

# Grants Made 2015

Name	Age	Grant	Details
	Yrs	£	
C	17	4,000.00	She has Cerebral Palsy, and is a full time wheelchair user. She has an electric wheelchair, but it is an indoor type, and is not very suitable for outside use, which greatly limits her independence. Unfortunately, the NHS can only afford to supply one wheelchair, and we were asked to help with the provision of a suitable unit which will give her much greater independence, and allow her to interact more with her peers. We agreed to fund the full cost of a new outdoor chair.
		1,780.00	The Victoria School in Birmingham has 200 students aged 2 to 19, 85% of whom are wheelchair bound. As part of the "Get Cycling" project, a number of options were assessed, including trikes, stabilised bicycles, tandems, and multi seater go carts. Of the 200 students, 28 would benefit from the use of two trikes, of different sizes, and fully adjustable, as they have sufficient mobility and coordination to ride them. In view of the scope of the project and the total cost, we were asked if we could help with the purchase of the two trikes. After considering the extent of use, and the beneficial effect they will have, we agreed to fund the full cost.
J	3	78.50	Mild Cerebral Palsy, global development delay, and he struggles to walk. Wheelchair Services provided a suitable buggy, but they never provide the accessory pack (rain cover, sun shade etc.). This limits outside use, and with the family unable to raise the funding, we agreed to purchase the items additionally required.
J	14	1,273.00	He recently transferred to another severe special school, and he requires a standing frame for his specific use. With other heavy demands on the equipment budget at his new school, we were asked if we could help with co funding the purchase, to which we agreed.
L	5	3,395.00	Cerebral Palsy, and complex visual impairment problems. He is very bright, and reading well already, but requires magnification to at least 36 point size due to his sight problems. The Children's Visual Impairment Service has funded a video magnifier for use at school, which has many functions, including line segregation and variable magnification, which greatly helps him to read. We were asked if we could help with funding a similar unit for home use, which although expensive, will make a big difference to his access to printed pages. We agreed to fund the full cost in view of the benefit to him.
H	1	391.88	She has spent most of her first year in hospital, has CHARGE Syndrome, a tracheostomy, and visual and hearing difficulties. She needs regular visits to hospital, but suffers discomfort and distress when using her existing car seat, and we were asked to fund a special support car seat and harness system for her, which we approved.
D	7	2391.62	Kabuki Syndrome, Club feet, and unable to stand or walk unaided. He has problems using the toilet as he is unable to support himself, or position his body correctly, and this results in bowel movement difficulties. Several special support toilet seats have been tried, and we were asked to help with the funding of a unit which was found to suit his needs. Having helped him previously, and being aware of the needs of the family, we funded the full cost.
T	4.5	617.00	Severe autism, and severely mentally impaired. He had outgrown his car seat, and needed a new seat which could provide both the support he required, and the restraint, for his safety. After assessment by Windmill Special Needs, and aware that the family were not in a position to provide any funding, we agreed to cover the purchase cost.
J	16	3,300.00	Diplegic Cerebral Palsy, resulting in muscle spasms and tightness in the arms and legs. He can walk around the house, but needs to use a wheelchair outside. To help to maintain upper body movement, he uses a self propelled manual wheelchair. While he has no problems on level ground, he struggles with hills, and we were asked if we could help with funding a smart drive power unit, which supplements manual input, to maintain the chair at the speed set by the user. This would greatly help his mobility, particularly at a time when he needs more independence. With the family able to raise £1,000.00, we agreed to fund the balance.
L	10	900.00	He has a range of physical difficulties affecting his general development, mobility, speech and hearing. He was originally thought unlikely to become independently mobile. Recently his mobility has improved, and he was assessed at the Footsteps Foundation in Oxford, for a course of intensive physiotherapy to further improve his mobility. Based on previous experience of this technique, we agreed to fund the balance of £900.00 required to cover the costs of one session of the full course.
P	12	237.46 + 132.50	She was born prematurely, and has been totally blind from birth. She is bright, and with the correct support, she is progressing well in mainstream education. She can touch type, and her school computer has speech software which reads out the page text, menus, and instructions, so that she is able to fully participate in schoolwork projects, by accessing the Internet on her own. At home she used older equipment with an earlier version of the software, but as this is now beyond economical repair, we were asked if we could help to fund a similar computer for home use, and the software updates, so that she can regain her independence. With the family unable to fund, we agreed to provide the grant required.
H	5	313.88	He has complex problems being unable to stand, walk, talk, or sit independently. Visually impaired, and fed by a tube to his stomach, he also has a rare form of severe Epilepsy. Request for a special car seat which has a turntable base to assist in lifting him in and out of the car, as well as providing the support he needs. With our agreed discount from our usual supplier, who was also chosen by the assessment centre, the cost reduced by 7.5%.
L	9	804.60	He has a rare chromosome deletion resulting in severe health problems, epilepsy, development delay, learning disabilities, and movement problems. He currently has to use a hard structured seat at home, into which he has to be securely strapped, and the request was for help with funding a special chair, which is comfortable to sit in, holds him in the correct posture, and into which he can be secured. The cost was £804.60, and we agreed to fund.
H	5	99.99	Significant learning difficulties, problems with speech, language and communication, and visual problems. His behaviour leads to

			situations where despite constant supervision, he can knock his head on the floor or corners of tables. With his special school concerned for his safety, we agreed to fund the purchase of a suitable safety protection system for his head, for use both at home and at school.
T	1.5	248.00	He has congenital myopathy, which presents as muscle weakness, joint hypermobility, fatigue, and he is unable to sit upright unless supported. His older sister has similar problems, and uses a wheelchair some of the time, as she can only walk short distances. Finding a suitable buggy for both has been difficult, but his mother has purchased a lightweight buggy with a platform at the rear on which the older sister can stand. It does not provide suitable support for him however, but special seat insert cushions have been tested, these being designed specifically for the purpose of additional support, and they have been found to work well. As the family could not raise the required funding, we agreed to purchase. This will now allow the mother to take out the two children together.
G	1	367.50	Born with hypoplastic left heart syndrome, which results from defective development of one of the main pumping chambers of the heart before birth. Coupled with reduced artery size, this causes blood flow problems, and a number of operations have already been carried out. She fatigues easily, and requires a supportive car seat, with a turntable and tilt system for easy access. With our agreed discount with our usual supplier, the cost was reduced by 7.5%, and we agreed to fund.
A	2	438.68	She has been diagnosed with Rett syndrome, which affects brain development. She has low muscle tone, gross motor delay, feeding issues, and seizures. Long term her development may further regress, and she will be at risk of developing scoliosis ( <i>curvature of the spine</i> ). We were asked if we could assist with funding a special car seat with a secure harness to hold her securely, to provide the support she needs, particularly with her postural problems, and have a tilt/turn facility to assist with lifting her in and out of the seat. Our agreed discount reduced the cost by 7.5%, and we agreed to fund.
T	1.5	389.93	He has congenital myopathy, which presents as muscle weakness, joint hypermobility, fatigue, and he is unable to sit upright unless supported. We recently helped the family with special buggy support cushions for him, and we were asked if we could assist with funding a special car seat with a secure harness to hold him safely, to provide the support he needs, and have a tilt/turn facility to assist with lifting him in and out of the seat. Our agreed discount reduced the cost by 7.5%, and we agreed to fund.
S	13	987.98	A brain tumour was removed in 2011, and while he has made good general progress, he has significant visual and physical impairment. His vision level is decreasing, exacerbated by the development of cataracts. At school he accesses all of his learning using modified large print, has individual support, and specialist software to provide large text and speech as required. We were asked if we could help with funding the provision of equipment and specialist software for home use, so that he can access his learning platform, and has the same computer access as at school. With the family unable to help, we agreed to fund the amount required.
M	5	2006.35	She has Cerebral Palsy and Epilepsy, is very restless when sleeping, and has fits, resulting in her falling out of bed. Various guard systems have been tried, but none found suitable. With Occupational Therapy already having funded a number of items for her, there was no other funding available, although a solution was urgently required. The proposal was to fund the purchase of a safe sleep system, which is manufactured by an American Company, and has proved very successful in similar cases. Having reviewed the market for other equipment, and specialised beds, the proposal was felt to offer the best option. With the family requiring help, we agreed to fund the purchase.
R	6	3040.00	Diagnosed with a syndrome without a name, he is permanently wheelchair bound. Although he has an NHS wheelchair, it is not very suitable for him, and his parents acquired a special buggy a few years ago, with the help of a charitable foundation donation. He has now outgrown this, and the proposal is to purchase a manual wheelchair, which will be more suitable for him. With no more State funding available, we were asked if we could help, and agreed to purchase the equipment.
M	3.5	760.00	Diagnosed with Angelman syndrome, we helped this child approx two years ago with the purchase of a special chair, initially for use at his day nursery, and to use at his special school when a little older. In the interim, he has outgrown the chair, and having also developed a rocking motion when seated, a different type of seating system, with suitable belt restraint, is now required. We were approached by the Alfie Johnson Fund, another local charity with whom we occasionally work, to consider co-funding the required purchase. This we agreed to do, provided that the original chair was passed on to a special needs day care centre, which was arranged.
		406.00	Penn Hall School Outreach Service requested help with a toilet chair, to be used for assessing mainstream pupils with special needs, and to be used by the Penn Hall residential facility when not on loan to a mainstream school. We agreed to provide the funding required.
		272.00	Penn Hall School Outreach Service requested help with the purchase of an educational i-pad with specialised programmes, which could also be loaned out to allow staff to record pupil's work. Detailed recording of pupil progress is now an essential part of the education process to ensure every child, whatever their disability, can develop to their own full potential, and we approved the funding for the purchase.
J	6	1379.95	Autism, severe learning disabilities, behavioural problems, and no communication skills. Large for his age, and needs exercise both for health and to try to develop his coordination. Assessment carried out by the supplier's expert in the presence of an Occupational Therapist, and a special bicycle selected as the best option. As we have a discount agreement, the final cost reduces to £1,479.55. With the family able to raise £100.00, we approved the balance.
M	22	3000.00 + 15.00	Born with spina bifida and hydrocephalus. Contracted meningitis at three days old, has epilepsy, Poland Syndrome, is autistic, and has learning disabilities. She requires a wheelchair for any movement outside. We were asked to help with funding the cost of a Service dog, specifically trained for use with autistic young people. The cost was £6,000.00, and we agreed to fund 50% of the cost, subject to the balance of the funding being found from other sources. We also arranged for some additional funding from another charity with whom we co-fund some applications. The provision of the dog will greatly improve the freedom of the young person, while providing some security, and will make a major change to her life.
C	4	2143.54	Born at 28 weeks, he has had multiple bowel operations. He suffered a bleed on the brain due to oxygen starvation, has brain damage, and many health problems. He has no concept of danger, is difficult to settle down at night, and can climb out of his cot.

			The proposal was to provide a Safety Sleeper system to secure and settle him. By purchasing a number of units for children with similar sleep problems at the same time, we were able to negotiate a discounted price.
D		1949.35	She has Cornelia de Lange Syndrome, and a number of other medical problems. She also requires peg feeding for 12 hours throughout the night, and so needs a safe sleeping environment that can also cope with the various feeding tubes needed. Again a Safety Sleeper was proposed, and we were able to obtain the discount on a bulk purchase.
	7	2066.04	Smith-Maegnig Syndrome, which is a development disorder, sleep problems being one typical effect. A Safety Sleeper was also proposed for this family, and with no funding available, we again funded the full cost, at the bulk discount price.
L	6	2038.66	She has a complex epileptic condition, and has been diagnosed with mitochondrial disease. She has a degenerative condition, and is life limited. She has already fallen out of her cot, and requires a safe and secure environment. With the need for tube feeding, and catheter waste disposal, she also needs a secure system, where the associated pumps are outside her reach. A Safety Sleeper system was again proposed, and made up the fourth purchase, enabling us to secure a bulk discount.
J	3	1708.79	He sustained a severe brain injury in 2013, and although the Local Authority provides one functional chair for his use, he is unable to sit in it for long periods. As we have found before, they will not fund a second comfortable chair, suitable for his use. The NHS Care Trust is prepared to fund £500.00 towards the cost, and we were asked if we could help with the balance. We agreed to provide the balance of funding required.
M	1	537.48	Child is life limited and receiving palliative care. Very difficult to settle her comfortably, and mother has to spend most of the day and night cradling her. A P Pod bean seat has been tested by the family and found to provide a comfortable and secure resting place for her, so we approved the funding.
A	12.5	2448.47	Cerebral Palsy mainly affecting lower limbs, which has made mobility difficult, and now uses a special walker. Her spine has become deformed, and one hip is beginning to dislocate. She required a special high seat comfortable chair to hold her in the correct posture, to limit further damage, and also help her to get up/down without assistance, as current seating is too low. This would give her some independence, as she currently requires family assistance every time she wishes to move. We agreed to approve the funding.
T	6	1442.50	Spastic quadriplegic cerebral palsy, visual impairment, epilepsy, and unable to mobilise himself. His hips are at risk of dislocation, and a standing frame has been recommended for school use, similar to one used at home. With his school already having funded two types of wheelchair and a hoist, we were asked if we could help, and we agreed to co-fund half the cost with the school.
A	4	453.28	Global development delay and challenging behaviour. His parents have health problems, and are unable to work, and the family has been provided with a Motability vehicle, with a suitable supportive car seat. However, he releases himself from the seat belts, and with his challenging behaviour presents a safety risk to the driver. We were asked to fund the purchase of a suitable Crelling restraint harness which will hold him safely and securely, and with the family on benefits, we agreed to cover the full cost.
R	3	198.75	She has Osteogenesis Imperfecta ( <i>otherwise known as Brittle Bone disease or Lobstein Syndrome</i> ) for which there is no cure, but suitable exercise is recommended to help her mobility. A secondhand special exercise trike of suitable size was available, and we agreed to fund the cost of the additional safety items required. The final cost was reduced by the agreed discount we have with the supplier.
C	6	1546.85	Problems with walking on his toes, frequent falls, reduced balance and learning disabilities. A special exercise tricycle was proposed to help to develop his balance, leg strength, and by stretching his legs it may help to reduce the tendency to walk on his toes. Due to his condition, a number of additional support accessories were required to be fitted to the tricycle, resulting in the cost being higher than usual, even after our agreed discount with the supplier.
E	3.5	890.43	Diagnosed with Hypermobility Syndrome ( <i>a condition where there is more than normal joint mobility, which can lead to Osteoarthritis. Low impact exercise is often recommended eg Swimming, or Cycling, to exercise the joints and build muscle strength</i> ), she tends to fatigue quickly. Her paediatric physiotherapist recommended muscle strengthening exercises, and she was assessed for a special exercise trike, adapted for her additional support needs. With the family unable to contribute, we funded the purchase.
L	8	1084.23	Ataxic Cerebral Palsy and severe learning difficulties, and she can only walk short distances using a support frame. We helped two years ago with the purchase of a special exercise trike, which she had outgrown, and which had been passed on to another child ( <i>see "R" above</i> ). We were asked if we could fund a larger model trike to help with her coordination and general condition, and we agreed to provide the full purchase cost, reduced by our agreed discount with the supplier.
		2247.67	A new pupil will start at Old Park School in September, who suffers with severe epilepsy, and is confined to a wheelchair. Her special educational needs statement highlights the need to spend part of the day on an Acheeva bed, and the three units the school has are all currently in use. With special schools facing budget constraints, we were asked if we could help, and agreed to a 50/50 co-funding, with the cost reduced by our agreed 5% discount with the supplier.
J	21	1700.00	He has been waiting for some time for an extension to the family home to help his independence. After many re-designs, the cost of the facility was finally reduced to £31,700.00, but the maximum grant available from the Local Authority, for which he was eligible, was only £30,000.00. Unless the balance could be found within the next month, work could not be started, and the project would again be delayed, and have to be recosted. We agreed to provide the balance for the work to proceed.
C		100.00	He has a diagnosis of autism, and has attachment difficulties. He is moved around in a buggy due to problems with his feet, but when he is in the car, he releases himself from the car seat, and presents a danger to the driver. With the family now a single parent and in rented accommodation following domestic abuse, we were asked to help by contributing £100.00 towards the cost of a suitable restraint system, to ensure his safety when being transported (estimated at £116.80 plus delivery), and we agreed to help.
F	1.5	355.00	Krabbes disease, which is a degenerative condition, usually fatal following a steady loss of control functions. He has started to lose head control, and active movement of both arms and legs, and needs a lot of support. We were asked if we could fund a special car seat with a tilt/turn facility to assist lifting him in and out of the seat, and we agreed to fund the purchase.
J	4	202.40	He presents with Autistic behaviour, has hypotonia, and is unable to walk very far. Additional complications include a Gastrostomy, as he has problems with his Oesophagus. Although a special buggy had been provided for him, as is usual, the

			accessories were not provided, so that there was no cover, rain cover, or basket. We were asked if we could help with the funding of the purchase of these, as we have been on many previous occasions, and we agreed to provide the help needed.
W	9	319.00	Down's Syndrome, problems with fine motor skills, and has periods of aggressive and challenging behaviour. Family break up due to domestic violence had resulted in him losing his iPad, with no possibility of it being replaced. He has problems reading, but was using it both for educational purposes, and to help to calm him. I pads have been found to be very effective with children with problems, and with the family unable to fund a replacement, we agreed to purchase a new one for him.
G	3	992.43	Left Hemiplegia, which has left her with weakness, some walking problems, and limited control. A special exercise tricycle was recommended by her Paediatric Physiotherapist to build muscle strength, and improve her mobility and control. We agreed to cover the full cost of the purchase.
C	5	214.00	Autism, challenging behaviour, sensory issues, and non verbal, it was felt that the provision of a sensory area would be a great help in calming him, when problems arise. With the family able to raise a small amount, we were asked if we could help to fund a Bubble column, and a sensory pack, which we agreed to do.
T	6	3267.00	Spinal Muscular Atrophy Type 2, and is wheelchair bound. Being weak, she requires a full powered wheelchair, with extensive facilities to enable her to be moved into the required positions to participate in classroom activities. Having recently outgrown her previous wheelchair, an application was made to Caudwell Children, who agreed to fund 80% of the cost (which is their usual maximum). With the family able to also raise a small amount, we were asked if we could help with the balance, and we agreed to provide all of the remaining funding required.
L	5	£225.00	Diagnosed with OI ( <i>Osteogenesis Imperfecta or Brittle Bones</i> ) at 10 months old, after a number of fractures. She has developed severe scoliosis,, requiring surgery to correct the curvature of her spine. This will involve a pioneering operation to insert a rod system, and she will be away from school for a long period. We were asked if we could help with funding an iPad, and educational software, to help her during her absence, as she is a bright child. With the family having raised £200.00, we agreed to fund the balance required.
S	4	453.28	Diagnosis of autism, and challenging behaviour. When being transported in the car, he regularly releases his seatbelt, and also that of his brother, who is similarly diagnosed autistic. The family have tried simple safety devices from which he has escaped, so a magnetic travel harness has been recommended, which we know will hold him securely. He has been assessed by Windmill Special Needs, and with our discount agreement, we have agreed to fund the full cost, which reduces to the figure shown.
I	6	2367.00	Significant physical disabilities, and health problems, she has outgrown the special support Panda chair that she uses at her special school. With the school facing a limited budget for new equipment, as funding is being reduced by 1.5% per year, while other costs are increasing, we were asked if we could help, and agreed to fund the full cost.
M	4	435.50	He has spastic quadriplegic cerebral palsy, and also requires a special support chair at the same special school. The chair that the child above has outgrown can be refurbished, fitted with new cushions and straps, and adapted for him. We were again asked if we could help because of budgetary constraints, and also agreed to fund the full cost.
		704.90	We were asked if we could help Penn Hall Outreach Service, which is based at Penn Hall Special School, with the funding of five items of equipment used to assess children at both special, and mainstream, schools. We had previously helped with the purchase of a toileting chair, which had been particularly useful, and we were asked to fund another one, along with a number of smaller items, which we approved.
		3436.67	We were asked by Chadsgrove Special School to fund a ClearView Speech - C unit which magnifies any selected text to help vision impaired pupils, and will convert text to speech to help those having difficulty reading. With school budgets very tight at present, this would greatly help a number of pupils at the school, and we approved the purchase.
L	4	838.08	Both children have Duchenne Muscular Dystrophy, and fatigue quite quickly. Now the one child is older than three years, the family has become entitled to a mobility vehicle, which will greatly help them with moving the children around, and the mother has just learned to drive. The children require special car seats which are fully supportive, and also have a tilt/turn facility, as the mother also has health problems, and would struggle to lift them in/out of the seat, without this addition. The special seats are not funded by the Local Authority, so we were asked if we could help, and agreed to fund the full cost, reduced by our agreed discount with the supplier.
N	2	634.58	
I	3.5	634.58	She has a diagnosis of Williams Syndrome, is non-verbal, and has development delay. A special car seat which is suitably supportive and secure, with a tilt/turn facility was required, and we were asked if we could help. In view of all the circumstances, we agreed to fully fund the purchase.
S	16	273.99	Has autism, and is selectively mute. He is able to communicate at school using an iPad, which he is not allowed to take home. He has an old Kindle at home, with a failing battery, and being a single parent family, with a number of parental health problems, there was no possibility of funding an iPad for home use. After extensive work with him, progress was being made with his communication problems, and we were asked if we could help by funding an iPad for home use, as it was felt that this would help greatly. After discussion, the school agreed to load on all the special educational software needed, and we agreed to fund the equipment purchase.
		2000.00	Request from Fort Royal Special School for help with raising the funding for an Acheeva bed, needed to replace a nine year old unit, and for use by a child registered blind, Club feet, Microcephaly ( <i>smaller than normal head size due to abnormal brain development</i> ), profound and multiple learning difficulties, little control over body movements, with no independent mobility and unable to sit unaided. The Achheva bed is a great help, and the school had raised £2,500.00 towards the original quote of £4,718.00. With our agreed discount, a further £2,000.00 enabled the purchase to proceed.
S	12	2430.51	Epileptic, relies on adult care, unable to weight bear, visual impairment, and is non verbal. He is at Old Park School, and his existing chair was assessed as no longer suitable for use due to its condition. As Old Park needed to replace a number of chairs, following the new school year assessment, we were asked if we could help, and agreed to fund two of the four for which they had already obtained quotations, this being one of them.
S	7	2456.41	Non verbal, unable to walk or weight bear, visual impairment, and uses a wheelchair. He is oxygen dependent, is unable to self propel his chair, and receives full time care support from Acorns. As Old Park need to provide him with a work chair,we were

			asked if we could help, as this was another of the new school year assessment requirements, and became the second seating system we agreed to fund.
J	17	5147.15	Cerebral palsy and Epilepsy, presents with Spastic Quadriplegia, and is a full time wheelchair user. Requires frequent suction and massage to aid breathing, which necessitates him being laid on the floor regularly each day. An Acheeva bed/seating system urgently required for home use, similar to the one used at school, as the continued manual handling out of his wheelchair to a level surface, particularly when he leaves school and will require attention throughout the day, is a major problem. With the family unable to assist with funding, we agreed to purchase, the cost being slightly reduced by deleting one item from the quotation, followed by our agreed 5% discount with the supplier.
S	13	4300.00	Rare condition of a Fumarase Deficiency, resulting in speech, language, vision, hearing and learning difficulties. She has regular epileptic seizures, and uses a wheelchair supplied by the NHS, which is not very suitable for her needs. She was assessed for a unit which would provide for all her needs, but at a cost of £5,418.90, and no State funding available, we were asked to help. A 5% discount was negotiated, the family had collected a small amount, the School was able to help with a £500.00 grant, leaving a balance of £4,300.00 which we agreed to fund.
<b>Total</b>		<b>£87,270.34</b>	