EVA'S BUTTERFLY WISHES FOR WALKER-WARBURG FAMILIES

What is the purpose of this program?

Eva’s Butterfly Wishes for Walker-Warburg Families program 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).

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 WWS diagnosed children their own butterfly wish, an experience designed especially for them that enhances their quality of life.

Walker-Warburg Syndrome (WWS)

WWS is a devastating rare disease associated with congenital muscular dystrophy and includes abnormalities of the muscles, brain and eyes. Unfortunately, children with this disease face a shortened life expectancy. There is no cure for WWS and treatment is palliative in nature. With this in mind, quality of life becomes an integral consideration in care.

Who is eligible to apply?

This program is designed to help patients who:

- Have a diagnosis of Walker-Warburg Syndrome
- Are US citizens or US residents of six (6) months or greater
- Meet the program’s financial eligibility criteria

Families with a child diagnosed with Walker-Warburg Syndrome may contact NORD directly for information. Clinicians treating Walker-Warburg patients may refer these families to the program.

NORD is Here for You

NORD, 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.
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 WWS, we hope you will use this program to create your own precious experiences and memories with your loved one.

About the program

Eva’s Butterfly Wishes for Walker-Warburg Families 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 WWS 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

Eva Juneja