The Jon Shaw Foundation provides at least partial funding for equipment to support **young people living permanently in the UK, under 25 years old and having a diagnosis of epilepsy. (We will consider those who can confirm that they are on the pathway to a diagnosis.** We can support the purchase of your preferred equipment and the Trustees are happy to discuss your particular needs or preferences.

Please find below a list of some of the items we do provide funding for

**Alarms and Monitors**, there are many monitors available, however, due to limited funds we are currently restricting the monitors we can consider funding. Hopefully this is a temporary restriction.

You can apply for funding towards Epimonitor, Medpage MP5v2, Alert IT Pulse Companion, Nightwatch and safety pillows**.**

*If there is an item you would like funding for which does not appear on the list, please contact us before you complete the application form. Depending on your circumstances we may potentially be able to assist.*

Please find below a list of some of the items we DO NOT fund (unless exceptional circumstances)

Donations to other charities, funeral services, home adaptations, holidays etc.

PLEASE NOTE. A completed application will include

* A letter from your medical team confirming diagnosis of epilepsy

**(We cannot process this application without a letter of support from your clinician.)**

* All details in this application form will be complete in full and both sections signed.
* Proof of address (we can take this from the clinicians letter)

In order to assess your eligibility for a grant for equipment please answer the following questions, giving as much detail as possible.

**Contact Details**

|  |  |
| --- | --- |
| Parent / Carer Full name  (Not required if self-referral-over 18s) |  |
| Referrers name if not parent |  |
| Permanent address |  |
| Email address |  |
| Telephone number |  |

|  |  |
| --- | --- |
| Young Persons full name |  |
| D.O..B |  |
| Permanent address if not the same as parents |  |

**Information about seizures (it is important you give as much information as possible)**

|  |  |
| --- | --- |
| When was the young person diagnosed with Epilepsy | Date: |
| Date of first seizure |  |
| What anti-seizure medication does the young person take |  |
| Has the young person tried different medication or combinations of medication. |  |
| Are the seizures being controlled by the medication |  |
| How regularly does the young person suffer from seizures?  e.g daily, weekly, monthly |  |
| What type of seizures does the young person have? Tonic Clonic etc. |  |
| Please describe seizures, e.g movement Conciousness, length |  |
| Does the young person suffer nocturnal seizures. |  |

**Support**

|  |  |
| --- | --- |
| Do you have support from other agencies, incl. NHS | If yes, please give details including contact information *(we may need to contact the agency for further information)* |
| Have you approached any other organisation or charity for funding or other support | If yes, please give details including contact information. (We may consider topping up if necessary) |
| Is the young person in receipt of PIP or other benefit which could help towards the cost |  |

**As part of the application process, we may need to contact any of the agencies/organisations regarding the equipment we are supplying. If this was the case, would you give us permission to do so? Yes (delete as necessary)**

**Equipment**

|  |
| --- |
| **Please specify** which monitor/alarm you would like us to consider as we can’t advocate specific equipment, choose on your behalf or offer advice.  Advice on equipment can be found on epilepsy alarms.co.uk or epilepsy.org. Alternatively, you can speak to your epilepsy care team. |
|  |

|  |
| --- |
| How would this equipment improve the young person’s life, and what impact would it have on the family as a whole? |
|  |
| Is there anything else you would like to tell us about the young person, including any other medical needs they have. |
|  |

|  |  |
| --- | --- |
| How did you hear about us? |  |
| **Part of the application process will include a request for feedback within 1 month of receiving the equipment. Do you agree to complete the short questionnaire?**  **Yes / No (delete as applicable)** | |

**Please ensure you have included all required documents we cannot proceed without them.**

**N.B We cannot replace equipment which has been lost, stolen or damaged, please ensure you have adequate insurance cover to replace any device. We are happy to chat through concerns, but any repairs or exchange of faulty equipment should be discussed with manufacturer/supplier**

Thank you for contacting The Jon Shaw Foundation, please continue to part 2.

Signed \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name (printed) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date \_\_\_\_\_\_\_\_\_\_

**Although this application can be completed by any agency or individual it must be signed by the young person (over 18) or the parent / legal guardian or Carer with Parental Responsibility to validate the information given**.

**Please continue to read and sign section 2 of the application**

**Part 2**

**Help us to Help Others**

**Funding**

We are a small fairly new charity, and our aim is to provide support to as many young people as we possibly can. To support this, we would ask that you consider contributing to our fundraising events and activities. We are also happy to support you with your Fundraising Events by providing leaflets, t shirts and collection bottles.

**Publicity**

Jon Shaw Foundation uses social media, Newsletters, local press and word of mouth to tell people about our services and to raise money to continue our work. We take photographic images (moving and still) of applicants and use case studies which can include these images and some personal information i.e. first name and medical condition to enhance and illustrate our publications and to make them more accessible and inspiring for our audiences.

In accordance with Data Protection, you have the right to withdraw consent and request erasure of all material. Please refer to our privacy statement on our webpage

By completing this form, you confirm that you:

* Understand that footage and photographs may be used at different times and that I will not be contacted each time any materials, footage and photographs are used.
* Give us full permission to use these images and any necessary personal information you supply to use. (This will not include contact details or surname but will be restricted to first names and any details of the impact of epilepsy you share in your feedback) in our media applications (incl. printed publications leaflets, adverts, website, electronic material, display materials and any other media we may use in the future) which reasonably promote or advertise the Jon Shaw Foundation aims. Images will not be used for any other purpose.

**Feedback / Testimonials**

We will contact you from time to time for feedback about the equipment we have funded and how the charity has helped so that we can include your story in our impact statement to the Charities Commission.

**Further information**

The Foundation does not select equipment or therapies, we only provide funding (where approved) therefore accepts no liability for any equipment supplied by third parties. The Foundation is not a provider or advisor in respect of equipment or any other matter.

Jon Shaw Foundation will not pay directly into a personal bank account; the invoice for any equipment will be at least partially paid directly to the suppliers.

The Trustees treat each application as sensitively as possible, handling personal data in accordance with GDPR regulations. We reserve the right to request further information as and when needed.

**Email address** [enquiries@jonshawfoundation.org](mailto:enquiries@jonshawfoundation.org)

We will endeavour to contact you within 4 weeks with our decision.

**PERSONAL DATA**

We are committed to protecting our personal data in accordance with the provisions of the General Data Protection Regulation (GDPR) and the Data Protection Act 2018. Your data will be

a. used lawfully, fairly and in a transparent way

b. collected only for valid purposes and not used in any way that is incompatible with those purposes

c. relevant to the purposes we have told you about and limited only to those purposes

d. kept only as long as necessary for the purposes

e. kept securely

We will use personal data provided to us, either in this application form or otherwise as part of the application process, in the following ways

To carry out background and reference checks (where applicable) and to decide whether to offer funding for equipment you are applying for.

We may use contact details to communicate with you about progress with your application

We may use contact details to send you updates about our work including fundraising events and newsletters which we think may be of interest.

**Sharing your personal information**

We may share your personal data with our trustees as part of the application process. We may also share it with certain third parties including suppliers, HM revenue and customs, regulators and other authorities including the Charities Commission as part of our impact statement. We will also share your personal information if we are under a duty to do so, to comply with any legal or regulatory requirement or as otherwise permitted to do so by law.

We require all third parties to respect the security of your personal data and to treat it in accordance with the law. We do not allow our third-party service providers to use your data for their own purposes and only permit them to process your personal data for specified purposes and in accordance with our instructions.

**Retention of your personal information**

We will only retain your personal data for as long as necessary to fulfil the purposes we collected it for, including for the purposes of our internal recording requirements and satisfying any legal accounting or reporting requirements.

**Data security** We have put in place appropriate security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed.

**Agreement**

As a new charity we are learning how best to help others, your feedback will help with this process. Funds and equipment are very limited at this time so we would ask that you help us to build our resources by agreeing to the following; -

* I give permission for my image and story to be used in publicity events and on the Foundation social media, website and newsletters.
* I further agree that I will provide feedback when requested and a written testimonial which will be used by the Foundation as part of an impact statement for the Charities Commission.
* I consent to you keeping my email address and further consent to you using my email to update me with information about fundraising events, developments in the support we offer and our quarterly newsletter.

**Please refer to our privacy statement on our website homepage** [**www.jonshawfoundation.com**](http://www.jonshawfoundation.com)

Name ----------------------------------------

(Young person (over 18) / Parent/Legal Guardian or carer with parental responsibility)

Signature ------------------------------------------ Date ------------------------------

Any promotion and positive statements on social media will help Jon Shaw Foundation grow and thank you for those. If there is anything which has upset or concerned you about our charity, please share it with one of the Trustees and we will do everything we can to resolve the issue.