



CEDSA/ACSDE

3-247 Barr Street, Renfrew, ON, K7V 1J6 | www.ectodermaldysplasia.ca

SUPPORT FUND GUIDANCE AND POLICY

Purpose

In response to the needs of Canadians impacted by ectodermal dysplasia syndromes we support, we have established the CEDSA/ACSDE Support Fund to provide small grants to fund equipment, treatment or care needs for supporters who are affected by one of the Ectodermal Dysplasias for any of the following needs:

- Cooling garments and products;
- Dental treatment;
- Wigs/hair pieces; and
- Any other appropriate support deemed applicable by the CEDSA/ACSDE.

Who may apply?

All supporters who have a Canadian citizenship or permanent resident card and currently reside in Canada can apply. Those 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 applicants apply for?

While financial support 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; and
- 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 Association receives 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 CEDSA/ACSDE.

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

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

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

In some cases the CEDSA/ACSDE may require a letter of support from your family doctor to accompany the application form.

Grants cannot be approved either by telephone or without the Board considering a request for financial assistance at their meeting.

The CEDSA/ACSDE will notify the applicant if the application is incomplete or if any necessary documentation is missing. If, within 14 working days after notification, all missing information is not submitted as requested the application will not proceed to the Board meeting for consideration.

Criteria

Applications will be reviewed to:

- Verify the applicant meets the minimum eligibility requirements;
- Ensure the application is properly completed; and
- Verify 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.

Any funds granted will only be paid to the supplier or medical professional who provides 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 or care provider for each piece of equipment, treatment or care need or provide justification for single source purchases – this should accompany the application form.

The CEDSA/ACSDE does not endorse or promote any care or service provider – the obligation is on the applicant to ensure quality professional services are retained.

Who makes the decision to award a grant?

The Board will determine in November/December of each year the amount of money to be allocated to the Support Fund for the upcoming year.

The overall decision for the award of financial assistance lies with the Board consisting of a majority of members who are present at a meeting (quorum).

The decision of the Board will be final and not subject to appeal under the following parameters:

- 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;

- Applicants cannot apply for a grant retrospectively; and
- If grants are not used within eight weeks funding support be cancelled unless you let us know why there is a delay in ordering the equipment or having the treatment.

When do applicants 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 Board meeting.

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

The Board meets six times a year; usually in January, March, May, July, September and November.

If the application is not suitable for funding, we will inform the applicant 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 Board.

How are grants paid?

Should the applicant be successful, the executive director 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 CEDSA/ACSDE for settlement directly with the provider.

Please return the form to:

CEDSA/ACSDE
3-247 Barr Street
Renfrew, Ontario
K7V 1J6

If you would like more information or would like to discuss your application please contact the CEDSA/ACSDE by telephone 1-613-432-9491 or email meghan@ectodermaldysplasia.ca