

BUTTERFLY BREAK RESPITE GRANT CRITERIA 2022

PURPOSE:

Debra Australia works to support those living with EB and their families. A strong focus of our organisation is the emotional wellbeing of those living with EB. The Family Support Program is now in a fortunate position to offer EB families, couples, or individuals an escape for some much-needed time away. 'Butterfly Breaks' will focus on an opportunity to have quality time together, respite, relaxation, a break from hospitals, medical clinics and appointments.

WHO:

Butterfly Breaks may be accessed by:

- Individuals living with EB and their carer/partner.
- Parents and siblings who wish to have some time away together with the person with EB.
- Parents/carer/siblings of those living with EB who wish to access some respite and time away from the rigors of caring for a person with EB.

HOW:

A total of \$20,000 has been allocated to this program. These funds have been generously donated by Future Generation Australia and are granted by the DEBRA Australia Board.

In order to access the funds for a Butterfly Break, there will be an application process. As part of this process, the person/persons applying will need to specify the reason for the application, the persons attending the break and their desired location.

In choosing a location / destination, families will be asked to choose places in Australia, preferably within or close to the state they live in.

WHAT:

The grant will provide approximately 10 individuals / families with an opportunity to access funding to a maximum of \$2,000 per application. Any extra expenses are the responsibility of the recipients and additional family guests are required to fund their own expenses.

Funds up to \$2,000 will primarily support accommodation expenses for 5 – 7 days, travel expenses and / or meals for the family. A gift card will be given to the family for fuel and meal purchases. All funding will be transferred to the service provider or reimbursed to the family upon receiving a receipt of purchase.

APPLICATION CRITERIA:

As there is a limited number of grants, each applicant is required to submit their application via the website or link provided once advertised. This program will be advertised via social media and direct email to families. The advert will stipulate the aim / purpose of the respite program, the criteria / eligibility of who can apply and the application process involved.

Application criteria include:

- Emotional and physical wellbeing of person living with EB.
- Emotional and physical wellbeing of person living with EB and their partner.

- Emotional and physical wellbeing of primary carer/guardian/parents/partner of those living with EB.
- Impact on family life of the daily routines of living with EB.

CONDITIONS:

- Only one application per EB individual and/or their family / carer may be submitted.
- If successful, members of this EB family cannot apply again for a 2-year period.
- Any person who has accessed DEBRA funded respite in the last 12 months cannot apply for a 'Butterfly Break' grant for a 2-year period (excluding EB camps).
- Individuals living with EB, 18 years of age and over, can apply for a 'Butterfly Break' in conjunction with their primary carer / partner.
- Individuals living with EB who are under 18 years of age, can apply for a 'Butterfly Break' including immediate family members but, excluding family members who have previously accessed DEBRA funded respite in the last 12 months.
- Siblings / family members are not eligible to apply for funding if they are not directly involved regularly with the care of an individual with EB.
- Bereaved families are eligible to apply for a 'Butterfly Break' for a period of 12 months after the passing of their loved one.

TIMETABLE:

Applications will close July 31, 2022. Decisions will be reached, and successful applicants notified by August 26.

- EB families will have the choice to select their preferred destination of travel.
- Successful applicants are required to book and pay for travel prior to December 31, 2022. DEBRA's Family Support Coordinator can assist the family if needed with accessing suitable accommodation in that chosen area.
- Travel can be taken in 2023 if preferred, however payment must be arranged prior to December 31, 2022.

CONSIDERATIONS:

- Any family that is awarded a Butterfly break grant will only be considered for another one after two years. In this way, DEBRA can ensure that various families can access the grants in an equitable manner.
- Applicants will need to complete a written application for Butterfly Break grants.
- The Family Support Committee will work together to allocate the grants according to need and individual family circumstances and the suitability of the proposals received.
- The FS Coordinator will provide advice regarding family circumstances, physical wellbeing, emotional wellbeing, and nature of the break to assist decision making.
- Families who access a 'Butterfly Break' must be willing to share their experience with sponsors by providing feedback and photos about their break. Information provided may be shared on various social media platforms.
- The 'Butterfly Break' program will be reviewed in early 2023 and may be modified for future years if required.