



SAM'S SUPERHEROES FOUNDATION

Charity No: 1210458

FIRES Grant Making Policy

1. Background

- 1.1 The Sam's Superheroes Foundation will seek to relieve suffering from Febrile Infection Related Epilepsy Syndrome (FIRES) by offering grants to UK children and their families in need because of FIRES through the provision of financial grants and assistance to fund specialist equipment, therapies, day trips/ holidays or experiences.
- 1.2 The grant is to give families financial aid to help support and relieve some of the impact and strain that they experience when a child is suffering from FIRES. Financial aid towards day trips, holidays or experience provides families affected by FIRES the opportunity to be able to spend quality time together.
- 1.3 The trustees apply the funds of Sam's Superheroes Foundation at their discretion and in accordance with the charitable purposes and objectives of the charity.
- 1.4 A minimum of three trustees will be required to consider and approve the distribution of beneficial grants on its behalf and to make a decision in accordance with the charitable purposes and objectives.

2. Priorities for support

The number of children and families that can be supported by the trustees is necessarily limited to the amount of funds that are available for distribution each year. The trustees have determined that the current priorities for funding are:

- 2.1 Assisting children and young people diagnosed with FIRES and their families in greatest need of financial support,
- 2.2 Grants to support FIRES research, and raising awareness of FIRES,
- 2.3 Assisting children and young people with their mental and emotional ill health with animal assisted therapies and activities, and
- 2.4 Assisting children and young people with their mental and emotional ill health with creative therapies and activities.
- 2.5 The priorities for support will be reviewed by the trustees every year and may be changed depending upon circumstances and the perceived effectiveness of the



application of funds. Any change to these priorities must still fulfil the charitable purpose and objectives of the charity.

3. Grants for FIRES Patients and their Families

3.1 Sam's Superheroes Foundation will offer grants to UK children and their families in need because of FIRES through the provision of financial grants and assistance to fund specialist equipment, therapies, day trips/ holidays or experiences.

3.2 The trustees would consider applications for a grant towards:

3.2.1. The costs of day trips to a wide variety of destinations of their choice, for example places such as the seaside, a theme park or the theatre.

3.2.2. The costs of experiences which may include things such as visit from an entertainer specific to that child's (or their family) individual wishes that can be either in the home or hospital environment where children are restricted due to being in the acute or chronic stage of FIRES.

3.2.3. The costs towards the cost of a family break or holiday to the seaside or the countryside, usually in the UK.

3.2.4. The costs towards specialist equipment outside of the hospital environment which will improve the quality of life for either the child or caregiver for example, specialist wheelchair, monitoring equipment, sensory equipment, hoists, feeding tubes etc.

3.2.5. Financials costs and practicalities associated with having a child in protracted intensive care such as care packages, and meal vouchers for the parents.

4. Principles Applied in Determining Support

In awarding grants, the trustees will apply the following principles:

4.1. The Trustees will consider any requests or known situation to be eligible for a FIRES grant. Applications will be considered:

- From any geographical area within England and Wales, and
- To support young people suffering from FIRES up to the age of 25, and their immediate family/caregivers.

4.2. Applications for a Grant can be made by completing the FIRES Grant Application Form available on Sam's Superheroes website, or other supporting partner's websites.



4.2. Each request or situation will be considered on its own merits. Where situations have been previously considered (whether successful or not) any due diligence undertaken to reach an earlier decision will be made available to the trustees.

4.3. The trustees will carry out sufficient due diligence to ensure that the request or situation meets both the charitable purposes, and the priorities for support set out in this policy.

4.4. The trustees are content to work in partnership with other grant making bodies where funding of an entire project is beyond the scope of any single organisation.

4.5 There is no financial criteria to meet when determining support i.e. no requirement for the applicant to be on low income etc.

4.6 There may be occasions where, due to limited funds, decisions to award grants may be made in partnership with medical professionals or other professional agencies, in order to prioritise funding to those with the greatest medical/financial need. As such, the applicant may be required to provide further information, and provide consent for the application to be reviewed by other third parties to aid the decision making process.

5. Applicant and Partner Due Diligence

5.1. The trustees will carry out sufficient due diligence on any potential beneficiary to ensure:

- The identity of the beneficiary,
- That funds are applied in accordance with the charity's charitable purpose,
- That funds are not knowingly used for:
 - Money laundering in accordance with the operative Money Laundering regulations,
 - Terrorist financing in accordance with the Terrorist Act 2000, and
 - Bribery in accordance with the 2010 Bribery Act.

5.2. In cases where the charity is not the only supporter of the work or project, and to protect its reputation, the trustees may choose to extend any due diligence beyond the proposed beneficiary and to include other partner supporting organisations.

5.3. The trustees will adopt a risk rated approach to due diligence. Risk factors will include; the size of the grant; the geographical location in which the grant will be applied; the nature of the relationship between the charity and the applicant.

5.4. Grant size will be an important risk factor and the larger the grant the greater will be the likely level of due diligence undertaken.

5.5. Where the proposed beneficiary is well known to the trustees and the relationship has been long standing and well established, the amount of due diligence undertaken is likely to be reduced.



5.6. The results of any due diligence will not last indefinitely. In cases where beneficiaries are supported for a significant period of time, additional due diligence will be undertaken on a change of circumstances that might impact the beneficiary, or in any case after a period of three years.

6. Administration

6.1. Grants will be made up to £500. Requests may be made formally, using the grant application form available on our website. This application form will also be available on other supporting websites or through agencies. Where specific needs or situations are known, grants may be made at the discretion of the trustees without any form of request. In exceptional circumstances, grants may be made in excess of £500 at the discretion of the Trustees, and subject to funds.

reement of the charity and the beneficiary, grants will be provided by means of an electronic banking transfer or a cheque. The charity's normal payment authorisation process will be applied to any payments.

6.3. Where the grant is for a specified project or purpose, and in situations where that purpose does not proceed or where any grant or part thereof remains unused, unused funds must be returned.

6.4. Where formal written applications have been received, or other records maintained, these will be stored and subsequently disposed of in accordance with the charity's policy on data protection and prevailing Data Protection legislation.

7. Decision Making

7.1. The decision of the trustees on whether to award a grant is final.

7.2. The trustees are not obliged to provide an explanation to applicants in the event that their application is not successful.



Change Record

| Version | Date of Change: | Changed By: | Comments / Key Changes |
|---------|-----------------|-------------|---|
| V01 | 1 June 2024 | Rachel Liew | Policy Created |
| V02 | 12 October 2024 | Rachel Liew | Added 6.1- Grant application form available on other websites 4.6 - There may be occasions where, due to limited funds, decisions to award grants may be made in partnership with medical professionals or other professional agencies, in order to prioritise funding to those with the greatest medical/financial need. |
| V03 | 1 April 2025 | Rachel Liew | Updated maximum award of grant. Over £500 may be made at the discretion of Trustees. |
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