NORD®
National Organization for Rare Disorders



EVA'S BUTTERFLY WISHES® FOR RARE CHILDREN

SPECIAL PROGRAM

What is the purpose of this program?

Eva's Butterfly Wishes® for Rare Children opened thanks to a donation from the Eva Juneja Foundation®. Eva's parents created the organization to give hope and respite to other families, like theirs, affected by Walker-Warburg Syndrome (WWS). Since its inception, the program has been expanded to support other children and families impacted by rare, life-limiting diagnoses beyond WWS.

In navigating life with a rare and terminally ill child, the Juneja family often felt isolated. In striving to make Eva's short life rich and full, they endeavored to create special experiences with her. That is the purpose of this program - to give rare diagnosed children their own butterfly wish, an experience designed especially for them that enhances their quality of life.

Who is eligible for this program?

- Individuals must be diagnosed with a rare, progressive, or severely debilitating life-limiting rare diagnosis and be 5-years of age or under at the time of application.
- Are US citizens or US residents of six (6) months or greater.
- Meet the program's financial eligibility criteria.

What is the application process?

- Families of rare children under the age of 5-years (at the time of application) may contact NORD directly for information.
- Clinicians treating rare pediatric patients may refer these families to the program.
- A NORD Patient Services Representative will guide the applicant through the application process and verify eligibility for inclusion in the program.
- Awards are based on meeting eligibility criteria and funding availability and are made on a first come, first serve basis.

What is NORD?

NORD, the National Organization for Rare Disorders, is a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

NORD was founded by families struggling to obtain access to treatments and whose advocacy for change led to the passage of the Orphan Drug Act in 1983. NORD assists eligible patients (those with medical and financial needs) in affording the treatments and medical services their healthcare professionals have prescribed.

Alone we are rare. Together we are strong.®

How do I get more information and apply?

Contact NORD

Monday-Thursday 8:30 am – 7:00 pm ET
Friday 8:30 am – 6:00 pm ET

877.291.7813

203.571.3189

EvasButterflyWishes@rarediseases.org

The quickest way to apply is on NORD's website at: bit.ly/patient-assist then scroll down to Eva's Butterfly Wishes Experience for Rare Children and click Apply Online

About the program

Eva's Butterfly Wishes® provides a child-centric quality of life experience designed specifically for the diagnosed child. Grants provided through this program may cover costs up to $2,500 per family.

Butterfly wishes:

- Focus on the child diagnosed with a rare disease/rare disorder and are consistent with the child's age and physical and cognitive abilities
- Include the diagnosed child and his/her immediate family
- Are not related to medical appointments, diagnostics or treatments
- Must be experiences based in the United States

Awards may cover (examples only):

- Admission cost to an event, site or experience such as a boat ride, zoo visit, park or farm
- A home visit from a costumed character
- Special dining experience to a themed restaurant (for children for whom this may be appropriate)
- Ground transportation such as car service, handicapped accessible van transportation to an event or destination

Why participate in this program?

For Fahr and Jamie Juneja the sheer delight their daughter, Eva, expressed when she was able to pet and ride a horse with them was invaluable. Eva's giggles and smiles as she wriggled her tiny toes in the sand at the beach provided so much joy for her family. Experiences like these enhanced Eva's all-too-short life and provided cherished memories that the Juneja family hold dear.

If you or someone you know has a child with a life-limiting rare diagnosis, we hope you will use this program to create your own precious experiences and memories with your loved one.



Eva Juneja

rarediseases.org

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