

# **Chris Westwood Charity for Children with Physical Disabilities.**

## **Update Report - Second Quarter 2024**

### **Background:**

2023 ended surprisingly quietly with little happening after the end of the first week in December. Then from the start of January we experienced a sharp change in activity with 7 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. Activity continued to be high throughout the Quarter and by the end of Q1 we had reached 28 grants completed, totalling £33,731.24 granted.

### **Progress in Q2 2024:**

Applications continued to run at a high rate and by the end of the second Quarter we were able to complete a further 20 grants, bringing the total for the year to 48 grants completed and £65,692.43 granted in the year to date. This brought our Reserves temporarily down to almost zero in June, and we had to start a short Waiting List for a couple of weeks from the middle to the end of June, before fundraising recovered sufficiently to at least clear the outstanding approvals.

For the last 5 years, the overall average grant size each year has been remarkably consistent, the figure being £1,078.37 with only minor variations above/below in each year, despite the usual wide variation in equipment funded. This year there has been a sudden noticeable increase in the average to £1,368.58, which is an increase of £290.21/grant. Over the 48 Grants made this year this amounts to approx £13,950.00 above what we might have expected in previous years, hence not perhaps surprising that we have experienced real pressure on our fundraising/reserves position.

It has also been noticeable that manufacturers have kept prices at a relatively consistent level until recently, so we must attribute some of this observed change to the effect of increasing costs now being passed on.

We do continue to seek discounts where possible and we are particularly successful with two of the equipment suppliers most often selected by the Healthcare Professionals which does help our total expenditure. Nevertheless, increased equipment costs are yet another challenge to our fundraising needs.

We have also recently received a number of very large applications where co-funding would be necessary due to the amount of help required, if we were to become involved further with a grant. In these cases we are awaiting the results of approaches to other charities by the applicants, to determine exactly what additional co-funding might be required before we could consider any further action. We are aware that there is a rapidly increasing need potentially arising for help with much more expensive equipment, putting more pressure on the outcome of our fundraising activities.

A further factor in the level of requests for help that we are now seeing is that Birmingham City Council is effectively in administration, and our local Dudley Council is in severe financial problems. More limited budgets and the inevitable cutbacks have already begun to hit the Disability Sector, and the dependence on charitable help is only likely to increase in the short term.

We can report that we have already seen a worrying trend. We are occasionally asked to help with severely life limited cases where help is urgently required with equipment needed for palliative care. In the last month alone we were approached twice by Healthcare Professionals desperate for equipment for such cases, and coming to us because there was no funding available and they knew that we can usually respond

very quickly. In both cases the equipment was being supplied from companies with whom we deal regularly, and in each case in less than an hour the Chairman had verbally confirmed our support with the Healthcare Professional and the Supplier, with the paperwork to catch up later. The items needed were able to be supplied, modified as required within a couple of days. While the Charity was pleased to have been able to help at such a difficult time, the sudden lack of any alternative sources of funding for such cases just highlights how critical charitable funding will be in the near future for the Disability sector and create more funding challenges for us.

With the total for grants approved for the half year of £65,692.43, and particularly as we usually expect the second half of the year to be busier than the first, it would appear that we are likely to see applications for at least £135,000.00+ this year, a rate of over £11,000.00/month. There are limits to what we can do and we would expect to need to form what will hopefully turn out to be short Waiting Lists, on a number of occasions during the second half of 2024, at the very least, to try to match the rate of applications against the funding that we can raise.

Sadly we may also have to decline some requests for help in the second half of the year as we can only complete grants within the capabilities of our fundraising, and as the first half year has shown, we may have to accept that being able to make 48 grants totalling £65,000+ is an achievement and we can only work within our limitations. We intend though, as always, to try and help as many cases as possible.

### Grants Made in Q2 2024:

Age Yrs	Grant £	Details
11	2304.97	She has a diagnosis of cerebral palsy with other significant disabilities including epilepsy and is non-verbal. We funded a Ppod Bean Seat to provide some comfort and secure seating five years ago, but after a recent growth spurt she has outgrown it and needs a larger seating system. She has a postural seating system supplied by the NHS, but can only tolerate that for short periods. With some deterioration in her recent condition we agreed to fully fund a new comfortable and secure seating system for her.
2	2122.32	He suffered a brain injury which has left him with global development delay, visual impairment and loss of motor skills. It is now thought that he will need a wheelchair for mobility. His NHS Trust has provided items of special needs equipment including a posture seating system. He is unable to tolerate this for long periods and a Ppod Bean Seat with a secure harness was proposed to provide some comfort when not using the posture chair. With the family not in a position to fund the equipment, we agreed to fully fund.
5	3600.00	She has a range of heart problems, has had open heart surgery and will require further operations in the future. Other problems include a severe learning disability, and having outgrown her existing car seat (funded approx. 3 years ago by the Charity) a new car seat system was required. Due to her weight having increased significantly, a car seat with a sliding system was needed to allow easy access, and having considered the application in detail we agreed to fully fund.
7	826.20	He has an, as yet, undiagnosed neurological condition and exhibits with global development delay, and low muscle tone. A special exercise trike was proposed to help to develop his leg strength, and improve his balance and co-ordination. With another charity providing some of the funding we agreed to provide the balance required after our discount agreement with the supplier.
5	1377.60	He has a diagnosis of WOREE Syndrome which exhibits with severe epileptic seizures, scoliosis, learning difficulties, feeding problems and visual impairment. The condition is life limiting and he is unlikely to reach adulthood. His NHS Trust has supplied a range of special needs items including a seating system to hold him in the correct position. He does, however, also need a comfortable seat to relax in which will also hold him securely. He has been using an old Ppod Bean Seat which he has outgrown and a new Ppod Bean Seat was urgently required to give him some comfort and rest from his postural seating. We agreed to fully fund the purchase.
4	145.00	He is life limited and under palliative care with a diagnosis of EIEE (Early Infantile Epilepsy Encephalopathy), requiring full time adult help. He recently received a new wheelchair but no rain cover is provided. He is registered blind but loves to be outside so a suitable raincover was proposed which we agreed to fund.
13.75	566.00	She has a diagnosis of Lennox Gastaut Syndrome and exhibits with complex epilepsy and global development delay. She uses a wheelchair but the family often use a McLaren buggy when taking her out as this is much lighter and easier to handle than the wheelchair. Having outgrown the buggy a new larger unit was required. We have helped her before in 2016, and knowing the case we agreed to fully fund.

7	3151.50	She has a diagnosis of Downs Syndrome, autism, lack of awareness of danger, low muscle tone and hypermobility. She needed a special car seat to hold her in the correct posture with the required additional supports and a secure safety harness system. We agreed to fully fund the purchase cost of the seat.
6.9	1406.00	She has a diagnosis of cerebral palsy and uses foot/ankle supports to enable her to have some mobility. Regular exercise was recommended (swimming and cycling suggested) to stretch her leg muscles and help to build core and hip strength, to further improve her mobility. She was unable to ride a bicycle but was fully assessed for a trike with the accessories required for her specific needs, which was very successful, and we were asked if we could help with the funding required. We agreed to fully fund the discounted cost of the trike, the price being reduced as we have an agreement with the supplier.
15	2247.60	He has a diagnosis of complex back problems, scoliosis, and visual impairment resulting in him being registered blind. He is wheelchair bound and while he does not exhibit with any problems with mental capacity, he requires adult care for many of his actions resulting in limited independence. He has had a comfortable Ppod bean seat for a number of years, but he has now outgrown it and as he already has a postural support system funded by his NHS Trust, they will not fund any further seating, leaving him with no comfortable and secure seating away from his wheelchair and his postural system. With the family unable to fund the equipment, we agreed to fund the Ppod seating system for him.
4.5	2994.00	She has a diagnosis of Mosaic Chromosome 7 and q10 deletion, and Microcephaly-holoprosencephaly (a brain disorder after birth where the brain does not separate into left and right hemispheres). She exhibits with global development delay, visual impairment, epilepsy and is PEG fed. She has also had a bone marrow transplant. She needed a fully supportive special car seat to hold her securely when being transported and we agreed to fully fund.
4	689.00	He has behavioural and communication problems with no sense of danger. When being transported he releases himself from his car seat and presents a risk to the driver. A secure magnet harness was proposed and he was assessed by Windmill Special Needs. Following an application to the Charity for help, we agreed to fully fund.
3	3309.00	She has a diagnosis of Angelman Syndrome and exhibits with associated medical problems. She had outgrown her car seat and needed a new fully supportive and secure special car seat. She was assessed at RDAC (Regional Driving Assessment Centre) and we agreed to fully fund the seating system required.
4	1485.20	He has a diagnosis of development delay, is weak in both core and leg strength and has poor balance. He is only able to walk a few steps and his Paediatric Physiotherapist recommended a trike to improve his co-ordination and leg strength. When assessed he was able to pedal a trike and the provision of a suitably adapted unit should help to improve his walking. With the family unable to fund the trike, we agreed to fully support the purchase.
11	1199.95	He has been severely sight impaired since birth and is registered Blind. In 2018 we funded a Perkins Braille for home use and as he will move to Secondary Education in September he needs a computer with screen reader software for the work he will need to do at home. He is learning to touch type and we were asked if we could again help, this time by funding the equipment proposed by the Dudley Vision Impairment Service. We agreed to fully fund.
15.5	819.00	He has a diagnosis of Phelan-McDermid Syndrome (22q13 deletion) and exhibits with associated neurodevelopmental difficulties and challenging behaviour. A secure TV cabinet was required to protect him as his behaviour can result in a serious risk of danger when he is unable to self regulate. We agreed to fund a lockable reinforced protective cabinet.
2	524.48	Sustained a catastrophic brain injury in 2023 due to her tracheostomy being blocked and having a cardiac arrest. At birth she was diagnosed with subglottic stenosis (restricted upper airway affecting her breathing) secondary to multiple extubations and is dependent on continuous Oxygen. She has other complex problems and needed a car seat to suitably hold and support her when being transported.
14	1400.00	She has a diagnosis which includes complex medical needs, epilepsy and juvenile arthritis. She is in mainstream education but uses a wheelchair, and needed a separate support seating system. The school was not provided with any additional budget for special needs equipment, although they were required to provide suitable seating. We agreed to help and co-fund the seating system which cost £2,733.60.
2	496.37	He has a diagnosis of Sandhoff's Disease, exhibits with problems with blocking his airways, and we helped him earlier in the year with a Ppod Bean seat to give him some comfort at home. His condition has recently worsened and he is now receiving palliative care. A suitable car seat was urgently required to support and hold him in the correct position to help his breathing. A rapid response was needed and we agreed immediately to fully fund the equipment.
4	1297.00	She has mobility problems and has been attending a Functional Electrical Stimulation Clinic. She is only able to walk a few steps and needs a wheelchair. As she can walk at least one step, Wheelchair Services will not fund a suitable chair, so we were asked to co-fund with another charity and agreed to provide the balance of £1,297.00 required.
	<b>£31,961.19</b>	<b>For a further 20 Grants (as above) completed in Q2</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 continuing collections 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, Company donations and the proceeds of our annual Gift Aid claim.

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 supporters have already joined us, and this is a zero cost option for the donor to help your chosen Charity.

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.