

SUPPORT FUND GUIDANCE AND POLICY

Aims

In response to the needs of the families we support, we have established the ED Society Support Fund to provide small grants to fund equipment, treatment or care needs for members resident in the UK who are affected by one of the Ectodermal Dysplasias for any of the following needs if you are unable obtain financial help elsewhere:

- Air conditioning unit/fans
- Humidifier
- 'Chillow Pillow'
- Cooling clothing
- Wigs/hair pieces
- Any other appropriate support deemed applicable by the ED Society.

Who may apply?

All members resident in the UK and over the age of 18 may apply on behalf of either themselves or their dependents providing such person has an Ectodermal Dysplasia syndrome.

How much can we apply for?

While any financial support granted is not means-tested, the following criteria will be taken into account when allocating full or part funding:

- The applicant's ability to pay some of the cost themselves
- Whether alternative funding avenues have been exhausted
- Value for money

There is no minimum or maximum amount for this grant. Allocation will very much depend on how many eligible applications that the Society receive in any one year.

What is the process for awarding grants?

An application form must be completed in all cases for each individual and returned with any necessary accompanying documentation to the ED Society Office.

Applications may be made at anytime during the year and will be considered on an individual basis by the Executive Committee at their next meeting following receipt of the application.

All applications received go through an objective review process and will be based on their individual merit and according to the following parameters.

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The Ectodermal Dysplasia Society, Unit 1 Maida Vale Business Centre Leckhampton Cheltenham Glos. GL53 7ER. England
Charity No. 1089135 Tel: +44 (0)1242 261332 Mobile No: +44(0) 7774 465712 www.edsociety.co.uk mail: info@edsociety.co.uk.

- Only completed applications submitted together with the required accompanying documentation will be considered
- Only one application may be submitted per individual
- Only one care need will be supported per individual per application

In some cases the ED Society may require a letter of support from your family GP to accompany the application form.

Grants cannot be approved either by telephone or without the Executive Committee fully considering a request for financial assistance at their meeting, except in the case of emergency.

The ED Society will notify the Applicant if the application is incomplete or if any necessary documentation is missing. If, within fourteen working days after notification, all missing information is not submitted as requested the application will not proceed to the Executive Committee meeting for consideration.

Criteria

Applications will be reviewed to:

- verify that the applicant meets the minimum eligibility requirements
- ensure the application is properly completed
- verify that funds are for appropriate equipment, treatment or care needs only. Funds are not permitted to be allocated or used for any other purposes.

Funds will not be provided for reimbursement of equipment, treatment or care expenditures made prior to the awarding of the grant, unless in the case of emergency.

Any funds granted will only be paid to the supplier or medical professional who provided the goods, treatment or care; the applicant will not be reimbursed directly, unless in the case of emergency.

Applicants must provide a quotation from a reputable company for each piece of equipment, treatment or care need or provide justification for single source purchases - this should accompany the application form.

Who makes the decision to award a grant?

The Executive Committee will determine in January of each year the amount of money to be allocated to the Support Fund for the coming year.

The overall decision for the award of financial assistance lies with the ED Society Executive Committee consisting of at least one third of the number of members of the Executive Committee for the time being or three members of the Executive Committee, whichever is the greater, who are present at a meeting.

The decision of the Executive Committee will be final and not subject to appeal.

- Unsuccessful applications will not be carried forward to the next panel meeting
- Unsuccessful Applicants can reapply to the next Executive Committee meeting but must submit a new application form
- You cannot apply for a grant retrospectively

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- If you do not use your grant within 8 weeks it will be cancelled unless you let us know why there is a delay in ordering the equipment

When do we hear if we have been successful?

The Applicant will be notified in writing of the outcome of the application within 10 working days following the Executive Committee meeting.

If a considerable amount of applications have been received, some applications may be postponed to the next Executive Committee meeting.

If the application would have better success at a later Executive Committee meeting, the Applicant will be contacted beforehand. The Executive Committee meet four times a year; usually January, April, July and October.

If your application is not suitable for funding, we will inform you by post or email.

What types of grant are awarded?

Grants will be awarded to members as a single payment and paid direct to the care provider. The decision on the type of grant rests with the Executive Committee.

How are grants paid?

Should the Applicant be successful, the Administrator will advise in writing that the requested equipment, treatment or care needs may be purchased or ordered and that the invoice be sent to the ED Society for settlement direct with the provider.

Please return the form to:

The Ectodermal Dysplasia Society
Unit 1 Maida Vale Business Centre
Mead Road
Cheltenham
Glos.
GL53 7ER

If you would like more information or would like to discuss your application please contact the ED Society office by telephone 01242 261322 or email info@edsociety.co.uk

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