

Voluntary trusts and charities

- ⇒ information needed;
- ⇒ sources of funding.

Information needed

A number of trusts and voluntary groups will help with a grant towards equipment although most will not help with financing adaptations. Some will accept letters of request direct from individuals and families and others require applications from a professional acting on their behalf. Most will want to know the following:

- confirmation that the applicant falls within their eligibility guidelines;
- financial situation of the applicant;
- reasons why a statutory source is not paying for the adaptations or equipment;
- details of the needs;
- if the request is for equipment, that it has been assessed and the reasons for the choice;
- the cost, where possible including an estimate.

Sources of funding

There are four categories:

- ⇒ employers and trade unions;
- ⇒ local charities in the area in which the person lives;
- ⇒ national charities;
- ⇒ disability groups.

Employers and trade unions

This is usually the most successful source of grants, as employers have a loyalty to their existing or former employees. Trade unions may also be prepared to help, particularly if they have a benevolent fund.

Local charities in the area in which the person lives

The contact names and addresses of local voluntary groups can usually be obtained from the public library and the Citizens Advice Bureau.

National charities

Most national charities have strict guidelines. These are published in a number of directories, most of which are included in the *FunderFinder People in Need (PIN)* computer programme. This software provides a quick and easy way of finding which charitable trusts (both national and local) might help and covers both individuals in need and others seeking funding for education and training.

The information to be entered into the computer

Users enter information about themselves (or whoever needs money) to create a search profile. The programme will need to be told a number of details, such as:

- the age, gender and marital status of the person;
- where the person currently lives;
- what the person wants money for (e.g. equipment).

The following information can also be added

This relates to criteria specified by grant-making trusts, as follows:

- other associations people have with an area, such as where they were born;
- current or former jobs;
- membership of a religious group;
- disability problems;
- whether they have served in the armed services;
- membership of certain clubs;
- nationality;
- other characteristics (e.g. housebound, single parent, expectant mother).

After the information has been entered

The search profile is matched against data about charitable trusts coded in PIN. Funders that do not fit are excluded, and results are displayed in alphabetical order. The user can then scan policy information to decide which trusts look promising and these can be selected for printing or saving on to disk. The names and addresses of trusts can be saved in a database file, which can be used in a mail merge.

The printout

The printout will give the name of the trust, its Charity Commission reference number (if it is a registered charity), information about its policy and how applications should be made, its address and telephone number, and a source of further information (such as a directory reference).

Armed with the printout, it must be remembered that most funders get many more requests for support than they are able to help. Because the quality of the application is what counts, be prepared to spend time in getting the application right and, where necessary, enlist the help of a professional who understands the needs and would be prepared either to lend support to the application or to apply on your behalf.

FunderFinder Ltd

Disability groups

There are two sources of funding for people with muscular dystrophy and allied neuromuscular conditions.

- ⇒ the Joseph Patrick Trust (JPT);
- ⇒ the Jennifer Trust for Spinal Muscular Atrophy (JT SMA).

The Joseph Patrick Trust (JPT)

JPT is the Equipment Fund of the Muscular Dystrophy Campaign of Great Britain and Northern Ireland.

Prior to making an application, the following information will be useful:

- ⇒ eligibility for applications;
- ⇒ what applications can be made;
- ⇒ discretionary powers;
- ⇒ how applications can be made.

- **Eligibility for applications**

“Applications will only be accepted from, or on behalf of, people with neuromuscular conditions and if their application falls within the guidelines that follow. The value of any grants given will depend on an assessment of all the relevant information made available to the Grants Panel and the resources available.

- Applications will not normally be considered for items of equipment where there is a duty on the statutory authorities to provide them.
- Grants will not be made for equipment that has already been purchased.
- JPT does not give grants for the full cost of the equipment requested. Only partial awards can be made and the major part of the cost will have to be found elsewhere.
- It is the responsibility of those receiving grants to make arrangements for the insurance, maintenance and repair of the equipment obtained.

- **What applications can be made for**

- **Adaptations to vehicles**

Grants may be considered for the adaptation of new or used vehicles, but will not be made towards the purchase or lease of vehicles, vehicle deposits, or for the maintenance or repair of vehicles.

- **Wheelchairs**

Grants may be made towards the cost of an indoor/outdoor powered wheelchair or other wheelchairs not provided by statutory authorities. Grants will not be made towards wheelchair repairs, insurance, or for items such as batteries, tyres, etc.

- **Specialised/therapeutic equipment**

Grants may be made towards the purchase of specialised/therapeutic items (e.g. adjustable beds, riser/recliner armchairs, standing frames, tilt tables, etc.). Assistance towards the cost of computers, other electronic equipment and assistive devices will also be considered.

- **Discretionary powers**

The Grants Panel has discretionary powers to make grants to help alleviate distress in exceptional circumstances.

Grants will not be made towards the costs of structural building works, or for household furniture or domestic appliances.

N.B. Grants are held open for a period of 12 months, after which time they will lapse and a new application will then be required.

- **How applications can be made**

All applicants must complete the specific JPT application form and submit appropriate professional assessments (see below) and official estimates/quotations of the costs of the equipment for which assistance is being requested.

Professional assessments, confirming the need for and the suitability of the equipment for which assistance is being requested, will be required in all cases. The assessment may be undertaken by FCOs or other appropriate professionals such as occupational therapists, physiotherapists, social workers or nurses. Ideally, the assessments should be sent in at the same time as the application form. However, if people applying have not been able to arrange for an assessment, this should be stated on the application form. In those circumstances, JPT will advise, after consultation with the FCO, on how matters will be progressed. Exceptionally, it may be necessary to obtain more than one assessment or to seek further information.”

Joseph Patrick Trust
Registered Charity Number: 2943475

The Jennifer Trust for Spinal Muscular Atrophy

Criteria for Equipment Fund Applications

1. *“The Panel will consider applications on behalf of any person with Spinal Muscular Atrophy – a statement confirming the condition is required. Applications cannot be made for other unrelated conditions.*
2. *All equipment remains the property of the Jennifer Trust and must be returned when no longer required.*
3. *The fund will assist with maintenance and repair costs up to a reasonable level.*
4. *Payments will not be made in retrospect, and applications must be agreed before purchase can be made.*
5. *The Panel will not consider grant applications towards the cost of motor vehicles or vehicle adaptations.*
6. *Persons applying for assistance with funding for electric wheelchairs must apply to their local wheelchair centre first as the Department of Health now provides outdoor powered wheelchairs. This applies to England and Scotland only. Applications will still be considered from Northern Ireland and Wales.*
7. *An up-to-date quotation for the equipment must be enclosed.*
8. *Supporting assessment by a relevant professional must be enclosed.*
9. *An application form must be completed in full.”*

The Jennifer Trust for Spinal Muscular Atrophy
Registered Charity Number: 327669

Providers and funding of adaptations, equipment and services

Equipment/Service required	Who should I approach?	Who funds it?	Is it means tested?	Who will assess the need?	Who will pay for insurance & maintenance costs?
Housing Adaptations, Housing Grant	Social Services Dept. occupational therapist (OT)	Grants Dept., Social Services Dept.	Yes – Improvement Grant (Scotland) Yes – Disabled Facilities Grant (rest of UK)	Hospital, paediatric or Social Services Dept. OT	Usually client (equipment funded with the grant) or sometimes provider
Equipment Bath & toilet equipment, electric recliner chairs, trolleys, etc	Hospital or Social Services Dept. OT	Social Services Dept., client	Not usually	Social Services Dept. OT	Provider
Environmental controls	Hospital or Social Services Dept. OT	Local Health Trust/ Board	No	Approved local medical consultant	Provider
Beds	GP, OT, district nurse, health visitor, social worker	Local Health Trust/ Board Occasionally Social Services Dept./GP Practice	Not usually	Provider	Provider
Specialist mattresses	GP, district nurse, health visitor, OT	Local Health Trust/ Board/GP Practice	No	Tissue viability nurse district nurse/ health visitor	Provider
Mobility Manual & indoor-outdoor powered wheelchairs	GP, or hospital consultant, physiotherapist (physio) or OT	NHS chairs through Wheelchair Services	No	Wheelchair Services therapists or accredited therapists	Provider
Chairs outside NHS range & trikes	Physio or OT	Child: Whizz Kidz, Variety Club, Joseph Patrick Trust (JPT) voluntary charities Adult: JPT, voluntary charities	No, but applicant's income & expenditure may be taken into account	Child: Whizz Kidz, therapist, paediatric OT/physio Adult: OT or physio	Client

Equipment/ Service required	Who should I approach?	Who funds it?	Is it means tested?	Who will assess the need?	Who will pay for insurance & maintenance costs?
Vehicles Cars, vans	Motability if client in receipt of higher mobility rate of DLA	Client, in conjunction with Motability if client in receipt of higher mobility rate of DLA & a grant is needed towards deposit	No, but if a grant is needed the applicant's income may be taken into account	Mobility Centres	Client - Hire Purchase Scheme, Motability – Lease Scheme
Vehicle adaptations	Motability	Passenger/driver – Motability Equipment Fund. Disabled person driving from a wheelchair – Motability Driver's Fund	No, but the applicant's income may be taken into account	Mobility Centres Motability	Client
Medical Standing frames respiratory equipment, corsets, shoes	Consultant, physio	Appliance budget holder	No, but there may be a charge	Consultant, physio	Provider (equipment, but not clothing)
IT Computers – school	Special needs teacher, OT	Education Dept.	No	IT tutor, Ability Net, Ace Centres, Communication Aid Centres	Provider
Computers – home	JPT, AIDIS Trust	Part JPT with referral to AIDIS Trust for balance	No	As above or AIDIS Trust	Client
Access to education	Social worker	City, Borough or County Education Dept.	No	Special educational needs officer	Provider
Community Care	Social worker, Community Care Services at Social Services Dept	Social Services, local Health Trust/Board, Independent Living Fund	In some cases, or there may be a charge	Care manager appointed by Social Services Dept.	Provider, or client who arranges own carers not employed by an agency

N.B. All services and equipment depend upon an assessment of need, taking into account budget constraints. In some cases, such as the provision of beds (unless there is proof that the supply will ease nursing services) there may be no one in your area who has accepted the responsibility of funding. In all cases, a request should be made to the statutory services, where necessary with the help of the Muscular Dystrophy Campaign Family Care Officer. In situations where the need is urgent, joint funding between a statutory service and the voluntary sector may be used.

VAT

The discussion covers the following:

- ⇒ equipment;
- ⇒ building alterations;
- ⇒ VAT-exemption form.

Equipment

Why some goods and services are zero-rated and others are not

"When VAT was introduced in the United Kingdom in 1973, it was agreed that disabled people should not have to bear the additional burden of the tax when they had to buy certain items designed solely for their use, or when requiring adaptations to standard equipment in order for them to be able to use it.

*Although the range of goods and services which may be zero-rated is now greater than it was in 1973, the basic principle still underlines the current VAT relief. The relief is not intended, therefore, to mean that supplies of all goods and services to disabled people should be zero-rated. Many goods which are of benefit to people with particular disabilities, may not qualify for relief because they are designed for wider use. Nor does the relief mean that eligible goods and services can be supplied VAT free to people who are not disabled. In short, both the goods or services and the recipient have to qualify before zero-rating can be applied".*²⁵

Who can obtain goods and services VAT free

*"The law provides VAT relief for certain specialised goods needed by people who are chronically sick or disabled".*²⁵ Details can be taken from the booklet obtainable from Customs and Excise listed in the telephone director, or via their website:

www.hmce.gov.uk/forms/notices/701-07.htm

Building alterations

Works zero-rated for VAT purposes

"The supply of the following works will be zero-rated for VAT where they are carried out to a person's private residence:

- (a) *the construction of ramps or widening of doorways or passages for the purpose of facilitating the disabled person's entry to or movement within the building, including any preparatory work or making good;*
- (b) *the installation of a lift for the purpose of facilitating the movement of the disabled person between floors of the building. Repair and maintenance are also zero-rated;*
- (c) *the providing, extending or adapting of a bathroom, washroom or lavatory where such provision, extension or adaptation is necessary by reason of the disabled person's condition. In addition, other work essential to the provision of these facilities can be zero-rated.*

*In order for this supply of goods or services to qualify for zero-rating the supplier or contractor must obtain an eligibility declaration from the disabled person".*⁶ (Annex I)

VAT-exemption form

A sample form which can be photocopied is enclosed in Chapter 11.