EB Community Support Grants Policy

Summary

DEBRA Member services aim to offer a range of support grants to DEBRA members to increase quality of life and comfort of those living with EB and their close family. Budgets and details of items funded are agreed annually.

DEBRA is committed to providing a fair and accessible application procedure for the allocation of charitable community support grant funding to all DEBRA members of any age living with any type of EB.

DEBRA support grants exist as part of the DEBRA Member Services provision which offers information, support, and advocacy to anyone living with any type of EB.

Document control

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1. Policy Statement

DEBRA is committed to providing a fair and accessible application procedure for the allocation of charitable community support grant funding to all DEBRA members of any age living with any type of EB.

DEBRA support grants exist as part of the DEBRA Member Services provision which offers information, support and advocacy to anyone living with any type of EB, across the UK.

2. Purpose Of This Policy

To provide a transparent outline of what grants are offered, the application procedure and decision-making process for all support grant applications and the expenditure of funds.

3. Scope

This policy applies to all DEBRA members living with EB and should be used by colleagues working within DEBRA. Information within this document will act as guidance to all applicants.

4. Objective

DEBRA aims to provide support grants to improve the comfort and quality of life of members living with EB through a fair, clear, timely and consistent approach.

5. Policy Details

5.1 What is the purpose of DEBRA community support grants?

The DEBRA support grant fund is a limited charitable resource accessible to DEBRA members living with EB and close family members for (although not exclusive to) the following purposes: **All grants are subject to criteria being met.**

A. Standard - Urgent and EB essentials grants

Incudes: Clinic travel and accommodation grants, in-patient grant, EB essential care and equipment, emergency grants (food, school uniform etc), household grant and end of life grant

- to relieve physical symptoms and psychological stress
- to improve health with known items that may prevent the deterioration of health, provide comfort, and improve function.
- to promote and facilitate safety.
- to assist with urgent essential needs

B. Non-standard- Quality of life grants

Includes: Quality of life grant (child's buggy, mobility scooter, counselling/therapies, household flooring and adaptive technology), DEBRA event grant, DEBRA holiday/ respite break in our holiday homes, learning and employment grant

- to encourage and enable well-being, independent living and improve quality of life.

C. Limited Edition Grants – with a specific focus and funding allocation (reviewed and agreed annually and dependent on available funding)

- To offer additional opportunities when funding allows to enrich and support EB specific needs.

5.2 Available funding

5.2.1 The three categories of support grants are financed through charitable funding. The amount available for EB community support grants may vary each year depending on funds available.

5.2.2 Any expenditure relating to a member will be allocated to the support grant budget as it is charitable expenditure.

5.2.3 We will ask members to give us an idea of their financial circumstances to help us make decisions.

Some items may be targeted for members who are on a lower income. These are usually general household goods and not those that improve health or comfort. (See appendix updated annually).

We will not routinely ask for proof of income but will on occasion ask to see evidence that a family is on a low income for example if they have asked for a lot of grants for general items or costs. Everyone is assessed on their own merit with the impact the grant may make, their personal circumstances, previous funding and the availability of funding taken into consideration. The DEBRA support grants are not a means of funding financial shortfalls due to any changes in welfare provision, such as stoppage of DLA or PIP. However, we will consider a one-off contribution if someone is in extreme financial crisis.

5.2.4 Budgets will be set each year, and only in exceptional circumstances will these be exceeded, for example, if urgent need arises and funds are available within DEBRA. Such applications will be discussed with the Director of Members Services and DEBRA's CEO.

5.2.5 Grants available with information that includes criteria and typical offer are communicated on our website and reviewed annually. See Appendix updated annually.

5.2.6 Each EB Community Support Manager will have a remit to authorise standard grants up to an annually agreed amount. All other grant decisions are made at a panel of experienced senior Member Services colleagues. An urgent panel will be called if a timely decision and action is required in the event of essential /urgent need. Information from the member including income and impact, criteria checks, recommendations from the EB Community Support Team and EB clinical team are considered to aid decision making.

5.2.7 DEBRA may have some donations that are given for a specific purpose. These are known as restricted funds. If any grant application meets the description for these restricted funds and falls within the remit of the grants policy, then these funds will be designated to fund the grant and the appropriate administration completed by the EB Community Support Team. When deciding to support a grant application, the decision-making process remains the same whether there is a restricted fund. Where possible it is preferable to have unrestricted funds so that support can be given where and when it is most needed without any restriction.

5.2.8 To allocate DEBRA funding appropriately, other existing funding should always be used where possible (e.g., Department of Work and Pensions and the National Health Service, Local Authority, sponsorship of goods by a company and other disability funding). If, however, this would mean an unacceptable delay, then a grant will be considered.

5.2.9 Trusts, companies, or individuals should not be approached directly on behalf of DEBRA to fund a support grant/funding requirement for a member of the EB community without authorisation by the Director of Member Services.

5.3 Who can apply for a DEBRA Support Grant

5.3.1 Grants are available to anyone living with EB, of any age, who is a DEBRA member. 'Living with EB' is defined as:

- an individual with EB

- a close family member
- a carer of a person living with EB
- a family member who has been bereaved:
- Non-British citizens residing and physically present in the UK, diagnosed with EB.

5.3.2 All applications need to EB related.

5.3.3 Access to grants is a benefit of becoming a DEBRA member and only available to DEBRA members unless exceptional circumstances apply (agreed by DEBRA director). Membership of DEBRA is free and can be applied for at the time of the grant application. For those who are not members, the membership registration form is to be submitted with the grant application, unless otherwise agreed by DEBRA in exceptional circumstances.

5.3.4 Grant applications are often supported by the recommendation of an EB clinical professional, a member of the DEBRA EB Community Support Team, or another health or social care professional or agency. All grant applications will be reviewed by one of the DEBRA EB Community Support Managers (if the applicant is not known to the EB Community Support Team, a manager will contact the applicant).

5.3.5 Trustees, DEBRA employees living with EB or members involved in raising awareness/fundraising will be treated the same as all other members for the grant decision-making process. Any grant that is made to a DEBRA Trustee must be declared in the annual accounts. This will be shown as the amount of grant funding received in any one year but no details of the nature of the grants will be given. Trustees must be informed of this prior to grant approval.

5.3.6 Grant applications can be made by anyone, but the person living with EB, or their guardian should be consulted and give their consent to the application.

5.3.7 The DEBRA support grant terms and conditions are available on our DEBRA website along with further information.

5.4 Decision process to authorise a grant.

5.4.1 The DEBRA EB Community Support Team will assess and make recommendations for each grant and a pre-authorised annual guidance document will be followed to award a grant directly or refer to the grants Panel. The Panel will be made up of, made up of Director of Member Services, Head of EB Community Support Team and other Head of services. Any high-cost requests over £5000 or unusual requests will be put forward to the CEO.

5.4.2 For non – standard quality of life grants and limited-edition grants, the final decision is made by the grants panel as outlined previously.

5.4.3 **Summary of criteria**

To be eligible for our grants

- You need to be DEBRA member (LINK - easy to join free lifetime scheme)
- The item/service requested is not funded/provided by statutory services e.g., local authority/NHS low income/benefit eligibility for services e.g., NHS appointment travel costs.
- We may suggest and help you apply to another grant giving charity in some circumstances.

One or more of the lists below should also apply. Note criteria may vary by item and type of grant.

A. Directly helps EB health/relieves pain and discomfort.
B. It benefits the physical and/or psychological health or safety of the EB client and/or their family.
C. it enables a person to reach a goal or opens opportunities to them in the areas of education, work, and leisure.
D. Items increase independence/function/mobility which is reduced due to EB.
E. Improves quality of life where it is reduced due to EB.
F. Basic essential everyday item needed – may be indirectly due to living with EB e.g., parent unable to work -to fund those on low income/difficult personal circumstances.
G. Indirectly improves health/quality of life e.g., vacuum cleaner (hygiene needs) cooker (nutrition needs) – to fund those on low income/difficult personal circumstances.

5.5 Summary of grants application procedure

5.5.1 All grant applications must be made on the support grant form and all grant applications (requested, approved, or not approved) are recorded on the community support grants spreadsheet (CRM when activated). Access to a person's previous applications and funding agreed will be considered in the decision-making process.

5.5.2 Applicant are encouraged to fill out the short grant request form themselves. But assistance is given if required.

5.5.3 All applications are assessed on individual merits and charitable funds available at the given time. Criteria and decision-making tools are used to help guide and ensure continuity of decision making.

5.5.4 Where a request falls outside our criteria an exception may be made if discussed with and authorised by the panel, Director of member services or the CEO.

5.5.5 All other sources of external funding must have been thoroughly explored before a DEBRA grant is awarded.

5.5.6 Where equipment has not been provided by statutory services or it is anticipated that there would be an unacceptable delay in provision DEBRA may prioritise the application.

5.5.7 A support grant may be considered to pay towards subsidised fee for members' use of the DEBRA holiday homes grant for a contribution to the costs of using the holiday home may offered for those on a low income or in difficult circumstances. (agreed annually).

5.5.8 Examples of items/activities not usually funded by DEBRA.

Retrospective funding of goods/activities/any cost where funding has not been formally agreed by DEBRA. All applications require a signed support grant form from an EB Community Support Manager or The Head of Community Support Team / Director of Member Services.

DEBRA does not normally fund:

- payment of ongoing household bills/rent
- legal costs
- full funeral costs
- when funding has already been issued by DEBRA, or another agency when DEBRA is aware of other funds that have been made available to the applicant.
- when previous DEBRA support grants have been used inappropriately

Exceptions to the above may be one-off crisis help (amount confirmed annually with decisions made by the grants panel) where extreme financial difficulty means families may not eat or their health is in danger due to low funds. This one-off payment gives the EB Community Support team time to sign post to specialist organisations and local help and assist with maximising finances through benefit checking etc.

5.6 DEBRA activity and events grants

5.6.1 At the start of each year a budget may be set, if any, and allocated to DEBRA activity and events grants for known/planned events.

5.6.2 Any member living with EB may apply for a grant to attend a DEBRA activity or event as guest/attendee, for example an Annual Dinner or a gala ball. A support grant form must be completed. Note: If DEBRA asks a member to attend an event to perform a specific role no grant application required and the directorate responsible for the event will incur the costs and make any arrangements with the member.

5.6.3 The opportunity to apply for a grant for DEBRA activity and events grant will be communicated by member e-mail, on the website and otherwise publicised as appropriate.

5.6.4 The Membership Team will keep a record of applications and interest in attending future events.

5.6.5 The decision to allocate a grant may be made on criteria such as the number of tickets or funding available, the number of members applying, previous attendance of events and previous grants awarded.

5.6.6 The Membership Manager will liaise directly with the event manager and the member concerned to ensure all necessary arrangements are made; this may include event tickets and may or may not include transport and accommodation.

5.6.7 Note: If DEBRA asks a member to attend an event to perform a specific role no grant application required and the directorate responsible for the event will incur the costs and make any arrangements with the member.

5.7 What if a grant is declined by DEBRA?

5.7.1 If a grant is not authorised by DEBRA, where possible the EB Community Support Team will signpost applicants to other agencies that may be able to assist. For example, this may include other charitable organisations that specialise in funding holidays and wish lists.

5.7.2 The applicant will be notified by either the nominated EB Community Support Manager or the Head of EB Community Support Team explaining why the application for funding has not been successful on this occasion.

5.7.3 A Member can appeal the decision and supply additional supporting evidence to the EB Community Support Manager. Where a member feels that a satisfactory outcome is not achieved, they can request an appeal to be forwarded to the panel which includes the Director of Member Services.
The DEBRA complaints process can be followed if a member has followed the above process and is not satisfied with the response.

5.8 How to make an application for a DEBRA support grant

5.8.1 Once a completed grant application form is received or a grant request is made, the individual's EB Community Support Manager will aim to respond within a week and a decision should be made within two weeks. Emergency and urgent grants will aim to be processed within 2 days. Some grants will be discussed with the Head of Community Support Team or Director of Member Services. For larger amounts of funding or exceptional circumstances the grant will be discussed with the Director of Member Services and grants panel before the decision is made to authorise or decline a grant application. Grants that need to go to panel may take up to 6 weeks for decisions to be made.

5.8.2 If an urgent grant request is made and a timely response is not received, then the EB Community Support Team should be contacted **communitysupport@debra.org.uk or ring 01344 577689 or 01344 771961 (select option 1).**

5.8.3 The EB Community Support Manager will access the request against the criteria outlined within this policy and information recorded.

5.8.4 Grants must be authorised before any expenditure. For emergency grants, verbal authorisation from the EB Community Support Manager or Head of EB Community Support Team/Director of Member Services may be sought, and a form filled out and supplied after this authorisation has been given. In the event of emergency, if none of the above can be contacted, DEBRA's Director of Finance can be called at Head Office.

5.9 Process of the support grant application

5.9.1 All support grant applications will be recorded by the EB Community Support Team.

5.9.2 Once an authorised support grant form is received, the EB Community Support Team will liaise with the DEBRA Finance team who will arrange any payments or invoices. Approval of the support grant will be documented, and applicant informed (usually by email) We will also request confirmation of receipt of goods/funding and feedback.

5.9.3 If the grant is to be paid directly to the applicant by DEBRA BACS, the EB Community Support Team must complete the DEBRA finance payment request form. All related receipts must also be attached. A purchase order will be completed by the EB Community Support Manager where relevant.

5.9.4 Where possible payment should be made directly for the item/service by the EB Community Support Team

5.9.5 Where a BACS payment is given directly to the applicant the applicant needs to acknowledge they accept the terms and conditions of the grant, and this is recorded on the database.

5.9.6 Any applications that go directly to the Senior Leadership Team or Trustees or any other team within DEBRA should be discussed with the relevant EB Community Support Manager before authorisation to ensure a clear and fair process for granting funds. This will establish whether the applicant is already receiving support from DEBRA and enable the sharing of information that may be relevant to the grant authorisation process.

6. Reporting and auditing

All records are maintained for audit purposes by the DEBRA EB Community Support Team. T.

Grant applications, both authorised and declined will be recorded on a spreadsheet (CRM support grants module when activated) and filed.

A monthly summary report will include:

- total number and cost per member granted.
- list of grants authorised.
- list of grants declined and reason for declining.

7. Confidentiality

DEBRA will act in accordance with the Data Protection Act 1998 and will not pass information relating to the applicant, grant application process or grants approved or declined on to any third party.

8. Compliments & Complaints procedure

Where a member wishes to raise a compliment, concern, or a complaint then they are encouraged to the EB Community Support Manager and/or the Head of EB Community Support Team. If a member wishes to escalate the compliment or complaint, then follow the DEBRA compliments and complaints procedure. Add link.

9. Monitoring, evaluation, and review

The Director of Member Services and the Head of EB Community Support Team will monitor the usage, value for money, effectiveness and member satisfaction with the DEBRA support grant application procedure and authorisation of grants annually. The Director of Finance will audit the authorisation and payment of grants annually.

10. Roles and responsibilities

Party / Parties	Roles and responsibilities
Head of EB Community Support Team	Oversee and manage DEBRA community support grants budget. Implement the support grants application procedure.
Panel (Director of Member Service & Head of EB Community Support Team)	Review support grant requests for non-standard grants
DEBRA EB Community Support Managers	Follow guidelines as set out in this document
DEBRA EB Community Support Team	Maintain records and process grants

11. Definitions and abbreviations

Term	Meaning
EB	Epidermolysis Bullosa
SLT	Senior Leadership Team
Member	Person living with EB or connected to someone with the condition

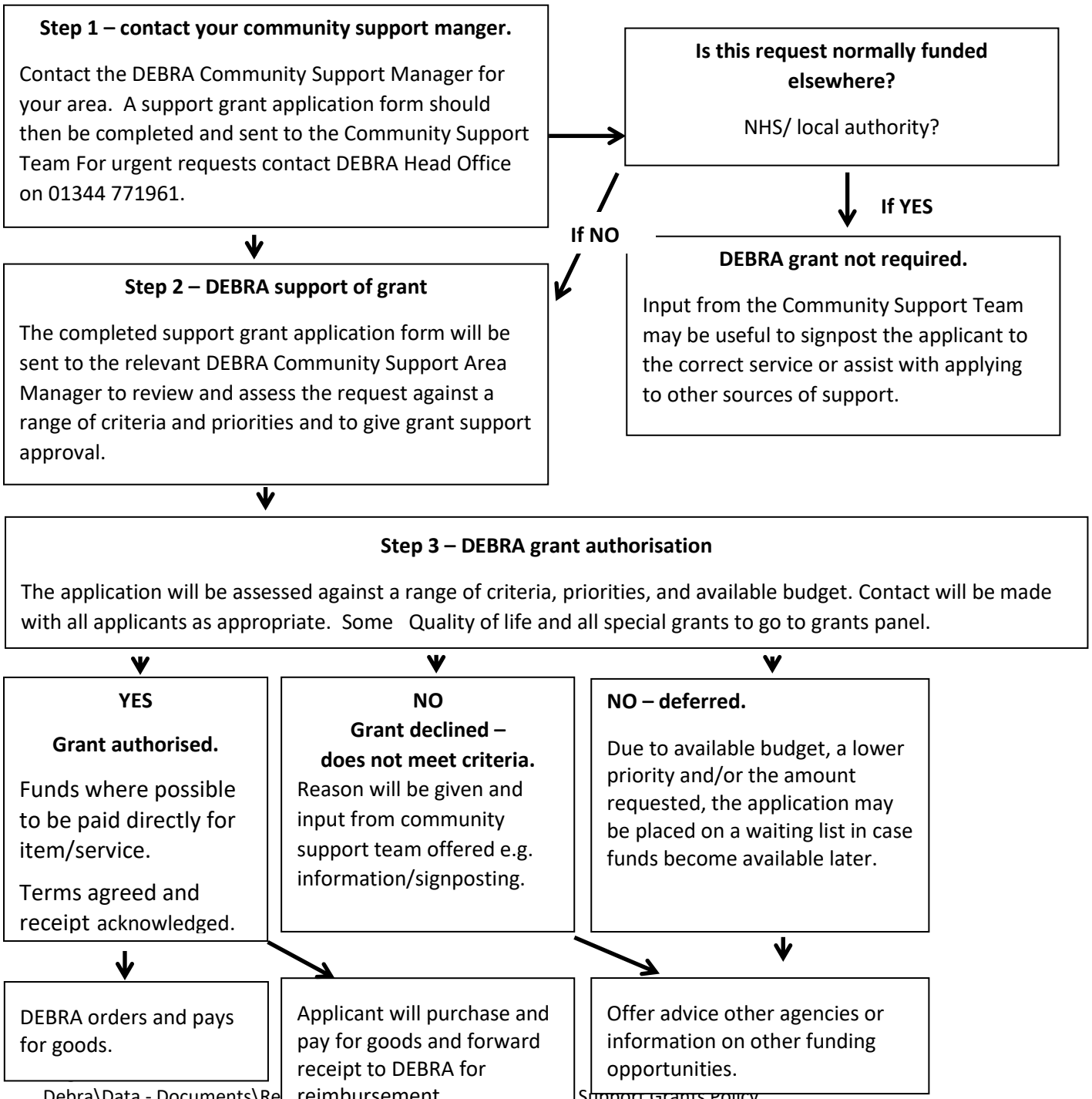
12. Policy amendments

DEBRA reserves the right to amend this policy and procedure at any time.

Sign-off

Name	Date	Signature
SLT	22.07.2025	

See meeting minutes

APPENDIX: HOW TO APPLY FOR A COMMUNITY SUPPORT GRANT

DEBRA aims to provide community support grants to enrich the lives of DEBRA members living with EB. The DEBRA community support grant fund is a limited charitable resource accessible to DEBRA members living with EB. Anybody with EB or their family can apply for a grant whether you have previously had contact with DEBRA or not. If you are not a DEBRA member, you can join free at the time of support grant application by applying online through our website at **www.debra.org.uk**.