

## Grants Made 2013

| Name | Age  | Grant                   | Details   |
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|      | Yrs  | £                       |   |
| M    | 1.25 | 1,538.00                | He has Angelman Syndrome, which is a condition caused by a gene defect. He is unable to support himself, and requires a special chair. One has been provided for home use, but he needs another for his Nursery, and the proposed chair will be suitable for a number of years use, so he will be able to transfer with it to his special school.   |
|      |      | 5,304.00                | The application was for phase 3 of the Greenspaces project at the Victoria School, and we have helped with both phases 1 & 2. This involves developing a small play area outside the Nursery and Infants section, for children aged 1 to 6. We were asked to consider helping with the funding of the purchase of several items of equipment, designed for use by children with special needs. Following the success of the wheelchair trampoline, which we funded last year, we agreed to fund six items of equipment, four different types of Springer, a four way see-saw, and a twin toddler swing. This will help to provide some suitable outside play facilities for the children. |
| E    | 5    | 1,648.00                | She contracted Pneumococcal Meningitis at seven weeks, which left her with neurological impairment, development delay, cerebral palsy, epilepsy, visual impairment & problems with motor skills. She has a problem at the base of her spine, and requires full support, but is in great discomfort unless sitting in a specially adapted chair/buggy. We were asked to co-fund with another local charity to purchase a suitable special buggy for home use, and we agreed to fund 50% of the cost, as she requires constant repositioning with her existing unit despite attempts at improving her comfort.  |
| C    | 10   | 1,715.00                | Diagnosed with Duchenne Muscular Dystrophy, he already has to use an electric wheelchair. His weight is now such that his parents struggle to move him in and out of the chair, and need a portable hoist to assist with the manual handling. We funded the purchase of a suitable unit, which is designed to fold into compact sections for easy transport.  |
| C    | 3    | 635.00                  | Severe autism, and epileptic. Unable to moderate his behaviour with medication. Family urgently needed help, initially requesting funding for a safe space area. Discovered they also needed a special car seat, which could hold and restrain him, for safety, otherwise they could not risk taking him out in the car. We agreed to fund the car seat, so that their application for this to another charity could be withdrawn and replaced with the need for a safe space, as this was the type of equipment the other (large) charity often funded.  |
| J    | 3    | 887.05                  | Recently diagnosed with Diplegic Cerebral Palsy, which affects the legs, and delays walking for a number of years. An exercise tricycle was recommended to build up strength in his legs and hips, and help him to progress, which we approved.   |
| C    | 7    | 294.00                  | Significant and severe delay in all areas of development, and has complex health and learning disabilities. She needs a high level of adult support, and a new seating system for classroom use will greatly help her. Approved.  |
| L    | 7    | 285.00                  | Diagnosed with Chromosome 1P36 Deletion Syndrome, this affects his general development, mobility, speech, and hearing, with some medical complications. Unlikely to become independently mobile, or develop speech. A new seating system for classroom use will greatly help him. Approved.   |
| S    | 5    | 545.00                  | Genetic disorder, requires oxygen and suction, as well as 24 hour care, as she forgets to breathe periodically, and her heart stops, requiring immediate action. Standing frames are no longer funded by Dudley Health, and 5 children require new frames for use in school, having outgrown their existing units. While she is likely to be the main user, the unit can be shared by all five of the children. After agreeing 50% matched funding with the school, this reduced the grant needed to £545.00, which we approved.  |
|      |      | 724.00<br>+<br>1340.00  | These grants will purchase a Toilet Chair (£724.00) and a Bath Lift (£1,340.00) for use by a range of children who visit the residential hostel at Penn Hall Special School. All of the pupils are given the opportunity to take part in the residential hostel experience, once a term, for one week. This opportunity enables parents to have respite time, and the pupils to gain residential experience, develop social and life skills, and improve independence. Some new equipment was required, and this will help a number of children at the school.  |
| L    | 4    | 1421.00<br>+<br>1130.00 | He has significant cerebral damage as a post operative event, significant development delay, dystonia with spasticity and significant cortical blindness. He is fully dependent for all of his care needs. His parents have split up, and he shares his time with each. We were approached to fund safety and care equipment at the father's home, similar to that at the mother's, so that he could be moved, handled and cared for safely. The items were a special support shower chair (£1,421.00), and a Pro Care bed with secure cot sides (£1,230.00). With the family only able to raise £100.00, we funded the balance.  |
| L    | 13   | 2369.70                 | She has complex medical & learning needs, including Epilepsy, Scoliosis, Global Development Delay, Speech & Language difficulties, visual & hearing impairment, is permanently wheelchair bound, and tube fed. Her condition is life limiting, and the provision of an Acheeva bed at school would really help to support her properly so that she can better take part in classroom activities, and receive the physiotherapy she also needs while in class. The school had raised £1,500.00, and we funded the balance,   |

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|     |      |         | which was slightly reduced by our 5% discount with the company.   |
| L   | 5    | 545.00  | He has very complex health needs, including Spastic Quadraplegia with Dystonia, Intractable Epilepsy, severe Cystic Encephalomalacia, Hypertropic Cardio Myopathy, Gastroesophagal Reflux (so tube fed), Oxygen support, suction and a nebulizer. The family need a larger mobility vehicle due to both a growing family, and the equipment needed to be carried. Motability will fund the vehicle, and conversion costs up to a limit, but the family urgently needed the additional funding, to cover all of the conversion work required, which we agreed to provide.  |
| D   | 12   | 478.79  | She fell out of an upstairs window when 5 years old. This left her with limited mobility, poor vision, brain damage, and severe learning difficulties. We were asked to fund the purchase of two items of equipment for the garden. The first was a trampoline, to help with exercise, muscle strength and coordination, and the second was a special hammock, designed specifically for special needs children, as she has problems sitting. These items will help her to at least be able to enjoy some time in the garden, and possibly slow the rate of deterioration in her mobility.  |
| D   | 6    | 430.15  | Diagnosed with autism, he has limited communication, and behavioural issues. When in the car, he releases himself from his seat and distracts his father, by grabbing at his seat belt. With the father having recently been made redundant, and the family struggling, we were asked if we could help with funding a secure car seat harness, and fittings. We approved the full cost.   |
| O   | 6    | 430.15  | Bi lateral hearing loss, development delay, low muscle tone, and learning difficulties. He exhibits challenging behaviour, and no awareness of danger. He releases himself from his car seat, and presents an accident risk due to interference with the controls and the driver. A suitable magnetic button secure harness was requested by his Outreach Coordinator, which was approved.  |
| H   | 2.75 | 1506.00 | Diagnosed with Infantile Epileptic Encephalopathy, and associated global development delay, he is unable to sit, stand, or walk unaided, and the provision of a suitable walker would greatly help both his mobility, and his muscle development. The family have raised £100 towards the cost, and we approved the balance.  |
| A   | 3    | 764.85  | Born with Prader Willi Syndrome, which leads to insatiable hunger, and can cause problems with obesity and early death. She has low muscle tone, and has only just started walking. An exercise tricycle was recommended by her Paediatric Physiotherapist, to try and improve her muscle development, and her mobility. The family could raise £250.00 towards the cost, and we approved the balance.  |
| H   | 2.5  | 963.00  | He has Downs Syndrome, Hirsprungs Disease, and partial AVSD (two holes in his heart). He needs a special buggy for outside use, with the facility to recline, which also provides suitable support. The family had raised £200.00 towards the cost, and we approved the balance required for the purchase of the buggy and the required accessories.  |
| L&C | 4.5  | 1000.00 | Twins aged four and a half, both autistic, and looked after by a single parent foster carer, have outgrown their car seats and need replacements. The final cost (after our supplier discount) was £1,235.85, and with the mother having saved approx £250.00 towards the cost, we provided a grant of £1,000.00 to allow the purchase to proceed.  |
| S   | 5    | 1100.80 | She has severe learning disabilities, has been diagnosed with Autism Spectrum Disorder, has hypermobile joints and limited walking distance. The paediatric physiotherapist proposed an exercise tricycle to help to strengthen her legs and improve the position of her joints. With the family not in a position to help, we were asked for assistance, and we approved the full cost.  |
| P   | 4    | 955.45  | She has a congenital myopathy, meaning that there was a muscle disorder present at birth. Her muscle tone is low, and she exhibits hypermobile joints. She also suffers from fatigue, and requires support to walk. Her Paediatric Physiotherapist recommended an exercise tricycle to help her muscle strength, which we approved.   |
| M   | 1    | 232.16  | Needed an oesophageal atresia and fistula repair shortly after birth. Also has heart and other problems. He requires a special car seat to support him properly, to help him to breathe more easily, and we approved the purchase.  |
| M   | 7.5  | 36.99   | He has Peters Plus Syndrome, which is genetic, and affects the eyes. He was recently stated to be blind. Additional complications are likely to include growth problems, and learning difficulties. He is small and has a severe learning disability. He has recently moved from a feeding tube to solid food, but is still in nappies, which he removes at night, requiring his father to sleep with him to prevent this. Funding for a sleep suit was requested, which will resolve the problem, and allow him to sleep alone. The father is disabled, and the family are struggling, so we approved the funding.               |
| M   | 10   | 1500.00 | She is 10 years old, has Cerebral Palsy, and can not walk independently. When not in her wheelchair, she uses a walker, which helps to strengthen her muscles, and her balance and coordination. She has outgrown her existing walker and requires a new unit. The School will provide a small amount of the funding needed, and we agreed to provide the £1500.00 needed for the purchase to proceed.  |
| A   | 7.5  | 455.00  | She has Spinal Muscular Atrophy Type 2, and will never be able to walk. She has severe Scoliosis of the spine, and is at high risk of respiratory problems. Having outgrown her powered wheelchair, a suitable new unit has been specified by Wheelchair Services, but they will not fund an additional raise/lower facility. This is felt by both the Physiotherapist and the School to be very important, as it will allow her to access various height surfaces, while maintaining good posture, and thus minimising respiratory problems. We agreed to fund the additional balance required for this facility to be provided. |

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|    |     | 3500.00 | To part fund the cost of an Eye Gaze system, to enable children at Fort Royal Special School, with severe physical disabilities, to access a computer independently. This will be used by a number of children at the school, and will help to develop their communication skills. With a cost of £7,000, the school was able to raise £3500, and we were asked if we could match fund. We consider this to be an important facility to help severely disabled children to become more independent, and we approved the funding.  |
| M  | 24  | 100.00  | Severely autistic, and has a weight problem. We have previously helped with a few items of exercise equipment, and were asked if we could once again provide a little assistance. Despite limited funding from the Local Authority, his carer has made considerable progress with him, and we were pleased to be able to help further.  |
| E  | 4.5 | 299.00  | At 14 months diagnosed with a brain tumour and had 18 months of chemotherapy. Recently diagnosed with both a second tumour and first tumour starting to grow. Child unable to walk very far, and with mother having recently had a baby, she is currently managing with a pushchair and a baby sling, but urgently needs a double buggy. Suitable unit found and tested by mother, and we approved the purchase.  |
| L  | 3   | 814.85  | We approved £814.85 towards the cost of a Quest 88 special exercise tricycle for a 3 year old boy. Born prematurely, he has had to deal with a range of medical problems, including Cerebral Palsy, which has been diagnosed as diplegic, as he has problems with both legs and trunk, sight problems, and breathing difficulties. At two and a half he started to walk, but has problems with both his gait, and stability. He has used a tricycle, but this is now too small for him, and the Paediatric Physiotherapist recommended a Quest 88 unit with a parental control bar, due to his poor sight, additional trunk support, and foot and leg braces to help to keep his feet in the correct position. This should help to develop his use of alternate leg movement, and with the parents able to make a contribution to the cost, we funded the balance of £814.85. |
| C  | 11  | 272.99  | He has a number of problems, all classed as severe, including learning difficulties, autism, and behavioural difficulties. Currently under the care of the clinical psychologist at CAMHS (Children and Adolescent Mental Health Services), he had been referred for further help. To help to calm him, funding from other charities has already supported a safe play area in the small garden, and a trampoline, but it was recommended that other activities were required, one of which was to take him out regularly on a suitable tricycle. We were asked if we could help, and in view of the problems, we approved the funding.   |
| D  | 5.5 | 957.25  | Born with Kabuki Syndrome, and diagnosed with kidney dysfunction, low muscle tone, global development delay, talipes repairs which has left him with weak ankles, and a heart condition. Unable to stand or walk independently, and requires support for all his daily activities. Following further recent ankle problems, his Paediatric Physiotherapist had recommended a special exercise tricycle, to try to build leg and ankle strength, and help in the process of getting him to stand and start walking, rather than currently moving around on his bottom. With the family unable to assist with the purchase, we funded the full cost.  |
| M  | 3.7 | 955.45  | Originally diagnosed as Cerebral Atrophy, he presents with Diplegia, ie both legs turn in and he walks on his toes. Has tightness of his leg muscles and is at risk of contractures and loss of mobility. Fatigues quickly, and the Paediatric Physiotherapist has recommended a special exercise trike, as it would help to build up his leg muscles and maintain mobility. Now believed it is a rare case of Cutis Marmorata Microcephaly, and in view of the help that exercise will bring, we authorised the purchase.  |
| L  | 8   | 639.20  | We have helped before at school. He has development delay, learning difficulties, a range of medical problems, limited speech, a gastrostomy, and uses a wheelchair. Now needs a special support car seat to replace the one he has outgrown. This requires a harness for support and restraint, and a swivel base for access. We arranged for an assessment by our contact and having obtained an excellent price, agreed to fund the purchase.  |
| E  | 9   | 963.55  | Sustained a right hemiplegia following a road accident in 2007. He is mobile, but has to wear an ankle foot orthosis, and his coordination and balance present problems. He works daily on a physiotherapy programme, and the Paediatric Physiotherapist recommended an exercise trike to build up his strength and coordination. We were approached as due to other problems his parents were unable to complete the forms for application to another charity for the funding needed. In view of the situation, and the need for the trike, we approved the funding required.  |
| R  | 3   | 1191.00 | A diagnosis of chromosomal abnormality with associated global development delay. He is unable to walk and has to be carried around the house. His Paediatric Physiotherapist recommends the use of a walker, and considers that without one, he will not be able to build muscle strength and coordination, and learn to walk. With neither the Health Service or Social Services providing this equipment, we were asked to help, and agreed to fund the purchase.   |
| LM | 5   | 895.45  | Cerebral Palsy, unable to walk independently but can manage to move around with a walker.. She has low muscle tone, and poor core strength. Her Paediatric Physiotherapist recommended an exercise tricycle to build up her leg muscles, and improve coordination and independence. The family had raised £150.00, and we agreed to fund the balance required.  |
| A  | 4   | 278.43  | Severe autism, locked in his own world with no speech and language skills, we originally helped in 2012 with an iPad with an Autism app. This has apparently been successful, and made a difference. There are still challenging behavioural problems, and the request was to help with the funding of an Autism Sensory pack from Caudwell Children, to help to both focus and calm him. Caudwell Children will fund 80% of the cost, and with the family unable to help, we agreed to fund the balance to allow the purchase to proceed.  |

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| J | 2    | 2082.15 | Has drug resistant epilepsy, chromosome micro-deletion 1 q2.1.1, global development delay, hypotonia, and gastro-oesophageal reflux. Recently had surgery for a fundoplication and gastrostomy. She suffers seizures most days and has clusters of up to 20 in two days. Gets very tired with sleep disruption and needs correct comfortable support to minimise risk of contractures and subsequent deformities. No suitable seating available from Social Services, but family found that the Symmetrikit Tiltrite seat both very comfortable and suitable for her until age around 7 to 9. Cost £2,297.00, but with our discount and a small sum from the family, we funded the balance.  |
| G | 16   | 4111.00 | He has Duchenne Muscular Dystrophy, needs assistance with everyday tasks, and a recent spinal operation has resulted in him being constantly in an upright position, with limited arm mobility such that he can no longer feed himself or use a computer mouse. A powered arm movement unit was proposed which would allow him some independence as he would then be able to accomplish some tasks. The Paediatric Physiotherapists had experience of this equipment, and although expensive, it was strongly recommended. While the NHS Trust approved the use of these units, there was no funding available, so we agreed to fund the purchase.   |
| S | 18   | 1601.00 | Very healthy until the age of ten, she then developed a brain tumour. After treatment she was diagnosed with Acquired Brain Injury, and now experiences difficulties with memory, mobility and balance (permanently confined to a wheelchair), left side weakness, learning difficulties and other medical problems. There has been some brain recovery, but she was provided with a powered wheelchair, and she needed this for at least part of the time, not being strong enough to use a manual chair alone. The powered chair is very heavy, and she can only go out if her father strips it down for packing in the car. A lightweight wheelchair would greatly improve her lifestyle, allow her to get out more, and will be a great help with exercise and work experience opportunities. With no other funding available, we agreed to purchase the wheelchair. |
| E | 3    | 577.00  | Born with Werner Mesomelic Dysplasia which meant that the tibia bone did not form in either leg, she had no ankle joints and club feet.. Attempts to lengthen her legs failed, so both were amputated from the knee, and she has prosthetic legs. She tires easily when trying to walk, and the intention was to purchase a hand pedalled trike. Funding only raised £1,500.00, and with the family desperate to raise the balance, we were asked to help. We arranged co-funding of the balance of £1,154.00 with another local charity, so that the purchase could proceed.  |
| R | 3.5  | 879.00  | His diagnosis is Polymicrogyria and Ventriculomegaly, which describe malformations of the brain. These typically result in a range of disabilities, and he has visual and hearing impairment, inability to sit unaided, limited leg and arm movement, and is unable to hold his head in a stable position. We previously helped him at the start of 2012 with a small car seat, but now he is bigger and heavier, unable to assist when being put in or taken from his car seat, and requires more support, a new car seat is needed with a swivel base, and the additional support for body and head. With the family able to raise £100.00, we approved a further £879.00, to provide the balance of funding required for a suitable new seat.   |
| J | 5    | 985.68  | Has a complex metabolic condition, Glutaric Aciduria Type 1, and has suffered permanent damage to the basal ganglia. This has left him with limited mobility, and athetoid movement in his limbs. During an assessment for a special exercise tricycle, it was found that he could operate the pedals, and if funded, it would help to exercise and build his leg muscles, and give him some mobility. We agreed to fund the full cost.  |
| D | 4.75 | 922.78  | Has a hemiplegia, which results in severe weakness of all the limbs on one side of his body, as well as cognitive difficulties. He fatigues quickly, and a special exercise tricycle was proposed to try to develop his movement ability, provide strengthening exercise, and improve his general mobility. With no other funding available, we agreed to fund the full cost.  |
| C | 12   | 2036.80 | He has a hemiplegia, and epilepsy. A special exercise tricycle was recommended to try to develop his muscles, and mobility. He was found to require one of the larger units, which could be fitted with the required additional support to hold him securely, and which would last him into adulthood. With no other funding available, we agreed to fund the full cost.   |
| T | 7    | 79.99   | Downs Syndrome and disturbed sleep patterns, currently still sleeps with parents. Baby monitor was requested, which includes infra red camera so that parents can move him to his own room and keep a close eye on him. We agreed to approve.  |
| B | 16   | 262.56  | She has global learning delay and ADHD, and also little speech and uses PECS (a form of picture communication). Occupational Therapy recommended some Sensory equipment, and Caudwell Children agreed to fund 80% of the cost of two of their Sensory Packs, but the family was unable to raise the balance of £262.56 required. We agreed to fund the balance so that the purchase could proceed.   |
|   |      | 3000.00 | The Victoria Special School has recently opened a College for 40 pupils aged 19 to 25, but there is no statutory funding available to equip the specialist environments required. A sensory room project will cost £27,509.00, and we were asked if we could possibly help. We have approved a grant towards the total cost, in view of the excellent service this new College will provide.   |
| L | 5    | 2674.18 | He has a range of medical conditions including a form of cerebral palsy affecting all four limbs, an anomaly in the brain, coupled with an abnormally reduced head size, thickening of the heart muscle, and optical problems, as well as needing some oxygen support. He has just started at a severe special school, and requires a special support seating system, complete with a harness, to help him to participate in class. We approved the funding required.  |

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| T            | 4   | 617.00            | Diagnosed with autism spectrum disorder, he makes little use of language or eye contact. He has no sense of danger, and repeatedly releases himself from his car seat, which has now outgrown. He requires a special support seat with a five point harness, and the family are unable to save towards the cost. We approved the funding required, after assessment by a supplier we use regularly, and with whom we have an agreed discount structure.   |
| C            | 4   | 803.23            | She has Prader Willi Syndrome, which results in various problems including continuous hunger. This often leads to obesity and premature death. She also exhibits limb weakness and fatigue, and is unable to pedal a standard trike. She can manage a special exercise trike which will help to build up her leg muscles, and help with coordination and balance which are current problem areas. The family could raise £100.00, and with VAT exemption and our agreed discount, the total cost reduced to £903.23, requiring a balance of £803.23 for the purchase to proceed, which we approved.                     |
| A            | 6.5 | 384.26            | Cerebral Palsy, a right side hemiplegia (which affects limb movement on his left hand side), global development delay, and gastro oesophageal reflux, means that he is very dependent on his pushchair for movement around the home, school, and whenever he is taken out. His special support pushchair was, as usual, provided without the accessory kit, and funding was requested for the much needed covers, basket and foot muff, which we approved.  |
|              |     | 1675.93           | The request was for an adjustable shower chair for three children at Penn Hall School. The special chair would be complete with a safety harness and foot straps, and was intended for use in the residential unit which provides short respite breaks for families, while helping the children to become a little more independent. We agreed to fund the purchase.  |
| J            | 7   | 780.83            | Diagnosed with Duchenne Muscular Dystrophy, which will result in progressive deterioration of his mobility, and he is likely to become fully wheelchair bound by the age of 12 yrs. While still mobile, he falls frequently, and fatigues, so a special exercise trike was recommended to try to help him maintain some mobility for as long as possible. With VAT exemption and our agreed discount, the cost reduced to £780.83, which we agreed to fund.   |
| E            | 4.5 | 841.18            | He has Cerebral Palsy and a Spastic Diplegia, which affects movement in the hips, pelvis and legs. This leads to muscle pain, arthritis, and difficulty in walking, although typically the condition does not continue to deteriorate. A special exercise trike was recommended to help to develop his strength and mobility, to improve his quality of life, and with VAT exemption, and our agreed discount, the cost reduced to £841.18, which we agreed to fund.  |
| R            | 9   | 59.95             | Severe learning disability, and atypical autism. Also faecal incontinent, and exhibits inappropriate behaviour with excrement if parents do not respond quickly to his toilet events. Popper vests proposed by the Clinical Psychologist to moderate this behaviour, which will help the family greatly. With no funding available, we agreed to cover the cost.  |
| R            | 3   | 931.58            | Cerebral Palsy, unable to walk but loves movement. He can just about manage to peddle a trike when recently assessed, and the recommendation from the Paediatric Physiotherapist was that a trike would help to develop his legs, give him some mobility, and help him to interact more with other children. We agreed to cover the balance required.   |
|              |     | 445.95            | We were approached by a non profit charitable organisation supporting families with children with disabilities in the Walsall area. They run a social support group, and were trying to provide improved facilities at their exclusive use venue. One particular problem was that they had no suitable changing table for the larger weight bearing children, and were having to use a temporary mat on the toilet floor. Having recently been granted funding for some other work, £250 was available, and we were asked if we could provide the balance required to allow the purchase to proceed, which we approved. |
| <b>Total</b> |     | <b>£66,853.31</b> |   |