

Chris Westwood Charity

For Children with Physical Disabilities



Progress Report as at 31st December 2017



Chris Westwood Charity
for Children with Physical Disabilities

Charity Commission Registration Number 1101230

What Do We Do?

Background

The Charity was founded on the 19th November 2003, specifically to help children and young people with physical disabilities, in Stourbridge and the surrounding areas, which for practical reasons we defined as being within a 50 mile radius of Stourbridge. The Charity Commission registered number is 1101230.

The stated aim is: *“The provision of financial assistance, at the discretion of the Trustees, to provide the relief of physically handicapped children. This includes improvement to the quality of life by the provision of financial or other assistance, or any other purpose the Trustees deem to be in accordance with the stated aim”.* We make grants for specific uses, where a significant difference can be made to both the life of the child/young person, and the family. Usually this is by the provision of the necessary funding for the purchase of mobility equipment, when there are gaps in the State support system. We endeavour to give a rapid response, typically within 24 to 48 hours, as sadly a number of cases involve degenerative conditions, or are life limited, with time being critical. We also aim to achieve all of this with no administration or operating costs.

Typical Areas of Assistance Provided to date

- Special exercise equipment, special exercise tricycles, walkers, and standing frames, to assist in regaining and maintaining mobility
- Wheelchairs, special mobility chairs, special car seats and safety harnesses, special seating, special beds, support and lifting equipment, vision equipment, and sensory room equipment, to improve the quality of life.

How we Assess Grant Applications

Following an initial approach, we request the submission of a detailed grant application. In order to assess the position, we typically require the following:

- Background and reason for the request
- Supporting information from a suitable professional person detailing the medical position and the advantages of the proposed equipment purchase
- A detailed quotation, following assessment by the supplier’s competent person
- Details of any funding already raised, any other sources of funding, and the financial position of the family

Provided that we are assured that our help will be for those in real need, the application is in accordance with our grant criteria, and we have the funding available, it will be considered for approval. Grants are funded either by a cheque or online payment to the supplier, to ensure that the funds are only used for the intended purpose. All remaining order and delivery arrangements are then left to the applicant, so that we are not involved in any administration costs.



www.chriswestwoodcharity.co.uk

What have we been up to in 2017?

The Headlines: 102 Grants completed and £137,187 granted in 2017 512 Grants completed and £626,700 granted since inception

We began the year with the reserves still benefiting from a substantial legacy and the Charter Court Financial Services support in 2016, although the £52,561.11 carried forward represented only around 4 months work at the 2016 rate of activity. The year ended with the total activity only a little above the 2016 levels, although there was a rapid increase in the final quarter. New records were established for the grants made and the total granted in a year, and in February we passed another milestone of £500,000 granted since we started in November 2003.

This recent level of activity is extremely worrying, as it is currently pushing us beyond our capacity to raise funds. As always, we shall endeavour to cope, but the need for more external help grows ever more pressing.

As usual, our funds in 2017 came from a number of areas, the key sources being:

Regular Donors: The number increased to 15 over the year, and in a full year we would now expect to raise over £5,000 (plus Gift Aid). During 2017, our total income was just under £4,200.00. Any addition to this group would be a big help.

Personal Donations: Reached £26,450.00 during the year. In addition, £1,700.00 was donated online to our main Everyclick page, and collection boxes brought in nearly £450.00.

Charitable Foundations: With no major supporter for 2017, we sought help from a number of Charitable Foundations, in a number of cases for the first time in three years, and received excellent support totalling £61,850.

Various events raised £6,000.00, and Company donations of £650.00, together with the final balance of £7,500.00 from the fundraising by Charter Court Financial Services in 2016, which came through during the first quarter. In total, a significant £14,000.00 to reserves.

Miscellaneous income included £4,000.00 Gift Aid paid by HMRC (within 8 working days under their new system), a final balance of £500.00 from a deceased estate, and £220.00 of Bank interest on our rapidly declining reserves balance.

Throughout 2017, the Hagley Golf Club Seniors have been collecting for us, and we expect to receive a donation at their AGM in February 2018, and for 2018/2019, the new Captain at Stourbridge Golf Club has selected us as a chosen charity. We received £2,000.00 from Rotary and £500.00 from an Asda Store collection in July, and £500.00 from Freemasonry in November. We now have an increasing number of small groups collecting for us, and, as always, a big thank you to all our supporters, without whom we would be unable to do this work, as we look forward to what is likely to be our most challenging year to date.



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How a Donation Can Help (1)

Special Car Seats.....



Aaron has a chromosomal deletion 22q11.21, which has resulted in a series of problems, leaving him unstable and difficulties with motor skills.

In particular, he needs to be lifted in and out of a car seat, and we were asked if we could help with the funding for a special support car seat to hold him securely, and also fitted with a turntable base, so that he could be more easily put into and taken out of his seat.

We were pleased to be able to help, and with our agreed discount from a regular supplier, the final cost reduced to £737.25. As can be seen above, he is now being held securely, and properly supported in his new seat. Using the turntable base, he has been rotated to face the door for easy access.

How a Donation Can Help (2)

Special Exercise Tricycles.....



Emily is 3 years old and has a genetic condition called Osteogenesis Imperfecta Type 5 (*often referred to as Brittle Bone Disease*). She also suffers with Hypermobility, has decreased muscle tone in both her upper and lower limbs, and uses a wheelchair for any distance due to weakness and the risk of falls.

The family encourages her physical development, and a special exercise trike was recommended by her Paediatric Physiotherapist to further help to keep her as active as possible, improve her trunk and core strength, her stability, and develop her current physical skills.

With the family able to contribute some funding to the purchase, we agreed to fund the balance required. Since we purchase a number of these units, we have a discount agreement with the supplier which further helped to reduce the cost.

The family reported back that Emily is progressing well, and kindly provided the photograph above.

How a Donation Can Help (3)

Walkers.....



Maelie-Sue is 7 years old and has a diagnosis of Cerebral palsy ataxic quadriplegia, and Angelman Syndrome. She is unable to walk and uses a standing frame daily to try and improve her muscle strength.

We were asked if we could help with funding a body steered walker to help to improve her coordination, further build her muscle strength, and get her body used to a walking action. While the prognosis for independent walking is not good, this should at least help to improve her weight bearing ability, as well as the ability to transfer between seating systems.

With our discount agreement with the supplier, the final VAT exempt price reduced to £2,093.95, and with the family having raised £1,000.00, we contributed the balance of £1,093.95, to allow the purchase to proceed.

The family has reported that she is very excited about using her walker, and with the additional exercise, everyone hopes her mobility will improve further.

How a Donation Can Help (4)

Powered Wheelchairs.....



Danyaal is 16 years old and has a diagnosis of cerebral palsy spastic quadriplegia. He needs a wheelchair for all but very short distances, but the chair supplied by Wheelchair Services is too heavy for him to self propel.

The original application was for the purchase of a lightweight chair, shown above, which would be of greater use for him (cost £2,856.00), and the family would then try and raise an additional £4,000 to fund the purchase of a battery pack and drive motor, to give him much greater independence.

After reviewing the case and discussing his needs, the Trustees agreed to fund the full cost in this case, and the chair shown is complete with the battery packs and drive motors, fitted within the wheels. He can both self propel or use the drive system by touching the inner wheel rim. This has now given him much more independence, and he particularly enjoys using it at his sixth form college.

How a Donation Can Help (5)

Special Buggies.....



Maryam is 9 years old, and has a diagnosis of cerebral palsy, with stiffness in all four limbs, as well as other problems. Unable to move around or sit up independently, she needed a special buggy to provide the required support when she was taken out.

She had previously used a special needs buggy, but having recently outgrown it, we were asked if we could help.

The Maclaren Lightweight buggy shown above was a suitable replacement, and at a cost of £364.50 we agreed to fund the purchase, to enable Maryam to be transported safely, and properly supported.

Details of a few more of the Grants Made in 2017

Age (Yrs)	Grant (£)	Details
4	649.38	She has a Chiari malformation (<i>a problem with space at the base of the brain and the top of the spine</i>) and will probably shortly have surgery. She also has hypermobile joints, learning difficulties, and delayed gross motor skills. She needs a special car seat to support her correctly, with a secure harness, which we agreed to fully fund
12	1228.00	Diagnosis of Kabuki Syndrome, severe global development delay, visual impairment, epilepsy, and feeding problems. He recently dislocated a hip and is having reconstructive surgery. He has outgrown his profile bed, and the NHS bed that has been provided does not have the high side support that he needs. With a danger of him falling out of bed during an epileptic seizure, we were asked to help with the purchase of a suitable bed for his needs, and we agreed to fund the full cost.
10.5	617.00	Diagnosis of Crie du Chat Syndrome (<i>also referred to as Chromosome 5p deletion syndrome</i>) which has resulted in severe speech and learning difficulties, and medical problems including scoliosis. She has to wear a spinal brace full time to prevent further deterioration. She has outgrown her current car seat and requires a seat which will also allow her to be held in both a safe and comfortable position while wearing the brace, and we agreed to fund the full cost
17	800.00	Fragile X Syndrome, presenting as severe and complex barriers to learning, and additional complex physical and health needs. He has limited comprehension and speech, and no sense of danger. He requires two adult carers at school and has a carer at home in addition to his mother. He needs a secure car seat harness system for his own safety in both his carer and his mother's cars, and he had outgrown his present systems. As a single parent family, help was urgently needed, and with other family members able to raise approx £200.00 towards the cost, we agreed to fund the balance.
11.5	3547.70	Duchenne Muscular Dystrophy, and he has recently stopped walking and standing, as his condition progresses. Without him being able to stand, he will lose further mobility, bone density, and will risk bowel problems. The proposal was to fund a supine standing frame to enable him to stand, and maintain his mobility for as long as possible. With no NHS funding for this item, we agreed to fund the purchase cost.
11.8	739.10	Cornelia de Lange Syndrome and ADHD. With no sense of danger, he releases himself from his car seat when in transit and presents a significant risk to the occupants. He was fully assessed in the proposed seat, which has secure restraint harnessing, and was comfortable. With the family unable to help, we agreed to fully fund.

The Organisation

We continue to run the organisation with four Trustees, who cover all the work necessary, and contribute any minor incidental expenses incurred, so that the Charity can operate with zero administration costs.

We are all in regular email and telephone contact, which, as a small group, enables us to give a fast response to grant application requests that are in accordance with our grant criteria. We hold two formal meetings a year, where we complete a full six monthly review of the organisation, and we can quickly assemble for any additional meetings, if necessary.

It is our intention to continue to operate with zero administration costs, and a fast response, to meet the needs of those who apply to us for help, and the expectations of those who so kindly contribute and support us. The only concern on our horizon is ensuring that we can raise adequate funding, which with the rapid growth we have seen in demand, constantly puts our reserves under pressure. This is a problem we continually face, and we hope that with sufficient help and support we shall again be able to complete our work in 2018.



l-r: Lewis Barnes Janine Barnes Chris Westwood Graham Wood, photograph taken after an October meeting

New Legislation affecting us in 2017/2018

Registered charities are closely controlled by the Charity Commission, and are required to submit Annual Returns which include statements that they have certain policies in place (eg Safeguarding, Risk Assessments, Reporting of Serious Incidents etc.), the extent of the list depending on the level of activity. Overall operations are covered by the requirements of the Charities Act (current version dated 2016), which is updated regularly.

Legislation in other areas can also impact upon us, and there were two new items in particular in 2017 for us to consider. These were the General Data Protection Regulations, and the Common Reporting Standard (from which we have exemption under current rules, and our present circumstances). Application forms for those charities complying with CRS have become worryingly complex, as charity work sadly now involves far more than just giving grants to those in need.

General Data protection Regulations (GDPR)

This comes into force on 25.05.18. Deemed consent disappears, which means that we shall require positive consent from our supporters for them to receive communication from us after that date. We also have to have procedures in place stating exactly what data we hold, why we need to hold it, how we protect it, and how our supporters may unsubscribe from future contact, if they wish. Charities will now have to make contact with all of their contacts to ask if they may in future contact them, and record the responses. All of this has been detailed in our Privacy Statement, which is on the Data Protection page of our website

(Editor - Sorry but those are the new rules for all charities, and we hope that our supporters will kindly take the few moments necessary to reply to our emails confirming that we may continue to contact them. Thank you).

Common Reporting Standard (CRS)

This came into force on 31.05.17, although we are currently exempt due to our level of Passive Income (*ie Investment income*). This could change longer term with the receipt of a Permanent Endowment (*typically a legacy where the capital must not be touched, but is instead invested, and the income used for the benefit of the Charity*).

The CRS is an International Information Exchange regime, aimed at promoting tax transparency and preventing offshore tax evasion. We are currently classified as an Active NFE (Active Non-Financial Entity), and if a charity does not fall within the definition of a "Financial Institution" it does not need to comply with the CRS regime. Charities are considered to be "Financial Institutions" if they rely on investments for more than 50% of their income (passive income) and where those investments are professionally managed by a Financial Institution under a discretionary mandate, both conditions needing to apply. We have no investments other than our cash reserves, which are not taken into account under CRS, so neither condition is currently applicable. We shall continue to monitor both our position, and any future changes to the legislation, as we could then be required to request more information from all new applicants.



Our Accounts

Reserves held as a Cash Balance and brought forward at 31.12.16: £52,561.11

Income:

Fundraising Events 6,045.20

Donation Income

<i>Personal Donations – Direct</i>	26,453.00	
<i>Online Donations via Everyclick</i>	1,669.54	
<i>Standing Orders</i>	4,189.00	
<i>Collection Boxes (All Sources)</i>	447.71	
<i>Company Donations</i>	657.44	
<i>Grants from Charitable Foundations</i>	61,850.00	95,266.69

Legacies and Collections

<i>Final Legacy Payment from a Deceased Estate</i>	467.06	
<i>Final balance from Charter Court Financial Services Fundraising in 2016</i>	7,520.60	7,987.66

Other Income

<i>Gift Aid: (April 2016 to April 2017 – claimed directly from HMRC)</i>	3,962.73	
<i>Interest on Bank Balances</i>	220.35	
<i>Grant Reserves written back due to further minor savings achieved</i>	242.52	4,425.60

Total Income: £113,725.15

Expenditure:

Grants made in the year to date: 102 in Total 137,186.81

Other expenditure/costs/overheads nil

Total Expenditure: £137,186.81

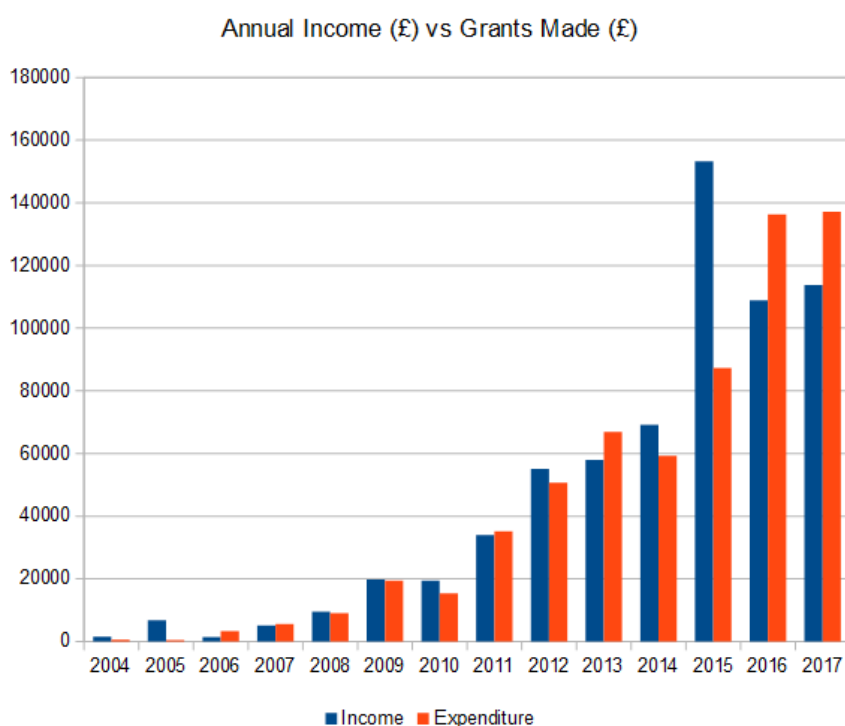
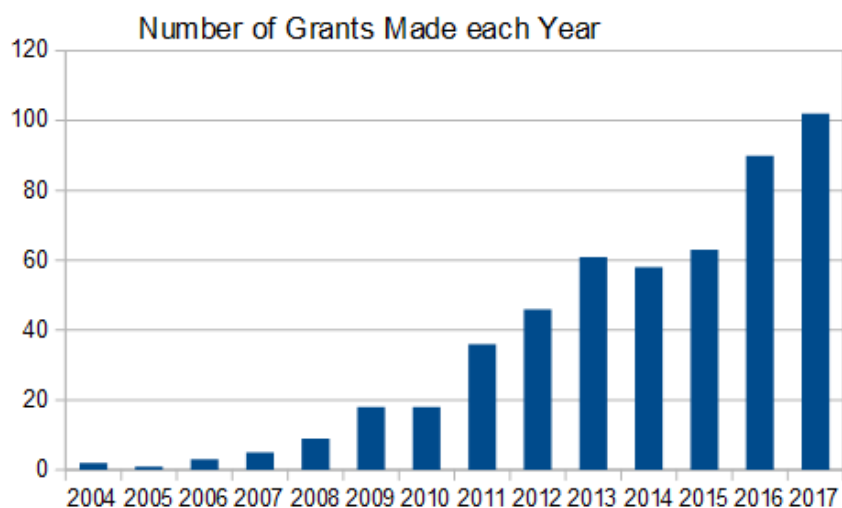
Excess of Expenditure over Income **-23,461.66**

Leaving a Reserve Cash Balance to be Carried Forward at 31.12.17 of: £29,099.45

(The Reserves represent 2.5 months of funding at the rate of activity in 2017)

The level of demand was such that we once again had to draw on our reserves. However, our aim is to use our funding for the purposes for which it was donated by our supporters. It just highlights how much help is needed in this area.

Funds Raised and Grants Made to Dec 31th 2017



2016 was an exceptionally busy year, with activity up 56% on 2015, and during which we completed 90 grants totalling £136,323.

2017 continued to be busy, during which we completed 102 grants totalling £137,187, and exceeded 100 grants in a year for the first time. Thankfully, the number of smaller grants increased, reducing the average grant size, so we managed to cope with the increased demand. Worryingly, in previous years when growth has paused, we have seen a substantial increase the following year, which only serves to highlight how much help is needed in this area, and the potential challenges we shall face in 2018 in trying to raise the funding needed.



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The Loan Talk Awards - Fundraising



On the 12th January the Chairman was invited to attend the Loan Talk Awards 2016. The Charity was nominated to receive the proceeds of both a table collection and a silent auction, and the Chairman was given approx 15 minutes to explain the work of the Charity to the audience.

The contact had come about as a result of one of the events held in 2016 by Charter Court Financial Services when they were fundraising for us. We would like to thank Mo Mulki (CEO and Founder of MediaNett Ltd., organisers the event), who had approached us at a Charter Court fundraising event, and who subsequently arranged contact with the Chairman in November 2016, with the invitation to speak, and be the nominated charity for the evening.

The audience consisted of approx 320 representatives from the Second Mortgage Industry, and they kindly donated a total of £1,380.00 which was an excellent result, and very much appreciated.

The event also enabled us to make two further contacts, which we hope may lead to further fundraising opportunities in the longer term.



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ASDA Green Token Collection

At the start of August we were informed that we had won the latest green token collection, held at ASDA in Merry Hill. This was a pleasant surprise as we had no idea that our name had been put forward.

As a result of being proposed by someone, we were fortunate enough to be selected, and for a period of several months, ASDA shoppers had the choice of which of three selected charities they wished to support. Clearly we must have extensive local support because we ended up winning, and receiving the first prize of £500.00, while the other charities each received £200.00.

The funding was greatly appreciated, and much needed, as requests for help had continued to grow, putting our reserves under increasing pressure.



The photograph was taken in store when the Chairman was invited to collect the cheque, and shows ASDA Customer Services Staff member Sophie, presenting the cheque.

Quiz Night

On Saturday 18th November, the event was again held at the Hagley Community Centre, as this has more space available than at St Saviour's Church Hall, which we had used in 2015, and an even lower price had been negotiated for the room hire as it was for charity use. The ticket sales were very much higher than 2016, with 134 people forming 18 teams, compared to 85 the previous year. The increased numbers contributed to a very successful event.

The tickets were priced at £10.00, which included Fish and Chips during a break in proceedings, and with the Bar and ticket profits, after allowing for the costs of the food and room hire, the event raised a total of £1,320.00. An excellent result, and the highest total we have achieved for this event since we started running it. Thanks once again to Miles and Carolyn for the enormous amount of organisation work, and to Nick, Lynn and Anita for running the Quiz.



The editor's team had scored a sixth place in 2014, a fourth in 2015, and a third in 2016 after losing a tie for second place in a sudden death play off. Sadly this year we only achieved twelfth place, although the scores were very tight. With a requirement for team names not exceeding four words and being political, there was a tie for first place between *All Heart no Trump*, and *I'm an MP get me out of here* (nobody quite worked out how the name squeezed past the scrutineers, containing eight words not four). After a sudden death play off, *All Heart no Trump* were declared the winners.

The event featured enthusiastic participation, the picture round being particularly difficult, and was enjoyed by everyone, as well as generating excellent funds for the Charity.

How Donations can be made to us

In addition to donations by cash or cheque, may we suggest consideration of the following:

Standing Orders

Any amount from £2/month upwards is of great value to us, and only requires the completion of a Standing Order Mandate, which can be stopped, or changed, at any point in the future, should you wish. A Standing Order Mandate can either be completed online from your Bank account (our Bank account details are below), or a paper copy of the required Bank Mandate is available on the [Forms](#) page of our website, and has also been reproduced on the next page.

If you complete a paper copy of the Standing Order Mandate, could you please send this directly to your Bank, so that we never see any of your Bank details.

Online Donations to our Bank Account

Our nominated Bank Account details for One-Off online donations direct to us are:

HSBC Bank, Sort Code 40-43-17
Account Number 72275813

Could you please use your name as the payment reference, so that we can track the payments into our account, and claim Gift Aid, where appropriate (please could you complete a Gift Aid form if you have not already done so, it enables us to claim 25p for every £1 donated).

Online Donations through Everyclick using a Debit/Credit card

There is an [Everyclick Donation](#) button on the [Donations](#) page of the Chris Westwood Charity website, to allow individual donations to be easily made online, and access can also be gained to our Everyclick webpage via www.everyclick.com/chriswestwoodcharity/info.

Anyone kindly wishing to set up a sponsorship page is encouraged to use the Everyclick facility, as we are registered with them, and there are no charges for a new sponsorship page.

Gift Aid

If you are a UK tax payer, you can increase the effectiveness of your donation by completion of a gift aid declaration form, a copy of which is available on the next page. If the third box down, of the three options on the form, is ticked, the completion of one form will cover all donations past, present and future. Provided that you are a UK tax payer, the Charity will receive an additional 25p for every £1 donated, which we claim annually from HMRC.

Please return any completed forms directly to The Chris Westwood Charity (address on the form).



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Gift Aid Declaration

giftaid it

The Chris Westwood Charity for Children with Physical Disabilities.

Please Treat

- The enclosed gift of £_____ as a Gift Aid Donation; OR
- All gifts of money that I make today, and in the future, as Gift Aid Donations; OR
- All gifts of money that I have made in the past 4 years, and all future gifts of money that I make from the date of this declaration, as Gift Aid Donations.

✓ Please tick the appropriate box above.

In order for us to claim Gift Aid, you must be paying an amount of Income Tax and/or Capital Gains Tax at least equal to the tax that the Charity will claim from HMRC on your Gift Aid donation. Currently, we are able to claim 25p for every £1 of eligible donations.

Donor's Details

Title _____ Full Name _____

Home Address _____

Postcode _____ Date _____

Signature _____

Please notify the Charity if you:

1. Wish to cancel this declaration
2. Change any of the Donor details
3. No longer pay sufficient tax on your income and/or capital gains.

Please send the completed form to: FAO Chris Westwood, Chris Westwood Charity for Children with Physical Disabilities, PO Box 7131, STOURBRIDGE, DY8 9FP.

STANDING ORDER MANDATE

To the Manager	
Name of Bank	
Address	
Post Code	

Please pay: **HSBC Bank, 114 High Street, Stourbridge, West Midlands. DY8 1DZ**

For the credit of: **Chris Westwood Charity for Children with Physical Disability**
Sort Code: **40-43-17**
Account Number: **72275813**

The sum of: (in words) _____ Pounds (£) _____
On the _____ (day) _____ (month) _____ (year)
And thereafter every month until further notice, and debit my account accordingly.

Name of account holder to be debited:
Account Number:
Sort Code:

Signed: _____ Date: _____

When completed, will you please pass this form directly to your Bank.

If you are a UK tax payer, and pay an amount of Income Tax, and/or Capital Gains Tax, at least equal to the tax that can be claimed on your donation, you can increase the value of your gift by using Gift Aid. This enables the Charity to reclaim the tax, which currently increases the value of your gift by 25p for every £1 donated.

*If you would like to help, will you please complete a Gift Aid form, and return it to:
The Chris Westwood Charity for Children with Physical Disabilities, PO Box 7131,
STOURBRIDGE, DY8 9FP*

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The Chris Westwood Charity incurred no costs in the preparation and printing of this booklet, which was a donation from Holmdale Print & Mail. Accordingly, the Charity would like to thank them for this help which is greatly appreciated.

If you would like to contact us:

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Email: chriswestwood@waitrose.com

Tel: 07968 008098



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