



GUIDELINES FOR GRANT APPLICANTS

About the Trust

The Joseph Patrick Trust is a grant giving trust providing funding for people with muscular dystrophy or a related neuromuscular condition towards the cost of essential equipment such as wheelchairs, computers, and electric beds. The Joseph Patrick Trust is part of Muscular Dystrophy UK.

Alexander Patrick established the Joseph Patrick Trust in 1986 in memory of his father Joseph Patrick who was a founder member of Muscular Dystrophy UK. Alexander Patrick is a major benefactor of Muscular Dystrophy UK and a Vice President of the charity, having formerly been Vice Chairman of the Trustees.

Joseph Patrick Trust Grant Criteria

- Applications will only be accepted from, or on behalf of people with muscular dystrophy and related neuromuscular conditions. If you are unsure please call us to check. Alternatively you can view a list of the conditions we support on our website <http://www.musculardystrophyuk.org/about-muscle-wasting-conditions/information-factsheets/>
- The Joseph Patrick Trust does not fund grants outside the United Kingdom.
- Grants are provided towards the cost of specialist equipment related to a need caused by the disability that are outlined in Section B of 'How to apply'. The equipment must have a positive impact on the quality of life.
- In most instances the Trust does not provide the full cost of the equipment and the applicant will be required to raise the additional funding from other sources. (In some circumstances applicants can be referred to other trusts that may be able to provide additional funding.) *The Trust will not fund equipment required to be provided by statutory services. However the Trust recognises regional differences in the access to certain NHS/Social Services equipment and differences in the quality and functionality of that equipment.*
- Under exceptional circumstances limited funding may be provided to families for 'relief of stress'. This will be decided on a case by case basis at the discretion of the JPT Grants Panel.
- Because of limited resources only one item of equipment may be considered at any one time. The Trust will also not normally consider funding the same item of equipment for the same individual within a three year period. In both cases, this is left up to the discretion of the JPT Grants Panel.
- Funding will be provided only where the individual / family understand their personal liability, repair and maintenance responsibilities. Funding is provided on the basis that the equipment is the property and full responsibility of the individual / family. The Trust does not take responsibility for the repair, up-keep, liability (insurance) and disposal of such equipment. *Adherence to this understanding will be required before funding is granted.*

- Grants will be held open for an 18-month period, after which they will lapse and a new application must be made to the Trust **unless an extension is requested in writing. If the grant is no longer needed you are required to notify the Trust so that the funding can be distributed to others.**
- Funding is allocated for the piece of equipment that was specified in the application. It cannot be used to purchase a different item of equipment. In addition, if the item was purchased for less than was originally stated in the supporting quotation, the surplus funds cannot be used to be put towards another item. A new application would be required in both these instances.

Joseph Patrick Trust will not provide grants for the following:

- Holidays and/or respite, structural household adaptations or building works, fixtures or fittings, furniture or domestic appliances.
- equipment which has already been ordered or purchased.
- Equipment that is second hand that is not provided by a specialist dealer
- recurring costs - equipment repairs, insurance, batteries, tyres, servicing etc.
- purchase or lease of vehicles; vehicle deposits; maintenance or repair of vehicles.

Funding will be paid upon the receipt of an invoice or proof of purchase to the equipment supplier when all of the funding for the equipment is available and or to a social worker, other charity or organisation.

HOLDING FUNDS

The Joseph Patrick Trust can also help individuals / families by holding funds 'in trust' for the individual. For example, another charity may wish to make a contribution towards the cost of the equipment. The Trust can hold this funding, paying the full amount to the supplier once the balance is raised.

Opening the 'account'

In order to open an 'account' please complete the Joseph Patrick Trust application form and send this back with a covering letter instructing us to open an account to 'hold funds' on behalf of the applicant, an account will be opened in the applicant's name.

Paying in cheques

All cheques to be paid into the account should be made payable to **The Joseph Patrick Trust**. Please ensure all cheques are accompanied by a letter with the applicant's name, this ensures the funds are registered against the correct applicant. When funds are to be paid in by other means please inform us beforehand with the names of the people raising the funds.

Claiming funds

All funds will be released upon the receipt of an invoice, cheques will be made payable to the supplier of the equipment for which the funds have been raised.

Interest

No interest is paid on any funds held.

HOW TO APPLY - FILLING IN THE APPLICATION FORM

If you need guidance to fill in this form or you want any more information please telephone the Joseph Patrick Trust team on **020 7803 4814** or **020 7803 4811**.

SECTION A - DETAILS OF THE PERSON REQUIRING ASSISTANCE

If you are filling out the form on behalf of someone with muscular dystrophy or a related neuromuscular condition (such as a parent or the applicant's representative), please fill it out in their name and with the details of the person affected. Please be as specific as possible about your neuromuscular condition.

*. You will also be required to provide your own personal contact information in the section Details of **Person Completing the Form**.*

SECTION B - WHAT DO YOU REQUIRE THE GRANT FOR?

1. Type of equipment

*It is expected that applicants will apply for the equipment they require from Statutory Services and come to the Trust **only** when this support has been refused, is not available, or when the equipment provided is not adequate or appropriate.*

At present the Trust provides part-funding for the following:

- **wheelchairs and wheelchair adaptations (electric, manual, sports);**
- **trikes;**
- **Scooters;**
- **electric beds;**
- **computers and tablets;**
- **vehicle adaptations;**
- **riser chairs;**
- **therapy equipment (such as standing frames)**

We have recently received funds now allowing us to broaden our scope of grant awards to cover items of equipment called Assistive Technology (AT). Assistive Technology is any item, piece of equipment, software or product system that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities.

At present, we can provide part-funding for items, which will aid communication. This includes the following items:

- **switch interface (to enable wheelchair or other item to operate IT/communication devices, eg Tecla Shield or similar device);**
- **tablet (with built-in assistive technology communication software);**
- **all-in-one PC (with built-in assistive technology software);**
- **eye gaze add-ons;**
- **Assistive technology software (eg for eye gaze add-ons)**

In applying for such equipment our terms and conditions remain the same as for all equipment for which awards are granted.

The Trust will however consider applications for other equipment, which meet the criteria detailed in the Guidelines for Grant Applications.

2. Equipment details

Please give accurate details of the equipment you require. Also provide model details and other specifications. **The application will not be processed without a quotation for the equipment, please make sure the quotation is enclosed.**

3. Equipment cost

Please give an indication the total cost of the equipment being applied for and specify the amount you are requesting. Please note that you can only request as much as the tariff allows, as JPT only part funds equipment. For more information on the tariffs and amount you can apply for please see our guidelines on our website: <http://www.muscular dystrophyuk.org/get-the-right-care-and-support/equipment-grants/jpt-grants/how-to-apply/>

4. Equipment assessment

Every application **must be** supported by an assessment carried out by a professional. This assessment should confirm that the piece of equipment is the most suitable for your needs. It should also detail (if appropriate) why this equipment is unavailable from the NHS or Social Services.

The letter **must be on headed paper, dated within the last three months**, and needs to contain the signature of the health professional. It also needs to detail all of the following:

1. Needs of the individual
2. Needs for this specific model / equipment specification
3. Health and safety - the ability of the person to use the equipment safely (e.g. if a wheelchair – road safety awareness, visual perception)
4. Reason the equipment cannot be provided by a statutory authority
5. Contribution (if any) being made towards the cost by a statutory authority (e.g. voucher)
6. Qualification / occupation / employer of professional with contact details (in case we need to get in touch).

The assessment may be carried out by a range of professionals if appropriately qualified, for example – a physiotherapist, occupational therapist, specialist dealer*, Regional Neuromuscular Care Advisors, social worker or nurse. **You are responsible for ensuring that an adequate assessment has been carried out and issues such as health and safety have been thoroughly considered.**

* If your assessment has been carried out by a specialist dealer, you will also need to provide a letter of support from another professional confirming the applicant's name, address their type of muscular dystrophy and confirming they require this type of equipment.

Please fill in details of the assessor, their name, occupation, qualification and employer (if appropriate).

PLEASE NOTE THAT APPLICATIONS WILL NOT BE PROCESSED WITHOUT THE ASSESSMENT LETTER AND QUOTATION. FORMS RECEIVED WITHOUT THESE DOCUMENTS WILL BE RETURNED.

5. Seeking additional funding for your equipment

In most instances the Trust does not provide the full cost of the equipment and the applicant will be required to raise the additional funding from other sources. We need to know that you are making efforts to identify the remainder. If fundraising is already underway, please let us know your fundraising activities. If you require help please see below.

You can download a publication from the Muscular Dystrophy UK's website called "Raising funds for individuals with Muscular Dystrophy". This will give you a list of other organisations you may also wish to

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apply to for funding. This is located in the publications section here:
<http://www.musculardystrophyuk.org/app/uploads/2015/02/raising-funds.pdf>

6. Telling us what difference the equipment will make

This is to be in the words of the applicant describing how the equipment will be of benefit to them. Specifically it should cite the difference this equipment will make to their life. We reserve the right to use the statement in our correspondence with our supporting trusts without the applicant's permission; however we would not use any personal details with this statement so applicants will never be identified unless they specifically agree. We would not use this information in general publicity material without the explicit agreement of the applicant.

SECTION C - APPLYING FOR A WHEELCHAIR

The information requested is for campaigning purposes and to understand what is happening in the NHS Wheelchair Service. **It is not used to determine whether or not to provide funding towards a wheelchair. Please complete as much as you can as this will help us with our work to improve the provision.**

Joseph Patrick Trust and Muscular Dystrophy UK actively campaign to improve health and social services for people with neuromuscular conditions, to tackle the discrimination they may face and to convince the Government and others to provide more money for research. We actively seek to raise awareness of the issues faced by people with neuromuscular conditions. Getting involved in campaigning could mean writing to your MP or local health providers, speaking to your local newspaper about an issue, which you feel strongly about, or attending campaigning events.

Grants may be made towards the cost of an Electric Powered Indoor/Outdoor wheelchair (EPIOC) or a light weight manual wheelchair. It is encouraged that you will have already sought funding / a wheelchair from the NHS Wheelchair Service. The Trust however recognises that there is a *postcode lottery* in relation to wheelchair and equipment provision. This means that waiting times for NHS assessments and equipment, assessment criteria and the quality of NHS equipment vary. Some people will have no EPIOC, some will have a heavy manual chair or a very basic EPIOC from the NHS, others will have a NHS voucher and require additional resources for a better quality private chair. The circumstances vary from region to region. If you have an **inadequate NHS wheelchair you can still apply for consideration for Trust funding**. If you need support to seek funding from Wheelchair services the Advocacy Service at Muscular Dystrophy UK may be able support you with this.

We are sure you will have thought very carefully before deciding to seek funding for a wheelchair. **There are of course advantages and disadvantages in seeking part funding through Joseph Patrick Trust.**

Before you seek funding for a 'private wheelchair' you may wish to consider the following:

- **You will need to ensure the wheelchair is suitable and any seating requirements and health and safety issues are addressed.** These are considered in detail by a NHS wheelchair assessment, but may not be if you receive your wheelchair privately.
- **How you will pay for repair and maintenance and any additional needs including seating systems.** This can be very expensive and additionally you could be without a wheelchair for a considerable period while it is repaired. Having a NHS supplied wheelchair means that the costs of repairs, maintenance and replacement are covered.
- **Shop around for the right wheelchair for you.** Do your research carefully, as some of the less well-known brands have the same functionality but are considerably cheaper than other better-known brands.

Another option is to discuss with your local NHS Wheelchair service a 'partnership' in funding your wheelchair. You could try and negotiate for a voucher from the NHS towards the cost of your wheelchair. You may also be able to agree free maintenance or funding for seating requirements from the NHS. It may

also be possible for the Trust to fund additional functions for your NHS Wheelchair, for example a new / different joystick or a new NHS Wheelchair part funded by the Trust.

If you are applying for funds for a class 3 wheelchair, for the use of a young person under the age of 14 years, the speed setting must not be more than 4mph. We would strongly recommend that you read the relevant sections of the Highway Code. You are responsible for ensuring that the wheelchair supplier has set the limiter to 4mph. You can find the relevant section of the Highway Code here:
http://www.direct.gov.uk/en/TravelAndTransport/Highwaycode/DG_069852

SECTION D - TERMS & CONDITIONS

Please be aware that equipment such as wheelchairs can be costly to repair and maintain so do consider these costs carefully when deciding to purchase an item of equipment. Please note that an award is provided on the basis that the equipment is the property and full responsibility of the individual / family. The Joseph Patrick Trust does not take responsibility for the repair, up-keep, liability (insurance) and disposal of such equipment.

The equipment that you are seeking to purchase is expensive and it is essential that it stays in good working order. The best option is to get an extended warranty but you will also need to purchase insurance for repair as well as damage and theft. Electrical equipment such as electric beds should be insured. It is your choice what insurance company you use. For equipment that is used only at home, the cheapest way may be to include the equipment as part of your home insurance policy. It may be possible to agree an arrangement with the NHS Wheelchair Service to maintain and repair an electric wheelchair.

JPT is unable to collect the equipment when you no longer have use for it. You need to make your own arrangements for equipment disposal and recycling. Local branches are often in touch with other families in your area and may know someone looking for equipment.

Equipment that is in good condition could be reconditioned for someone else to use and you may wish to get in contact with a local dealer who might be able to help with this. If the equipment is old and worn, we recommend you scrap it safely, particularly if there are electrical components, batteries etc.

APPLYING FOR POWERED MOBILITY EQUIPMENT (including scooters and electric wheelchairs)

Applicants are **required** to insure **powered mobility equipment** – an electric wheelchair or scooter, **for accidental damage and personal (public) liability** under a recognised specialist insurance policy. You are required to provide us with the name of the company on the application.

The following insurance companies may provide you with competitive quotations and are experienced in insuring equipment for people with disabilities.

(This is in no way an endorsement of their policies.)

- Fish Insurance Services - Freephone: 0500 432 141, 01772 724442, Fax 01772 733773, Freepost, 3-4 Riversway Business Village, Navigation Way, Ashton-on-Ribble, Preston PR2 2YP Website: www.fishinsurance.co.uk/ e-mail address: info@fishinsurance.co.uk - Specialist disability insurers
- Chartwell Insurance and disabled Drivers Bureau 0800 089 0146 Website www.chartwellinsurance.co.uk - specialist disability driving and wheelchair insurance

Given the cost of the equipment we also require you to have considered the maintenance costs. You need to do this by ensuring you have a warranty of at least two years and if possible three years; agree with the NHS Wheelchair service that they will provide free maintenance and another wheelchair if needed; or take out maintenance insurance. Maintenance insurance can cost over £100 per year (depending on the cost of the wheelchair).

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The Trust is happy to **partnership fund** your Wheelchair with a NHS Wheelchair Service (see below) and this might mean they will 'own' the chair but they will cover maintenance costs.

SECTION E - DECLARATION

Please make sure you sign the form and include the required documents.

ADDITIONAL SUPPORT, INFORMATION AND PERMISSION FORM

The information that you provide on these pages will help us provide you with more help if you wish.

These pages are optional and **none of the information on these pages will be given to the JPT Grants Panel or used when considering your Joseph Patrick Trust grant application.**

1. Funding from other sources

Saying yes to this question will enable us to send on your details to others with funds. It will also enable us to offer you additional funds, should they become available (Joseph Patrick Trust has additional funds on occasions.)

2. Telling your story

The Joseph Patrick Trust and the Muscular Dystrophy UK actively campaign to improve health and social services for people with neuromuscular conditions, to tackle the discrimination they may face and to convince the Government and others to provide more money for research and equipment etc. We actively seek to raise awareness of issues they face and this is where you can help. Personal stories always make magazine features, fundraising packs or news articles much more compelling and show very powerfully the impact muscular dystrophy has on people's lives. If you say yes to this question we would always contact you before telling your story to anyone to check you are happy for us to do so.

We reserve the right to use your comments in any thank you letters with our supporting trusts without your permission, however we would not use any of your personal details so you could not be identified unless you specifically agreed. We would not use this information in general publicity material without your explicit agreement.

3. Contacting you

We may like to contact you about your application but if you tick the box 'You do not wish to receive further information' we will not add you to our standard mailing list.

5. More advice and support

Regional Neuromuscular Care Advisors provide practical and emotional support for people with muscle disease and their families. They are based at NHS neuromuscular clinics in various regions throughout the UK. They can offer specialist advice and support to children, families and adults with neuromuscular conditions. There may be a Regional Neuromuscular Care Advisors who covers your local area. We are happy to put them in touch with you if you wish. You can also find their contact details on our website here: <http://www.musculardystrophyuk.org/get-the-right-care-and-support/people-and-places-to-help-you/care-advisors/>

WHEN WILL YOU HEAR FROM US?

We will write to you to let you know we have received your application and when it will be assessed. Your application will be considered at a meeting of the JPT Grants Panel and we will notify you of the outcome in writing within 14 days of the meeting. You can find the meeting dates on our website:

<http://www.musculardystrophyuk.org/get-the-right-care-and-support/equipment-grants/jpt-grants/application-deadlines/>.

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Help is available on how to fill in the application form and on putting the background information and supporting material together. *If you need help or want more information please telephone 020 7803 4814 or 020 7803 4811.*

CLAIMING YOUR AWARD

Once you have raised all the funds for your equipment, please place an order and ask the supplier to invoice us for your award. We will contact you following receipt of the invoice to confirm the order has been placed and a delivery date has been set. Until we receive this confirmation, we will be unable to pay the supplier. The award will remain open for a period of 18 months from the date of this letter. The award will be automatically reverted unless we hear from you and in the event of this, you will be advised to reapply.

If you have been awarded a grant towards a computer, please place an order and ask the supplier to invoice us for your award. If the supplier is unable to invoice us we would ask that you pay for the computer yourself and send us a copy of the receipt at which point we will send you a cheque to the value of the award. Alternatively, please send the balance of the funds to the Joseph Patrick Trust along with details of the computer you wish to purchase and delivery details and we will order the computer on your behalf. If you wish to discuss this with us please get in touch on 020 7803 4845 or 020 7803 4811.

Please pass our contact details on to the supplier in case there are any queries or they need confirmation of the award.

THE TARIFF

JPT GENERAL TARIFF

<i>Equipment Type</i>	<i>Amount</i>
Electric Wheelchairs (Adults)	Up to £2500
Electric Wheelchairs (Children - under 18)	Up to £1500
Sports Wheelchairs	Up to £1000
Electric Scooters (Adults)	Up to £1000
Electric Scooters (Children - under 18)	Up to £900
Manual Wheelchairs (Adults & Children)	Up to £300
Manual Wheelchair Adaptations (Adults & Children) i.e. Seating, Joystick etc	Up to £300
Electric Wheelchair Adaptations (Adults & Children) i.e. Seating, Joystick etc	Up to £500
Riser for new NHS fully funded electric wheelchair (Adults)	Up to £2500
Riser for new NHS fully funded electric wheelchair (Children)	Up to £1500
Electric Beds	Up to £400
Trikes	Up to £300
Computers, including laptops and tablets	Up to £100
Vehicle Adaptations/Adapted Vehicles (First and Subsequent)	Up to £400
Riser Chairs	Up to £500
Mobile Arm Supports	Up to £1000
Therapy Equipment	Up to £200

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Portable Aids	Up to £200
Discretionary Payments (Relief of Stress)	Up to £200
Funeral costs	Up to £1000

Additional funds may be available to make further awards towards a grant for an electric wheelchair. In some circumstances the panel are able to offer up to 15% of the total cost of an electric wheelchair, where the current tariff is less than 15% of the value of the wheelchair.

JPT ASSISTIVE TECHNOLOGY (AT) TARIFF

<i>Equipment Type</i>	<i>Amount</i>
Switch Interface	Up to £300
AT Software (specialist communication software)	Up to £300
Eye Gaze Add-on	Up to £2000
Tablet (with built in specialist communication software)	Up to £2000
All In One PC (with built-in assistive technology features)	Up to £2000

Additional funds may be available to make further awards for these assistive technology items and additional accessory components that are essential for their function. Please apply for all items that you need and applications will be considered on a case by case basis in line with the tariff and funding available.