### **Edwards Syndrome**

Edwards Syndrome, also known as Trisomy 18, is a rare genetic disorder caused by the presence of a third copy of all or part of chromosome 18. This causes abnormal development in many of the baby's organs. About 1 in every 6,000 babies is born with Trisomy 18, and most are female.



Babies who survive birth usually die within their first month of life. Only five to 10 percent of children with Trisomy 18 live past their first year of life but with severe intellectual disabilities.

#### **Contact Us**

P.O. Box 6391

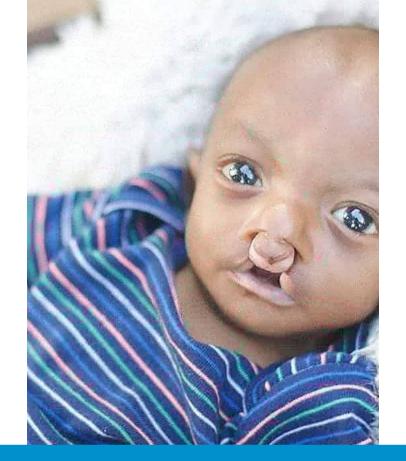
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## **Our Mission**

To support families affected by Edwards Syndrome, Trisomy 18, while changing the medical perspective through efforts of advocacy, education, and public policy.



# **Our Why**

We believe early access to diagnostic therapies can create better outcomes for chronically ill infants. We believe patients with chronic illnesses should have immediate access to quality healthcare, medical resources, social services and rare disease management, without prejudice.

### **LEAP**

LEAP is an educational resource program promoting health literacy, community education, and patient advocacy. The LEAP program focuses on optimizing health to improve the overall well-being of individuals, families, and communities.

## ZEBRA

**ZEBRA** is an end-of-life solutions program providing support to families facing infant & child loss due to Edwards Syndrome. **ZEBRA** offers intervention, counseling, and bereavement resources to assist with addressing these needs.

## **STRIPE**

stripe is a financial assistance program designed to help with out-of-pocket medical expenses due to the high cost associated with specialized medical care. Families facing economic hardship due to Edwards Syndrome may request assistance.