

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

## **Update Report – First Quarter 2018**

### **Background:**

We completed 2017 with grants made during the year reaching £137,186.81, a very small increase over the £136,323.44 completed in 2016, when we had seen massive growth of 56% over our work in 2015. We were grateful that we had had a pause, although pause barely describes the vast amount of work we still completed during the year, and we were rather glad of the slowdown in the rate of growth. This enabled us to at least try to stabilise the reserves, so that we could face 2018 with the prospect of being able to again cope with the requests for help received. We closed 2017 with reserves of £29,099.45, and we approached 2018 with some concern that we may well see another surge in demand after the recent pause. This has happened previously, which might then result in a struggle to respond to every application we would wish to approve, unless we could increase our fundraising. So, as always, fundraising was going to be the main priority for the year.

### **Progress in 2018:**

We started the year briskly, and expected another busy Q1. However, while we have had a number of application enquiries, not all have progressed to a completed application (this does happen sometimes when families are very keen to obtain equipment and do not discuss it first with their Paediatric/Occupational therapist). By the end of Q1 we had completed 22 grants, totalling £27,210.81, down on the 27 grants and £42,243.30 we completed in Q1 2017, but still running at a rate of over £100,000/year.

With considerable effort in fundraising initiatives, we have managed to maintain the reserves at just below the starting level, at £28,520.37, at least giving us some confidence to fund Q2, as we shortly have a substantial Gift Aid claim to submit.

We have already noticed two changes in 2018, the first being that the average grant size has reduced from the Q1 2017 figure of £1,564.56 per grant, to £1,236.86 per grant in Q1 2018. For many years we averaged between £1,500.00 and £1,600.00 per grant, but as we moved through 2017 we began to notice a large increase in smaller grants, reducing the average to a similar lower figure to the one we are now seeing ("small" being defined as grants of less than £1,000.00). A detailed analysis of 2017 showed that over the year as a whole, 52% of our grants were for small applications, amounting to only 16% of the total granted, the remaining 48% of the 102 grants we made taking the balance of 84%. This may be a short term change, and we may then return to the previous averages, or the continual increase in our contacts may be bringing in many more cases where a small grant to a family can make a major difference. Already in 2018, 50% of our grants have been for small applications, so the trend continues for the moment.

The second significant change has been that we have been approached a number of times by families who have asked us how to proceed, sometimes after already having received a quotation for the equipment they are looking for. In each case we have referred them to the website, but we have also provided the full details of the information necessary, and the reasons it is required, to help to speed up the application process. However, we have not as yet received a completed application in some of the cases, which perhaps highlights the importance of having a very clear system, to enable us to establish the validity of the applications received.

In order to ensure that our funds (from your donations) are used correctly, we require two key pieces of information with every application, a detailed report from a suitable medical expert, explaining the problems the child has, the equipment proposed, and how it is hoped this will help, together with a detailed quotation from the supplier's expert, who will usually have carried out a detailed assessment. We need these in order to be in a position to sign the VAT exemption certificate (we can claim exemption as a result of a confirmed medical condition), and to calculate a revised final cost, depending on the discount structure we may have negotiated with the supplier, so that we know the exact amount of grant required. We then carry out certain other checks of our own, before proceeding further.

Currently we are aware of at least five potential applications, which we would expect to require around £10,000 if they were subsequently found to comply with our grant criteria, and were approved. Of these, we would expect two or three to certainly progress further, but the remaining queries have been pending for some time. With no further paperwork yet submitted, we are unable to proceed until we have received all of the required information, which means that those that do progress will have slipped into Q2.

No doubt we shall see a sudden increase in demand in the near future, but in the interim it has allowed us to pursue further fundraising initiatives.

### **Our Income Position:**

At the end of 2017 we were contacted by Alloy Wire International, based in the Brierley Hill area, and this resulted in a very much appreciated donation of £10,000.00, received in January. The Barbara Ward Foundation also gave us £5,000.00, as the first of three annual grants, again of great help to us, the Edgar Lawley Foundation (a local charity) £1,500.00, and the Edward Cadbury Charitable Trust (another locally based charity) £2,000.00..

We have also been helped by a number of smaller groups collecting for us, including Hagley Golf Club Seniors, who collected all year (£2,083.89), Kinver Floral Arts (£1,000.00), Clent Hills Rotary (£300.00), Paul Matty Sportscars (£250.00), Miller Roofing (£250.00), and we are waiting for a Butterfly2012 meeting to be rescheduled following the recent bad weather, as they have promised that the proceeds of the event will be donated to us. The main group collecting for us at the moment is Stourbridge Golf Club. We have been chosen as one of the Captain's charities for his two year term of office to the end of 2019. A donation page has been set up on Everyclick (with a donation button also on the homepage of our website), and this has already raised £1,100.00.

With regular donors now running at £422.00/month, and another donor possibly due to join, this is also beginning to become a significant source of funds, but we would welcome further help, however large or small.

We are due to make our Gift Aid claim for 2017/2018 as soon as possible after April 5<sup>th</sup>, and we currently expect to submit a claim for £6,653.18, which will be a very helpful addition to our funds.

This year we have set up a *Give as You Live* donation system, which we have been testing since February, and which are now hoping to roll out over the coming months as our major fundraising initiative for 2018. We have great hopes that with the help of our supporters, we can generate significant funds, at no cost to the donor.

We have set up a webpage on our website, with a button on the Homepage (bottom left of the block of buttons), and this explains the system in detail. Commission payments are made to the charity of your choice whenever purchases are made either in-store (for which you need the relevant store card), or online through the *Give as You Live* website.

For in-store use, you only need to register, pay a one-off fee of £2.50 for the relevant in-store card, which

comes directly from the store group, and every time you top up the card with cash, a commission (typically £2 for every £100 put on the card) is paid to your nominated charity. When you reach the till, you just use the card to pay. The funds are held by the store group, and you receive a receipt after each use informing you of the balance (which can also be checked by inputting the card details on the store group's website).

For online purchases, having registered the first time you use the system, you select the store group, you are taken to their webpage, and you order in the normal way. Commission payments are received for one off purchases from many store groups. However, for certain regular online purchases (typically grocery shopping), the payments are only available to new customers unless you use the relevant in-store card. By using the in-store card, which earns the commission without any problem every time it is topped up, it is still possible to gain the maximum benefit for your chosen charity when grocery shopping. For other online purchases you can use a credit card as you would normally do. After a successful purchase, you will receive an email telling you the amount you have raised for your chosen charity (which we hope will be us).

During testing, the Trustees have completed online purchases through Amazon, Screwfix and Wilko, all without any problems, and all the purchases have resulted in small commission payments. A Trustee is now using an in-store card at Waitrose, and this has already generated useful cash commission payments to the Charity. There are also regular special offers which increase the donation made for selected periods.

Over a year, using this system, a significant sum could be raised, at no cost to you, and with a number of supporters, this could become a major source of funding for us. The funding is available to be claimed, so we would greatly appreciate any commission payments you could generate for us.

## Grants Made in Q1 2018:

Age Yrs	Grant £	Details
4	309.00	Autistic Spectrum Disorder, with no awareness of danger. He becomes very stressed when out, and runs off unless restrained. We funded a Crelling Harness to hold him securely in his car seat in mid 2016, and this request was for a special needs buggy to allow him to be taken out safely, and under control. We agreed to fully fund.
8	2,600.00	He has a diagnosis of Lissencephaly ( <i>a severe brain malformation</i> ) which has resulted in severe development delay, a range of medical problems, and a poor prognosis for life expectancy. With his condition deteriorating, he has been struggling to support himself in his wheelchair, and an Acheeva bed was proposed for use by his school, to help to provide the support he needs. After discussion with the School, we agreed on a co fund basis, obtained a revised quote with our supplier discount, and agreed to contribute just over 50% of the cost. With the school able to fund the rest, the equipment should soon be available to help him.
?	1,645.60	He has a diagnosis of Scoliosis with spinal cord tethering, for which he has recently undergone major surgery. He needs a special car seat with vacuum cushions and additional support, so that the seat can be adapted to his requirements, especially as he needs to travel long distances for his regular hospital visits. We agreed to fully fund the purchase cost, reduced by our discount agreement with the supplier.
5.5	2,277.47	He has a diagnosis of cerebral palsy spastic quadriplegia. He is immobile and unable to support himself in a sitting position. While he has special seating at school, he has nothing suitable at home, and inadequate postural support will impact on his condition. His Occupational Therapist recommended a special support chair for him, and with the family able to contribute £100.00, we agreed to fund the balance required for the purchase to proceed.
8	1,794.00	The young man already mentioned, with the diagnosis of Lissencephaly, also needed a wider single profiling bed at home. With the County Council only prepared to support a hospital bed (cost £525.00), we were asked to help. It was agreed that if the Charity fully funded the purchase, the Council would subsequently provide their contribution of £525.00. In view of the urgent need, we agreed to fully fund, and await the refund from them (since received).
17.9	2,113.75	Duchenne Muscular Dystrophy and full time wheelchair user. He is fully dependent on his carers for all transfers, and needs a fully supportive chair to help with relieving pressure points, and capable of holding him correctly. Currently he has nowhere suitable to sit, and has to use his bed which is unsuitable and can not be replaced with a hospital bed due to lack of space. He needs to be held correctly when sitting and we agreed to fully fund.
10.5	1,025.10	Down's Syndrome, heart problems, skeletal dysplasia, other medical problems, full time wheelchair user and has severe learning difficulties. She needs a fully supportive special car seat, suitable for her condition, to hold her securely. With another charity contributing part of the cost, we agreed to fund the balance.

15.5	287.14	Visual impairment and further investigation was in progress relating to Marfan Syndrome, and Meares-Irlen Syndrome. The Dudley Visual Impairment Service recommended a special iPad, suitable for his condition, and we were asked if we could help to fund the cost. We agreed to cover the full cost of purchase, in view of the circumstances.
11	1,422.35	Cerebral palsy spastic quadriplegia, currently able to walk using a walking frame, special footwear, and wearing a protective helmet. The proposal was to fund the purchase of a special exercise trike to try to overcome his leg weakness and improve his mobility. Having proved he was capable of using the pedals on the selected trike at an assessment, we were asked if we could help. The total cost reduced with our agreed discount with the supplier, and we agreed to fully fund.
4	3,820.00	She has a diagnosis of a chromosomal abnormality, Trisomy 9 Mosaic, and partial Trisomy 11 Mosaic. She exhibits complex medical problems, physical and learning disabilities, and is a full time wheelchair user. She has to use special seating both at home and in school, and was using a special cot bed which was on loan from another charity, and needed back. She requires constant monitoring and oxygen during the night, and the bed has proved to help the family greatly. We were asked if we could help with funding a similar replacement unit, and with the family having raised some funds, we agreed to contribute the balance required.
6	550.50	She has a diagnosis of severe non verbal ASD with global development delay and sensory processing difficulties. Having outgrown her special car seat, she was using a standard seat belt when in the car, and releasing herself regularly. She then presented a serious danger to the driver and passengers by opening doors/windows, and with no sense of danger she urgently needed a special car seat with suitable restraint to hold her securely. With our supplier discount and the family able to provide a small amount of funding, we agreed to provide the balance to allow the purchase of a suitable seat to proceed.
6	606.00	She has a diagnosis of global development delay, sensory processing difficulties, epilepsy, dermatographism, ADHD, and hypermobility. Having outgrown her car seat, she is using a standard seat belt, and is not being held securely and safely. She can also escape and present a hazard to the driver. A suitable special support car seat was required, and with the family only able to contribute a small amount of funding due to a second special needs child, we agreed to fund the balance required for purchase, the cost being reduced by our agreed discount with the supplier.
9	1260.75	He has a diagnosis of cerebral palsy spastic quadriplegia. He can only walk short distances, and needs otherwise to use a wheelchair. A special exercise trike was proposed to help to improve his mobility by easing the tight muscles in his legs and building his leg and core strength. With a family contribution of £250.00, we agreed to fund the balance required for purchase.
7	1440.20	He has a diagnosis of cerebral palsy hemiplegia, which presents as weakness all down his right hand side. While he can walk, he has balance problems, and a special exercise trike was again proposed to help to improve his leg and core strength. We agreed to fund the full cost of purchase.
2	259.00	Global development delay, and he can only walk short distances indoors. He will need the support of a special buggy for a number of years. With the family able to raise £50.00, we agreed to provide the balance required for the purchase to proceed.
3.5	355.00	Rett Syndrome, which affects brain development and results in learning and mobility difficulties. She is non-mobile, and is unable to sit with the correct posture. The requirement was for a portable posture support seat for her, and we agreed to fully fund the purchase.
10	1000.00	Cerebral Palsy, unable to sit or move unaided. Request for an eye gaze system for home use to help her (Special School unit has been broken for the last three years, and would have been a great help if available). Due to the cost (£4,998.00, we agreed to pledge £1,000.00, subject to the balance of funding being raised from other charities, which the family was already approaching.
7	138.00	He has a diagnosis of arrested hydrocephalus and left hemiplegia, and was unable to support himself to sit correctly. We were asked to fund a special posture cushion which would provide the additional support he needed, to which we agreed.
10	947.32	He has a diagnosis of Kabuki Syndrome, club feet, and a range of medical problems. He uses a standard wheelchair which does not provide head and neck support, and is not very comfortable when he is taken out. The request was for help with funding a special buggy which would hold him securely, provide the head and neck support required, and be more comfortable for him. We agreed to fund the buggy, and the family raised the balance for minor accessories.
8	1200.00	He has a diagnosis of Sickle Cell Anaemia, with duplication of two chromosomes, and he also exhibits global development delay. He suffers with leg pain, has regular physiotherapy, and his Paediatric Physiotherapist recommended a special exercise trike to try to build his leg muscle strength and improve his mobility. With the family having raised a small amount towards the cost, we agreed to fund the balance.
11	310.99	He has a range of complex vision problems which can not be corrected by glasses. He needs magnified print, but at school there is no room in class for his video magnifier, which excludes him from a number of activities, and he struggles to read at home. Dudley Vision Impairment Service recommended an Ipad, similar to units we have funded before for children with this type of problem, and we agreed to fully fund.
5.5	1848.64	She has a diagnosis of spastic cerebral palsy, with further complications, epilepsy, and a deteriorating spinal condition. She has some lung function problems, and as she is unable to roll, crawl or sit unaided, she needs to be held securely. Her local NHS Trust will only supply one type of special seating system, which is no longer suitable for her, and with her deteriorating back condition she urgently needed the correct support. We agreed to fully fund a P-Pod Bean Seat for her.
	<b>£27,210.81</b>	

## **GDPR Progress Report:**

The Annual Progress Report for 2017 was circulated to all of our supporters at the start of January, and we requested confirmation that we may continue to contact you, as required by the new regulations, which come into force on 25<sup>th</sup> May. A large number of you have kindly confirmed that you do wish to continue to follow our progress, but there are still a few others from whom we have not yet received a response.

This quarter, we have sent a separate email to those who have not yet responded, as we will not be able to circulate the Q2 report to them without confirmation. We appreciate that a number may no longer wish to be contacted, and we can only thank them for their previous support.

On our website we have set up a webpage specifically covering our approach to Data Protection, and we intend to update this regularly.

## **Future Progress:**

We have managed to continue to operate with no administration costs, and it is our intention to ensure that we maintain this strategy.

We have also continued to develop our website (which is operated at no cost to the Charity), where you can find copies of our recent reports – please visit the *Reports Current* webpage, the website address being: [www.chriswestwoodcharity.co.uk](http://www.chriswestwoodcharity.co.uk)

Our main challenge for 2018 will be to continue to try to develop our various fundraising initiatives, the main one being *Give as You Live*, which enables all of us to claim money for charity, at no cost, so we are hopeful that we can develop this source of funding. Please try it, and at least claim the charity funding that is available at no cost to you, even if you would prefer to donate elsewhere, it all helps the charity sector.

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

We now look forward to a challenging second quarter, but with your help we are optimistic that we shall be able to cope once again.

Chris Westwood.