

# Grants Made 2014

Name	Age	Grant	Details
	Yrs	£	
T	4	1,297.00	She has spastic quadriplegic cerebral palsy, and Social Services have provided a supportive chair for home use. During treatment sessions it has been found that she sat much straighter and was better balanced when astride a roll. An assessment was carried out with a saddle seat, which exercises her trunk, and also helps her to sit at the table. This exercise chair can only be used for short periods as she fatigues quickly, but it will help her greatly. With Social Services only able to supply one chair per child, although this type of chair is designed specifically for this condition, we agreed to fund the purchase cost.
H	5	124.75	She is both big for her age, and physically strong, with global development delay, and challenging behaviour. She has outgrown the harness that fitted her car seat, and use of the seat belt has been unsuccessful as she releases herself from it. A suitable safety restraint Crelling harness that will fit the seat, and prevent escape, was proposed. We agreed to fund.
H	3.5	612.38	He is unable to sit unaided, and is not yet able to control his head. He requires postural support to help to prevent contractures, and to make him comfortable when travelling. He also suffers frequent fits, so good restraint and support is essential. Following assessment, we were asked to help with the funding for a special car seat, and we decided to provide the total funding required.
E	2	289.50	She has a diagnosis of hypotonia due to a chromosomal abnormality. She has problems with her posture, and can slump in her car seat, particularly when tired. After assessment, a tilt and turn seat was recommended, to improve access, fitted with a five point harness to hold her in the correct position. With the family having already faced considerable expense in equipment provision, we agreed to fund the cost of a new car seat, the final cost being reduced to £289.50 with our agreed discount with the supplier.
T	8.5	652.15	He has a diagnosis of a left hemiplegia, and autism. He has difficulty staying still, and has uncontrolled movements of both arms and legs. He is weaker on his left side, and needs additional support when in the car. The seat recommended cost £652.15, with our agreed discount, and we agreed to fund the purchase.
H	5	1574.50	Diagnosed with severe autism, muscular dystrophy, sleeping and feeding difficulties, the family has recently been relocated to specially adapted housing, as his muscular dystrophy is expected to get worse. With funding from another charity for a new bed and bedroom furniture, we were asked if we could fund the cost of a sensory area in his new bedroom. This would help to calm him, and after assessment, the final cost for the recommended equipment was £1,574.50, which we agreed to fund.
A	8	1000.00	Cerebral palsy with leg spasticity, making it difficult to learn to walk. Three years ago we contributed to the funding for an operation in USA to help his condition. Family subsequently funded extensive physiotherapy at the Adeli Centre in Slovakia, and some progress has been made, as he can now walk a short distance. Further extensive physiotherapy is now required at the Adeli Centre, costing £7,000 for a three week session, and we again agreed to make a contribution to the funding required in view of the progress made to date.
J	7	148.32	We had approved £780.83 for the purchase of a trike, but were sent the wrong quotation. The trike actually required was larger, and an additional amount was authorised once we had been informed by the suppliers. The trike is for a boy with Duchenne Muscular Dystrophy, whose condition is deteriorating, and who is expected to become wheelchair bound in the next five years. The trike will help to maintain some mobility for as long as possible.
T	4	281.50	She has Spinal Muscular Atrophy type 2 and is wheelchair bound. Although the NHS system provides a wheelchair, this is manual and has limitations, particularly as she is not very strong. Her mother has managed to obtain a secondhand powered wheelchair, through a charity for children with this condition, at no cost, as the previous child has outgrown it. Due to her size and strength, the child requires a special harness to use the powered chair, for which funding is not available through the NHS. We were asked to help, and agreed to fund the purchase and installation of the harness, so that full use could be made of the chair.
E	4	1931.00	She has a diagnosis of Cerebral Palsy, severe encephalopathy, global development delay, and is gastrostomy fed. She can only crawl, and has problems with involuntary limb movements, but with the correct walker, she could gain mobility. She has been assessed, and the only suitable walker is a Leckey model, which she has been able to manage. We agreed to fund the cost, in order to help her to continue to progress.
C	10.5	1038.80	Has a spastic diplegia, and needs regular stretching exercises. His Paediatric Physiotherapist has recommended a special exercise trike to help with the regular muscle stretching exercises required, and to help to build up his strength, which we agreed to fund.
J	6	780.83	He has hypotonia and was slow to develop movement and walking. He has swallowing problems, so has a gastrostomy, and has dysmorphic features. He also suffers from chest infections, and a special exercise trike was recommended to try to build up his health and general strength, and improve his walking, which we approved.
G-M	6	1367.00	She has a range of medical problems, including Dandy Walker syndrome, Thoracic Scoliosis, and development delay. The request was for a new special car seat, with a turntable feature, to assist getting her in and out of the car, as she has now outgrown her previous seat, and as she gets heavier, moving her becomes more difficult. She was assessed in the seat proposed, and we approved the purchase.
M	3	349.00	He has a diagnosis of Jams Syndrome, which includes microcephaly, lymphoedema, and sight problems. Requiring a lot of help with daily tasks, an iPad was recommended to help his development. While we do not usually support

			these, due to his particular condition and circumstances, we agreed to help and fund the purchase, as we are aware of their benefit from the Chairman's experience of their use at two special schools.
E	18	500.00	She suffered a brain haemorrhage, and stroke, and a subsequent operation was unsuccessful. She has brain damage, and will require constant care. We were asked if we could co-fund the purchase of a hoist with another local charity, for use at home when she returns from hospital. The hoist will cost £2,045.00, and we were asked if we could provide the balance of £500.00 needed, which we approved.
		250.00	We pledged a small goodwill donation of £250.00 to the Smile Special Needs Group, subject to them being able to raise the balance of funding needed for a holiday for twelve families with special needs children. This would allow both the children and their carers to have a holiday as a group.
		2830.00	The Victoria College is a new specialist provision, attached to the Victoria School in Northfield, Birmingham, specifically for young people in the 19 to 25 age range, with complex needs. Prior to this there was no provision for this age range, and with limited statutory funding available, we were asked if we could help to fund a wheelchair accessible greenhouse for the 40 young people who will use this facility. These are some of the young people with the most complex needs in the Birmingham area, and a grant will help to improve their lives. As a result, we considered the expenditure an excellent way to help a number of young people, and agreed to fund the full cost.
S	12	457.90	She has severe learning difficulties, and her problems include speech and language difficulties, vision and hearing difficulties, and rare conditions of a Fumarase deficiency, and a metabolic deficiency associated with epilepsy. She releases herself from her seatbelt, and either grabs at the car driver or starts to damage the seating. A magnetic harness restraint was proposed to safely secure her in position, and we approved the funding.
O	3	342.08	Diagnosed with cerebral palsy spastic quadriplegia, he has been provided with a buggy by Wheelchair Services. However, they do not supply the accessories which are required for general use, ie sun shield, rain cover and a shopping basket. It has been very difficult to find a comfortable seat for him, but he is now successfully using the buggy as a general chair. One further accessory would be helpful for this general use, and we approved the funding required for the accessories requested.
R	6	202.46	He has a diagnosis of autism, and is not able to tolerate the presence of other children, or the noise. We were requested to fund the purchase of four items of play equipment for him, to help with his behaviour, and quality of life, and we approved the funding required.
M	3	982.28	He has a diagnosis of Jamas Syndrome, which includes microcephaly, lymphoedema, and sight problems. He also has learning difficulties, and requires orthopaedic boots due to his joint problems. We helped him earlier in the year with an iPad, and we were asked if we could fund a special exercise tricycle to help to build up his leg strength. With the family not in a position to provide any funding, we agreed to cover the full cost, which was reduced by our agreed 15% discount.
R	5.5	1011.18	He has learning difficulties, and is still undergoing tests for a full diagnosis of his condition. He presents with generalised hypotonia (low muscle tone), fatigue, and pain in both legs. A special exercise tricycle was proposed to try to help with building strength in both his trunk and legs. During an assessment, he was able to pedal the trike, and with the family unable to provide any funding, we agreed to cover the full cost, which was again reduced by our 15% discount with the supplier.
S	12	3014.00	She has a diagnosis of Spina Bifida and Hydrocephalus, and a range of complex disabilities including scoliosis, epilepsy, and cerebellar hydroplasia ( <i>a rare condition with the part or complete absence of the part of the brain controlling motor and cognitive functions</i> ). She also has bowel, bladder and renal problems, is paralysed from the waist down, learning difficulties, gastrostomy fed, and can not sit or walk. She has an electric wheelchair set up for indoor use, which is unsuitable for outside, which limits greatly any activity outside, or the opportunity to leave the house. The request was for a specially supportive manual wheelchair, as only one chair is supplied to a family. In view of the circumstances, the need, and the profound effect it would have on the quality of life for the family, we agreed to fund the full cost.
G	6	500.00	She was born with multiple congenital abnormalities, presents with global development delay, and requires full assistance in all activities of daily living. She has outgrown the walker currently used at her local special school, and we were asked if we could help with funding a replacement. We have helped her before, and are fully aware of the problems she faces, so we were pleased to be able to help further by providing the balance required for the purchase to proceed.
L	4	983.98	She was diagnosed with Angelman Syndrome at 26 months, after being unable to speak or walk. With extensive physiotherapy, she can now walk, but still has balance and coordination issues. Paediatric Physiotherapy has recommended a special exercise trike to try to build up her muscle strength, she was assessed, and a detailed quotation obtained. With our 15% discount, the cost reduced to £983.98, and we approved the purchase.
M	5.75	926.18	He has global development delay, can sit independently, but uses a bottom shuffle to move around. He is developing, and can now stand, and can manage a few steps with support. His Paediatric Physiotherapist recommended a special exercise trike to help to build up his leg muscle strength, and to improve his coordination and motor skills. With the family unable to help with any funding, we approved a grant for the full purchase cost, which, with our 15% discount reduced to £926.18.
		3000.00	The Victoria School in Birmingham has 200 pupils in the 2 to 19 age range. 85% of these are wheelchair bound, and 70% have cerebral palsy, which affects both arms and legs, so that they are unable to propel any form of tricycle. The School is trying to purchase a range of special trikes to allow them to experience more outside activities, and we were asked to consider funding a wheelchair transporter trike, which allows one child, in a wheelchair, to be pedalled around by an adult. The cost is £4,000.00, and with the School able to find £1,000.00 towards the cost, we agreed to

			fund the balance, as we feel that this will allow them to experience a form of cycling, despite being confined to a wheelchair. With the number of potential users, this equipment is likely to see considerable use.
D	6	617.00	He suffers from a rare condition called CHARGE Syndrome. He is unable to stand or walk, is classified as deafblind, and needs substantial support when being moved. After assessment, a special car seat was recommended, and our usual supplier had been selected. With our 7.5% discount, the cost reduced to £617.00, which we approved.
Z	4	879.43	He was born prematurely, and has Cerebral Palsy, which affects his left side. This has resulted in weakness and poor balance, and a special exercise trike was proposed to try to help to build up his muscle strength, and improve coordination and balance. With the family unable to help with any funding, we approved a grant for the full purchase cost, which, with our 15% discount reduced to £879.43.
P	12.5	3343.25	Cerebral Palsy with Spastic Diplegia (known as Little's Disease), which presents with a high and constant tightness and stiffness of the muscles in the lower part of the body. He also has hypotonia (poor muscle tone), and requires regular muscle stretching exercises to keep some mobility. He can walk short distances slowly, but tires rapidly and a trike was proposed to help his muscle strength and exercise. Due to his size, a full reclining seat type of trike is required to prevent the risk of toppling over, and in view of his condition we agreed to fund the purchase.
G & R	6 & 3	370.20	Two brothers who are autistic, and as a single parent family, have to share a bedroom. They exhibit disturbed sleep patterns, despite medication, and sensory facilities were proposed to try to provide a calming influence, and help them to sleep. Family clearly needed help, and the equipment proposed was similar to that supplied in previous cases. Approved.
S	17	191.34	Severe learning difficulties, autism, challenging behaviour and sleep difficulties. His severe special school uses hammocks as part of the sensory facilities to calm children down. He has started to self harm, and provision of an identical hammock at home, to the one used at school, was proposed by his Clinical Psychologist to help to control his anxiety and calm him. Approved.
K	14	299.10	Severe learning difficulties, autism, challenging behaviour, sleep difficulties, and epilepsy. His severe special school uses hammocks as part of the sensory facilities to calm children down. He has recently exhibited further anxiety, and his Clinical Psychologist feels that the provision of an identical hammock for home use will help to calm him. The hammock he is familiar with is different to the young person above, hence the variation in price. In view of the perceived benefit, we approved the funding.
X	8.75	413.00	Has a rare genetic condition called Optiz G Syndrome, which gives rise to a number of medical problems, including breathing and feeding difficulties, and he is Gastrostomy fed ( <i>tube into the stomach</i> ). He also has severe learning difficulties and autism, and suffers frequent chest infections. Due to the large amount of medical support equipment that needs to be taken with him, whenever the family goes out, we were asked if we could help with the purchase of a lightweight suction pump, as the standard units are heavy, making carrying all his equipment difficult. We approved the purchase, as this should help to increase the opportunity for the family to take him out more easily.
L	16	2153.35	She has cerebral palsy, affecting her left side, and is unable to maintain an upright position, which causes pain in her lower back. She has exacerbated lumbar lordosis ( <i>excessive curvature of the lower spine</i> ) and needs a special support chair to sit comfortably. While she uses a specially adapted chair at school, this must remain at school when she leaves, and we were asked if we could fund one for home use, as she will soon be at home for most of the time. She was assessed for a suitable chair with fittings including a 4 point lap belt, and lateral and multi adjustable headrests. We approved the purchase.
H	13	154.71	He is autistic and has sleep problems. The recommendation was to provide a weighted blanket, as this type of therapy, providing a gentle pressure on the body, has been shown to help with sleeping difficulties. We had previously supplied a similar item to another child, and were aware of the therapeutic effect. With the family unable to fund the purchase, we approved the funding required.
T	3.75	124.75	He has a complex communication disorder, and can become aggressive, with no sense of danger. He frequently releases himself from his seatbelt, and grabs at the controls when in a car. The request was for the purchase of a Crelling restraint harness, from which he would not be able to release himself. With one parent acting as a full time carer, the family were unable to raise the funding required, and we agreed to cover the full cost.
E	19	2728.00	She sustained a brain injury in January 2013, and further surgery failed to improve the position. She was eventually found a place at Tadworth which specialises in rehabilitation, and is now due to return home, although she will require full time care for all of her needs. State funding has supported alterations to the family home, and some of the equipment needed, but with no further funding available, we were asked if we could help with a grant towards the cost of a special bed. In view of her condition and her long term needs, we were pleased to be able to help, and funded the full purchase cost.
J	5	989.93	He sustained a head injury in December 2011, and has been left with mobility issues, visual difficulties, hearing loss, problems with his right arm, and epilepsy. He can walk, but is unsteady, and fatigues quickly. A special exercise trike was proposed to improve his mobility and his leg strength. We approved the full cost.
F	6.75	1024.78	She exhibits autism, has learning difficulties, no speech, and behavioural problems. A special exercise trike was proposed as she has hypotonia in her arms and legs, and it will help to build her strength, and help with social contact. We approved a grant for the purchase.
E	1.5	300.00	Diagnosed with Spina Bifida and Hydrocephalus, request was for a small wheelchair to provide mobility. Supporting information from both her Paediatric Physiotherapist and from SHINE (a Spina Bifida and Hydrocephalus charity) stressed the importance of mobility as early as possible, to give her every opportunity to develop some independent movement. The NHS do not support a child under 3 yrs old, so the family had raised £500.00, and asked if we could help with the balance of £300.00 needed for a ZipZac chair. Approved.

E	11	1591.80	Has a diagnosis of ASD, with associated severe learning disability, and significant sensory processing problems. Family lives in a small house, he has to share a room, and with sleep disturbance this is causing problems. Sensory facilities proposed to help to calm him, and we agreed to fund a number of items.
K	5.5	904.93	Global development delay, and problems with her left hip due to development dysplasia. She had surgery at one year old and has to wear a raised boot. She has problems with stamina and coordination, and a special exercise trike was proposed to help her. With the family not in a position to raise any funding, we agreed to support the application.
M	2.5	201.75 + 244.75	She has a diagnosis of cerebral palsy quadriplegia, has poor head control, and is unable to sit independently. She is gastrostomy fed ( <i>tube into the stomach</i> ) and is dependent on her mother for all her needs. Wheelchair Services have provided a special buggy which will provide the support that she needs, but they do not provide the additional accessories such as the rain cover and sunshield. The total cost of these is £201.75, which we approved. In addition, she has a younger sibling, and as special needs double pushchairs are very expensive, and her younger sister only needs a standard chair, alternatives were looked at. A Buggypod is a separate pushchair which can be clipped to the special buggy, and will provide the extra space needed at a reasonable price. It can also be used as a stand alone ordinary pushchair, so we approved the £244.75 needed.
R	9	462.15	She has severe and complex learning difficulties, severe visual impairment, hearing loss, and microcephaly anaemia, which presents further complex medical problems. She requires transport everywhere, and releases herself from her seatbelt regularly. Following assessment, it was decided that a full magnetic button harness would be required, so that she could be transported safely, and with the parents unable to raise any funding, we approved the grant required.
M	3	670.00	He has Cerebral palsy – spastic quadriplegia. He required special seating to allow him to be able to sit at the table, to take part in class activities, to be regularly monitored, and his position to be regularly moved. The recommended item was an X Panda chair, made by R82, a local company, and an assessment was carried out. We were asked by his special school if we could help with the funding required, and agreed to cover the cost.
S	3	2108.00	She also has Cerebral palsy, is 3 years old, and is another new member of the Nursery class at the same special school as above. She required greater support from a stable seating system, to enable her to try and develop her fine and gross motor skills. She was also assessed, and needed very much more support, including a footplate, and foot rests, armrests, head support, and a lap belt. We were again asked if we could help her special school with the funding required, and agreed to cover the cost.
		1518.00	The request was for a Rifton chair. This is a fully adjustable seating system, which can be used by a very wide range of children, specifically for assistance when using the toilet, and washing. The whole system is adjusted for the child, and fits over a toilet bowl, where it can be tilted for ease of entry/exit, and the child is well supported and can be strapped in. By allowing the child to use normal toilet functions, it is excellent for their general development. The whole system is waterproof, and can also be used for showering, which again allows the child more freedom. Such an item would be used by a number of children at Penn Hall special school, when staying in the residential facility, which helps them to have some time away from their families, and develop some independence, within their limitations. We were asked if we could help with the funding, and as this would be used by a number of children, we agreed to fund the full cost.
T	6	1262.55	He has severe autism, and with the family struggling financially, he has limited facilities in his bedroom. With several other problems at present, he needs a safe, calm place, and we have previously funded sensory room equipment in similar cases, to provide a refuge. His father has done what he can within the bedroom with the funds available, and we were asked to fund the additional equipment proposed, which we agreed to.
H	4	615.00	Hypotonia, epilepsy, and global development delay. He is unable to stand or walk independently, but is now able to support himself sufficiently to sit unaided for approx 2 mins. He normally uses a special support seating system, but this holds him upright, which is not very comfortable for long periods. As he already has one seating system, Social Care will not fund additional equipment, and we were asked if we could help with the funding of a reclining supportive seating system, so that he can sit in comfort for longer periods, when he is at home. We approved the amount required, as this will further help his development.
		4397.30	The Victoria College was recently formed, alongside the Victoria School, to cater for up to 40 young people with disabilities, in the 19 to 25 years age range. This is an area where facilities are limited generally, and much needs to be done for this age group. While this pilot scheme is being partly funded by Birmingham, the School is required to find the rest of their funding needed from its budget, which is already under pressure. We were asked if we could fund an Acheeva bed, which will be used by 4 of the current cohort of 16 pupils, and is a much needed item of equipment, particularly for wheel chair bound students. We agreed to fund the full cost, which, with our discount, amounted to £4,397.30.
T	5	1061.33	He has a diagnosis of Cerebral Palsy, Epilepsy, and visual impairment. With arm and leg problems, he is unable to move independently, being able only to move to his standing frame. To help with preventing contractures ( <i>muscle stiffness</i> ), and to help to strengthen his legs to further aid mobility, his Paediatric Physiotherapist had recommended a special exercise tricycle. With the family unable to raise the funding required, we were asked to help, and agreed to provide the full purchase cost, which was VAT exempt, and subject to our agreed discount with the supplier.
J	3	318.00	He has a diagnosis of autism, and requires constant attention. He has been struggling with eating, and is only able to feed himself if he is securely strapped in a seat at the table. We were asked to help, as his parents were using his buggy, which was too low for the table, but at least created the conditions needed for him to eat. After finding a suitable design seat, which would hold him securely, at the right height, and which could be adjusted as he grew, he was assessed, and the cost was £478.00. With the parents only able to raise the funding for the chair without all of the much needed accessories (£160.00), we agreed to provide the balance of £318.00 required.

A	6	913.43	He has Neurofibromatosis Type 1, which is a tumour disorder, resulting in tumours the nervous system, and was recently diagnosed with Optical Nerve Glioma, which may require chemotherapy, but as this has a sporadic effect on vision, it may be left without further treatment. He frequently falls, and needs extra support in the classroom. He is unable to walk any distance, and spends most of his time in a wheelchair. A special exercise tricycle was proposed which will give him some independent movement, and the opportunity to exercise his legs. With the parents unable to help with the funding, we approved the total amount required.
A	10	987.80	He has global development delay, epilepsy, behavioural difficulties, and abnormal spinal cord tethering. A special exercise tricycle was proposed to help to improve his stamina, and his leg muscles. The parents are keen to do all they can to improve his quality of life, but being unable to help with the funding, we agreed to approve the total amount required.
G	6	879.43	She has Spina Bifida, can walk independently, but is vulnerable, and frequently falls, particularly when tired. She previously had a special exercise tricycle, which was well used, but had outgrown it. This trike was given to another small child, enabling further use to be made of it, and we were asked if we could help with a larger tricycle which would last for a number of years. Again, with the parents not in a position to provide any funding, we agreed to fund the amount required. As usual, the tricycle purchases have been VAT exempt, due to the child's condition, and we have received our usual discount on the list price.
S	5	83.94	Severe learning difficulties, autistic features, challenging behaviour and sleep difficulties. His Consultant Clinical Psychologist recommended a trampoline to help to provide his sensory needs at home, similar to the unit he uses at the special school he attends. This is found to calm him, and would help the parents to control his behaviour. With the parents facing a number of difficulties, we agreed to fund the full cost.
I	3.5	982.28	Cerebral Palsy and significant epilepsy, development delay, and limited mobility. Can only walk short distances using a rollator, and with help, otherwise limited to crawling. A special exercise tricycle recommended by her physiotherapist to try to build her leg and body strength, and improve her mobility. With the parents facing significant expenditure in adapting the house for her, we agreed to fund the purchase of the tricycle.
<b>Total</b>		<b>£59,238.07</b>	