bath seat three years ago for her, which she has now outgrown. A new seat system was proposed with growing room to enable her to be held safely in the bath. We agreed to fully fund.
1.5	740.34	He has a diagnosis of Sandhoff disease, which is a rare inherited condition that progressively destroys nerve cells in the brain and spinal cord. The prognosis is a maximum life expectancy of 3 years, but recent deterioration in his condition means that on his latest discharge from hospital in a few days, he will need palliative care for what may be a much shorter period of life. Unable to now tolerate the special seat he was given at the start of the year we were asked to fund a Ppod Bean seat to hold him securely, safely and in comfort while receiving care for his remaining limited period. The application was urgent and we agreed and arranged to fund the item immediately.
9	767.75	He was born prematurely, has a diagnosis of Cerebral palsy with a wide range of additional medical problems, and is a wheelchair user. A new wheelchair was recently funded by several charities but following a change in his condition we received a request for accessories to improve his seating comfort and to provide an armrest, mounted on a swivel base for easy access to the wheelchair. We agreed to fully fund.
<b>Total</b>	<b>£33,731.24</b>	

## Fundraising:

We would like to thank the various groups who have been holding collections and have transferred funds to us already this year, including Pens Meadow School, the staff at Sunrise Medical, Clent Hills Rotary, and collections already from both the Ladies and Gentlemen's Captains at Stourbridge Golf Club who are both offering support during their terms of office, which is very much appreciated. In addition to our regular monthly donors, whose support provides a very useful stable source of income, we have also received

several personal donations and company donations.

While they have all provided income which has been a great help with funding, may we once again ask if you can encourage anyone who might be interested in supporting us to consider a small regular monthly donation. These can be made from just £2/month upwards, by Standing Order (form on our website – [www.chriswestwoodcharity.co.uk](http://www.chriswestwoodcharity.co.uk)) or by setting up a Direct Debit from your bank account (our Bank details are on the *Donations* page of our website). We are always keen to add new members and the current group adds (with Gift Aid) approximately £7,250.00/yr to our funds which helps to provide some stable income.

We are also promoting the use of the Easyfundraising online purchase commission portal on our Facebook page (details are also on the *Donation* page of our website under option 6. *Easyfundraising*). Some of you kindly supported us through Amazon Smile, where, once registered, your online purchases resulted in a 0.5% donation from Amazon at no cost to you. Sadly Amazon decided to end the scheme early last year and just donate a fixed amount to their selected charities, but Easyfundraising currently has a promotion of £7.50 to your nominated Charity when you register with this online portal and make one online purchase from a selected retailer (there are over 8,000 retailers participating in the scheme including most of the major retailers), and the donation percentages are usually much larger than the 0.5% we used to receive from Amazon Smile.

In addition, their current offer includes a further £7.50 bonus to be paid to the Charity once purchase commissions exceed £7.50 (ie they will double that amount of commission earned), and again all at no additional cost to the purchaser while earning funds for your selected Charity. A few supporters have already joined this year and further additions would be a useful source of new funding.

If you would like to contact us regarding this report, please email us at [chriswestwoodcharity@outlook.com](mailto:chriswestwoodcharity@outlook.com).

Thank you to all our supporters for their continued help, and we will do as much as we can to respond as quickly as we can to new applications, hopefully without the need for a pause in our work.

Chris Westwood.