# **Chris Westwood Charity**

For Children with Physical Disabilities



Keira is our Mascot and enjoys her morning walks

**Progress Report as at 31st December 2022** 



### What Do We Do?

### Background

The Charity was founded on the 19<sup>th</sup> 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".

#### How we can help

We can provide the funding, or balance of funding, required for the purchase of mobility/sensory/vision equipment when the NHS Trusts/Families are unable to provide support. We aim to respond within 24 to 48 hours as we consider a rapid response is essential when children have degenerative or life limiting conditions. We operate with zero administration costs so that every penny donated goes to help those the donor intended to support. Typically we fund:

- 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, sensory room equipment to improve the quality of life, and vision equipment to assist those with deteriorating eye conditions.

### **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 relevant healthcare professional 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 a brief description of 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 normally funded by online payment directly 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.



# **Progress in 2022**

Another busy year where we completed 92 grants at a cost of £92,946.56. The total was down on the expected level due to a supplier ceasing trading (as detailed below), this resulted in a reduction in grant approvals as some approved equipment could no longer be supplied. We expect this to be corrected during Q1 2023 as revised assessments are carried out with alternative suppliers and applications re-submitted.

Fundraising has continued to be challenging as we have sought to re-establish our relationships with the many small groups that collected for us until the COVID pandemic caused disruption to their meetings and their ability to raise funds with only limited contact allowed. We have managed to fund our activities but with more funding available earlier in the year we could have avoided the need for a waiting list for a short time in Q3, and have done more.

The big disruption to equipment purchases during the year involved one of the major UK suppliers of special exercise trikes and walkers. The equipment supplier selected is specified by the Healthcare Professional involved in the assessment of the child with the Supplier's expert. As we were on the Supplier's approved charity list, many families used to make an initial query to us before being directed to the application procedure and the expert reports required. With significant business we had negotiated a substantial discount which helped to spread our funds further. Typical expenditure over a year was £35,000 with this supplier, but after a big cut in the discount given, to one flat rate for all charities at the start of Q2, they ceased trading at the end of Q3 as continuing imported equipment supply problems made operation no longer viable.

This resulted in cancellation of some orders, refunds where equipment had already been funded but not yet supplied and the need to notify some applicants that their pending orders could no longer be completed or even placed. Fortunately the Charity has suffered no losses but it resulted in a lot of extra work. We have, when requested, funded special trikes from at least two other UK suppliers during any year (although previously in very small numbers) and the final cost from one of those suppliers is now likely to be of the same order as previous approvals as with an increase in business already, we have again been able to negotiate a substantial discount.

In the current financial climate these problems were not that unexpected, particularly as we had seen delays in deliveries caused by shortages of parts due to import problems with a number of different suppliers, especially since the COVID pandemic. The situation now appears to be improving so we can hopefully soon get back to our normal speed of response.

Q3 was still exceptionally busy, and with limited reserves at the start of the quarter it was necessary to both introduce a waiting list (as mentioned above) and to limit some approvals to a co-fund basis. With the disruption we then were able to clear the waiting list in only a few weeks, as some grants already made were cancelled, so we ended 2022 with a lower overall grants made total than originally anticipated. The Reserves are also temporarily lower than anticipated as an end of year donation normally credited to the account in Christmas week has been delayed so does not appear in the end of year accounts and it is now expected in early January 2023.



# A Special Exercise Trike funded with the help of Rotary

Trikes are usually proposed to try to build leg and trunk strength, improve co-ordination and help mobility. The decision on the equipment to be specified is made by the relevant Healthcare Professional following assessments by the supplier's expert. The Charity acts solely as a funding facilitator, responding to the expert opinion provided.

During the year Clent Hills Rotary Club arranged to help us with matched funding from their District Foundation Fund, and from the applications being received at the time we selected a proposal for a trike for an 8 year old who had contracted TB Meningitis. He had sustained a significant brain injury as a result and was unable to sit or stand unaided having become fully dependent on adult care. The trike has enabled him to exercise to improve muscle strength and co-ordination and is part of an intensive physiotherapy programme he is receiving.



The final cost after our agreed discount with the supplier was £1,584.10, so the Rotary contribution of £1,000.00 towards the total cost was a great help to us. In recognition of this grant the trike frame has two Rotary stickers attached to acknowledge this valuable help.

This Trike is a model which has a rear parental control bar (bottom right) to enable the steering to be controlled by the parent and with suitable upper body support so that the child can concentrate on gaining the exercise from pedalling, eventually taking over full control as coordination improves.



# **Details of a few of the Grants Made in 2022**

Age (Yrs)	s) Grant (£) Details			
11	761.04 + 1785.00	She has a diagnosis of Ehlers Danlos Syndrome, exhibiting with weak joints, joint displacement problems, skin and eye problems. Two items were proposed, firstly a support suit to assist her mobility and help to minimise joint displacement, and second to fund a special comfortable support seat to hold her when she needs to rest due to joint pain. We agreed to fully fund both items.		
17.25	534.35	She has a diagnosis of Irlen Syndrome which affects her perception of peripheral vision. She has to use large text to be able to read but is progressing very well at school. While the school provides a laptop for her use, it must remain at school and with increasing quantities of written work required she needed a large screen laptop for home use. Following the recommendations of the Dudley Vision Impairment Service, we agreed to fully fund the equipment they proposed.		
5.5	664.00	She has a diagnosis of Smiths Magenis Syndrome, and exhibits with delayed speech, language, motor skills, challenging behaviour and a sleep disorder. She has outgrown her special pushchair and the only larger option offered by Wheelchair Services was unsuitable for the transport available. We were aware of the case having helped previously and as a result we agreed to fully fund a lightweight and portable pushchair, suitable for her needs.		
2.75	325.71	He was born with Periventricular Leucomalacia which developed into Cerebral Palsy affecting his trunk and lower limbs. He is unable to sit unaided and Wheelchair Services provided a Snappi Buggy for him, but they do not supply the accessories also needed for general use – canopy, raincover and tray. We agreed to fund these items so the buggy could be of much greater help to the family.		
10	1847.91	Diagnosis of Prader Willis Syndrome and exhibits with development delay, learning disability, scoliosis, excessive hunger, and low muscle tone. Prior to the COVID lockdown she had some mobility but this had deteriorated with a lack of exercise. Proposal to fund a special exercise trike to help to build her core strength, improve her leg muscles and regain/improve her mobility. We agreed to fully fund.		
7	523.00	To fund a Birillo Walker for a child with a diagnosis of CHARGE Syndrome. He has had multiple operations for a series of complex needs, and is still unable to roll or crawl. He was able to use the Birillo Walker and this will help to build his muscles with a view to greater mobility. We agreed to fully fund.		
7	1404.69	He has a diagnosis of Sotos Syndrome, a genetic disorder resulting in overgrowth and some medical problems. He has scoliosis, learning difficulties, and is classed as autistic. He had outgrown his existing trike and a larger unit was required to help with his exercise. With a contribution from the family, we agreed to fund the balance.		
3.5	477.64	He has a diagnosis of Metachromatic Leukodystrophy, which is a genetic hereditary condition, with a poor long term prognosis. Unable to support his head with his existing car seat, he needed a suitable seat to provide the required support and head control so that he could be transported safely and in comfort. We agreed to fully fund the seat, the total cost being reduced by our discount agreement with the supplier.		
3.75	525.00	She has a diagnosis of Dravet Syndrome which exhibits with uncontrolled frequency and length of epileptic seizures. Her existing alarm monitor system for SUDEP (sudden unexpected death in epilepsy) was unreliable and costly to maintain, so a pulse companion pager system specifically designed for this condition was proposed and we agreed to fully fund.		



### The Walk to Snowdon

A sponsored family event held to raise funds for the Charity after we had helped by funding a special exercise trike for their young son.



The long walk



The summit reached despite the adverse conditions

The Charity received an application for a grant from a family with a five year old child called Vinnie who has a diagnosis of Cerebral Palsy. His Paediatric Occupational Therapist had recommended the use of a special exercise trike to help to develop his leg strength, co-ordination and mobility, and after a detailed assessment by the supplier we received an application. As the trike was VAT exempt in this case and we had a substantial agreed discount structure with the supplier the cost was reduced to £1,477.45 which we agreed to fully fund.

Despite his problems, Vinnie has a great love of life and adventure and was very keen to make full use of his trike. Since receiving it he has been able to benefit from the additional exercise, muscle development and social interaction.

His family were very pleased that we had been able to help and his father kindly offered to raise funds to cover part of the cost of the trike by walking the 90 miles from where they live (he originally thought the challenge would be 80 miles) with his own father, to reach the summit of Snowden. They set up a fundraising webpage with a target of £1,000, and the funding raised exceeded all expectations, eventually reaching £1,400.

With the distance involved, the challenge also required overnight camping stops, but they succeeded, and we were very pleased to receive the additional funding. Thank you to the family for helping us and best wishes for Vinnie's continued progress.



# 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, Telephone and Zoom 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 quickly assemble for any additional meetings, as necessary.

It is our intention to continue to operate with a fast response, and with zero administration costs to both meet the needs of those who apply to us for help, and the expectations for our use of the funding so kindly granted to us by our supporters.

Our business model is based on acting solely as a funding facilitator, responding to the expert opinion of a Healthcare Professional and the Supplier's Expert. If we subsequently approve an application for a grant, we provide the necessary permission to proceed along with any additional paperwork - usually a VAT Exemption Certificate (following the Healthcare Professional Report) - and a revised cost calculation where we have negotiated a discount structure. We then request the applicant to place the order, and make all the resultant arrangements. The Charity pays the supplier directly by BACS transfer - to retain control of the funds for the use intended - and our work is then complete. This system eliminates the need for any additional volunteer involvement and results in a fast response process.

#### The Trustees:









Chris Westwood MBE – Chairman (and also Chair of the Anthony and Gwendoline Wylde Memorial Charity)

Dr Janine Barnes MBE - Medical Adviser

Graham Wood - Treasurer

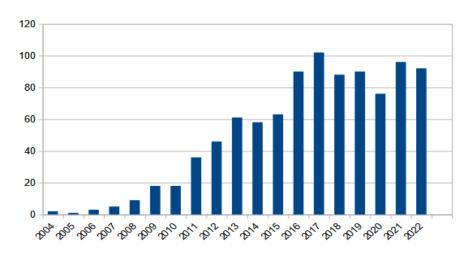
Lewis Barnes - Trustee (and also Chair of the Somerville Heart Foundation)



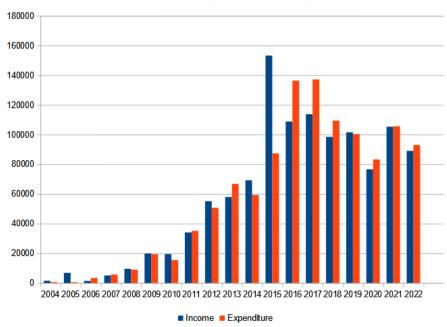
www.chriswestwoodcharity.co.uk

### Funds Raised and Grants Made to Dec 31st 2022

Number of Grants Made each Year







2020 activity was affected by the COVID pandemic and restrictions on contact which delayed equipment assessments.

2021 was a more normal year when we again reached just over £100,000 in grants made.

2022 was anticipated to be around the same as 2021, but late in Q3 a major supplier of special exercise trikes and walkers ceased trading which meant that some approved grants could not be completed, so the total grants figure for the year has reduced pending revised assessments and quotations from alternative suppliers. Stated income for 2022 was also down as a donation payment was delayed and will now be received in Q1 2023.



# **Our Accounts**

Reserves held as a Cash Balance and brought forward at 31.12.21:				
Income:				
Fundraising Events		4,869.00		
Donation Income				
Personal Donations – Direct	13,476.00			
Online Donations via Everyclick	2,230.00			
Regular Donor Standing Orders	6,276.00			
Collection Boxes (All Sources)	80.00			
Company Donations	1,400.00			
Grants from Charitable Foundations	51,442.00	74,904.00		
Legacies and Funeral Collections				
Funeral Collections	364.00	364.00		
Other Income				
Gift Aid: (Claimed directly from HMRC)	6,494.00			
Interest on Bank Balances	24.00			
Purchase Commissions & Other Income	195.00			
Sale of Donated Items	409.00			
Extraordinary Income	1,707.00	8,829.00		
Total Income:		88,966.00		
Expenditure:				
Grants made during 2022 92 in Total		92,947.00		
Other expenditure/costs/overheads		nil		
Total Expenditure:		92,947.00		
Excess of Expenditure over Income		-3,981.00		
Leaving a Reserve Cash Balance to be Carried Forward at 31.12.22 of:				

The accounts do not include a donation which has been confirmed but not yet received due to a delay over Xmas. The additional funding, when received, will be a help in meeting the expected surge in new applications in Q1.

# Grants, Donations and the Stability of Income

Our Objectives when determining the size of a Grant award (having determined it complies with our Grant Criteria and we have the Reserves available) are:

- Firstly, to look for any fundraising that might have already occurred which would reduce the total amount needed from the Charity for the purchase to proceed.
- Secondly, whether or not we can claim VAT Exemption (which is applicable in most cases) and is a very useful cost saving. This is the reason we ask for medical details of the applicant so that we can check if the application is exempt.
- Thirdly, although we take no part in specifying the supplier, where equipment is purchased regularly from a specific supplier, we look to both negotiate discounts and improve those discounts when/if there are further increases in business.
- Finally, we fund the balance required directly to the supplier retaining full control of the funds to be used for the purchase. With large requests or when we have limited reserves, we try to help with co-funding with other charities to spread our limited funds further.

#### The Limitations of our Reserves:

To be able to make a grant we need funding, and this is where stability of income becomes particularly important. We currently have no permanent endowment income to provide a small contribution to the funding we need so we are constantly looking to find ways to increase both the fundraising methods we can use and to improve the stability of any funding then generated.

#### **Regular Monthly Donations:**

In a full year with Gift Aid where applicable our Regular Donors contribute approximately £8,000 or around 8% of our income. We are always keen to add new donors to the list and from as little as £2/month (50p/week) you are very welcome to join and increase this stable flow of income. Full details and forms are available at the back of this booklet.

#### **Amazon Smile:**

This is one of a number of no cost options we have available where funds can be raised for your selected Charity at no cost to you. Details of all the no cost options are at the end of this booklet but if you register with Amazon Smile and then enter the Amazon site via Amazon Smile, you will reach your account in the normal way, shop as usual and when you come to pay Amazon will contribute 0.5% of the purchase price, at no cost to you, to your nominated Charity (which you can change at any time). If we could encourage more people to take advantage of the free donations, we could significantly increase the amount we already receive each quarter.

### Other Commission Payments:

Again these are listed at the end of the booklet, but once registered with Give as You Live or Easyfundraising, no cost commission payments are made on online purchases, direct to the nominated Charity. You just register and create a new icon to access by the correct route. Free charity donations from many of the major retailers are available often of 2% or more, and again at no cost to the online purchaser. Increasing numbers would help to build a more stable and more significant income flow. Please have a look at the Donation pages at the back of this booklet.



# Why is our charitable funding needed?

While the NHS and other Government organisations will provide a number of items of equipment for disabled children, with the inevitable funding constraints there are restrictions on the extent of help available, and with seemingly ever increasing demands on the system, the rules regarding what will be supplied are constantly tightening. The resultant unfunded need leads to requests for help, either directly from families, or via relevant healthcare professionals such as the Paediatric/Occupational Therapists working in the Children with Special Needs Departments of the local NHS Trusts, and from the Special Schools where constant tightening of budgets has led to increasing requests for help.

Typically, the equipment the Charity funds falls into these general categories:

- Exercise: Specifically to develop the necessary muscles and coordination to either improve independence in daily activities, or to slow a deterioration in current mobility.
   Typical equipment funded includes special exercise trikes, walkers, and standing frames
- **Special Seating:** For school or home use, to provide the correct postural support, and enable a child to fully participate in activities in either location.
- Comfort: Many of the cases helped involve severe mobility problems, often wheelchair bound, with the need to periodically change position, provide the correct postural support, and relieve pressure points. Equipment funded includes special comfortable support chairs, Acheeva beds, and special support seating systems. We also fund additional wheelchairs (often portable), powerpacks for manual wheelchairs and special buggies to enable children to be taken out safely, as well as the required buggy accessories (eg rain cover) as we find that if the NHS Trust does fund a buggy, it rarely funds the accessories that are needed for regular use.
- Health and safety: Special car seats to provide the support a child may need, and special
  harnesses to hold them securely, as certain children would otherwise release themselves
  from their car seat and endanger driver safety. Also including any form of equipment
  specifically to hold a child safely and provide the correct postural support, as well as
  hoists and equipment to help with daily living needs.
- **Sensory:** We receive a number of requests for equipment to help to calm and control a range of behavioural problems, and provide quiet and safe areas.
- **Sleep:** Requests usually involve equipment specifically to hold a child in the correct position to avoid hip dislocations, and all types of special beds eg. profile beds, high sided cot beds and safety sleepers to provide the correct environment for sleep.
- Vision: All types of vision equipment to help registered blind children achieve their
  potential when the Vision Impairment Service is unable to obtain the necessary funding
  for the equipment required. We receive a number or requests from the Dudley Vision
  Impairment Service for a wide range of computer based equipment.



### How Donations can be made to us

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

### 1. Standing Orders

Any amount from £2/month upwards is of great value to us, and 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 has also been reproduced at the end of this brochure. 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.

#### 2. Online Donations to our Bank Account

Our nominated Bank Account details for One-Off online or regular 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).

#### 3. Online Donations: Everyclick

There is an *Everyclick Donation* button on the *Donations* page of the Chris Westwood Charity website, allowing individual donations to be made online, and access can also be gained to our Everyclick webpage via <a href="https://donate.giveasyoulive.com/donate?cid=145243">https://donate.giveasyoulive.com/donate?cid=145243</a> (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).

### **QR Code for Mobile Phone Donations to Everyclick:**

We now have a QR code facility on the website for those who prefer to donate to Everyclick via their mobile phone.





# How Donations can be made to us (2)

# 4. Online Donations: Give as You Live/ Amazon Smile/ Easyfundraising Give as You Live:

You can also raise funds through *Give as You live* for any charity you wish to nominate, at no extra cost. Please see the *Give as You Live* webpage on our website for details of contributions that can be gained at no cost by using either a *Store card*, or making *online purchases*. Access to the Give as You Live website is by: <a href="https://giveasyoulive.com">https://giveasyoulive.com</a>

#### **Amazon Smile:**

The Charity is also registered on *Amazon Smile* so that we can be nominated to receive your commission payments from purchases made using *Amazon*. Once you have registered your chosen charity 0.5% of the purchase cost is donated by Amazon to the Charity chosen, at no cost to the purchaser.

To start, please just enter Amazon via this link: <a href="mailto:smile.amazon.co.uk">smile.amazon.co.uk</a> then sign in as usual and you can then register your chosen charity. Shop in the normal way, make sure you check out via smile.amazon, and an Amazon donation will go to the Charity. Then in future just enter the site via <a href="mailto:smile.amazon.co.uk">smile.amazon.co.uk</a> and shop in the normal way. You can change your charity choice at any time.

#### **Easyfundraising:**

We are also registered with this shopping commission website, which is a competitor of *Give as You Live*, and where you can again select a charity to receive a commission payment on your purchase, at no additional cost to you. You can login to the website, and join at <a href="https://www.easyfundraising.org.uk/">https://www.easyfundraising.org.uk/</a>

Depending on the retailer, there are various percentages and from time to time, additional bonus donations offered.

### 5. Recycle4Charity (Used Printer Ink Cartridges)

This website: <a href="https://recycle4charity.co.uk">https://recycle4charity.co.uk</a> collects and recycles used printer ink cartridges, and provided you have registered and nominated your chosen charity, the charity (hopefully us) then receives at least £1.00 for each printer ink cartridge returned, which is on their acceptance list (this requires cartridges where a printed circuit board is visible on the side the cartridge plugs into the printer). The full acceptance list is available on the Recycle4Charity website. Freepost return labels for your chosen charity can be downloaded after registration, but please ensure that you enclose at least the minimum number of cartridges, otherwise the funding is not granted due to postal costs.

### 6. Gift Aid

You can increase the effectiveness of your donation by completion of a Gift Aid declaration form, (copy available on the next page).

Provided 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).



www.chriswestwoodcharity.co.uk

### **Gift Aid Declaration**



The Chris Westwood Charity for Children with Physical Disabilities.

P	riease Treat:
T	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.
	<b>√</b> Please tick the appropriate box above.
Ta	n order for us to claim Gift Aid, you must be paying an amount of Income Tax and/or Capital Gains ax at least equal to the tax that the Charity will claim from HMRC on your Gift Aid donation. urrently, we are able to claim $25p$ for every £1 of eligible donations.
D	Oonor's Details
Ti	itleFull Name
Н	ome Address
_	
P	ostcode Date
Si	ignature

### 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:	ease pay: HSBC Bank, 114 High Street, Stourbridge, West Midlands. DY8 1DZ							
For the credit of:	or the credit of:  Chris Westwood Charity for Children with Physical Disability Sort Code:  40-43-17 Account Number: 72275813							
The sum of: (in wo	rds) _			Pounds (£)				
On the	e(day)		(month)	(year)				
And thereafter every month until further notice, and debit my account accordingly.								
Name of account h	older	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 (a copy of the form can be downloaded from the Forms page on our website) and return it to:

Chris Westwood Charity for Children with Physical Disabilities, PO Box 7131,

STOURBRIDGE, DY8 9FP

### If you would like to contact us:

For the attention of Chris Westwood,
Chris Westwood Charity for Children with Physical Disabilities,
PO Box 7131,
STOURBRIDGE,
DY8 9FP

Email: chriswestwoodcharity@gmail.com

Tel: 07968 008098

