

Financial Burden Research Project

2021 Financial Literacy Data Report



E.WE Foundation

A Healthcare Advocacy Organization

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WHO WE ARE

The E.WE Foundation is a 501(c)(3) healthcare advocacy organization established in 2019 to raise awareness about Edwards Syndrome, commonly known as Trisomy 18, a rare genetic chromosome abnormality affecting 1 in 5,000 live-born births.

MISSION

Our mission is to support families affected by Edwards Syndrome, commonly known as Trisomy 18, while changing the medical perspective through efforts of advocacy, education, and public policy.

VISION

Our vision is for all families affected by Edwards Syndrome, Trisomy 18, to have equitable access to quality healthcare, early intervention, and social services.

VALUES

We believe patients with chronic illness like Edwards Syndrome, Trisomy 18, should have immediate access to quality healthcare, medical resources, and economic support, without bias or prejudice.



WHY IS THIS PROJECT IMPORTANT?

Financial literacy in the context of health involves the ability to assess, understand, and use financial information in ways that support good health and financial outcomes. The study identifies an urgent need to explore research opportunities, enhance awareness, and improve access to diagnoses, treatment solutions, and overall quality health.

CONTRIBUTING DATA

A study conducted by the [EveryLife Foundation for Rare Diseases](#) concluded that the estimated economic cost of 379 rare diseases reached nearly \$1 trillion in the U.S. in 2019. To generate the data for this study, EveryLife identified both direct medical costs, via an analysis of claims data, and indirect and non-medical costs, via a survey (The Rare Disease Impact Survey) of 1,399 members of the rare disease community.

PROJECT OBJECTIVES

- To assess the financial burden associated with a Trisomy 18 diagnosis
- To explore individualized financial concepts
- To identify whether early access to financial education and resources can contribute to proactive planning for families living with medical complexities
- To identify whether access to financial concepts can contribute to lower out of pocket expenses by proactively preparing for a Trisomy 18 diagnosis.

WHAT IS EDWARDS SYNDROME?

Edwards Syndrome, Trisomy 18, is a rare genetic disorder caused by the presence of a third copy of all or part of chromosome 18 which causes abnormal development in many of the baby's organs. About 1 in every 5,000 live-born babies is born with Trisomy 18, and most are female.

About half of babies who are carried full-term are stillborn. Boys with Trisomy 18 are more likely to be stillborn than girls. 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.



There are three types of Trisomy 18:

- Full Trisomy 18. The extra chromosome is in every cell in the baby's body. This is the most common type of Trisomy 18.
- Mosaic Trisomy 18. The extra chromosome 18 is only in some of the baby's cells. Approximately 5% of individuals born with Trisomy 18 will carry this type. This form is also rare.
- Partial Trisomy 18. Affected individuals have two copies of chromosome 18, plus the extra material from chromosome 18 (part of the long (q) arm) attached to another chromosome. This type of Trisomy 18 is very rare.

Women of all ages can have a child with Trisomy 18, however the chance increases as a woman gets older. A first trimester screening that includes a blood test and ultrasound offers early information about a baby's risk of having Trisomy 18. A second trimester blood test called a quad screen can also aid in early detection. More precise methods take cells from the amniotic fluid (amniocentesis) or placenta (chorionic villus sampling) and analyze the chromosomes to confirm diagnosis.

The E.WE Foundation's Financial Burden Project received twenty participant responses. Eighty-five percent received their child's Trisomy 18 diagnosis in utero. **The E.WE Foundation believes early detection and access to therapeutic treatment solutions can create better health outcomes for baby's diagnosed with Trisomy 18.**

Eighty percent of the families surveyed report having a child with Full Trisomy 18; 70% of these children are still living. Five percent report having a child with Partial Trisomy 18 and 5% report having a child with Mosaic Trisomy 18. Ten percent of the families surveyed do not know which Trisomy 18 type their child has. The median age is 1 year old and the majority are female.

The median total family annual income for those surveyed is \$75-\$100K. Most of the families have checking and savings accounts, retirement and investment accounts, and life insurance. Sixty percent are single income families, 35% have two incomes (either 2 full-time positions or 1 full-time/1 part-time positions), and 5% are unemployed. It is important to note that majority of the families with annual incomes of \$0-\$50K report they do not have a bank account or they only have a checking and/or savings account. Additionally, families with an income of \$0-\$50K report not having private payor health insurance, life insurance, or retirement and/or investment accounts.

Living with a rare disease like Edwards Syndrome or caring for someone with a rare disease can sometimes create unforeseen challenges. Household finances can be negatively impacted if you or your caregiver lose wages from time off work or are unable to find employment with flexible leave or affordable health insurance. Fifty percent of those surveyed report having to stop full time and/or part time work to care for their Trisomy 18 child. Many have been unable to return to work.

Families living with Trisomy 18 have an extensive list of medical needs. They generally see several doctors, have multiple tests, and have specialized medical needs including nutrition support, durable medical equipment, and therapeutic services.

Eighty-three percent of those surveyed report having private payor insurance, though many of the services needed for Trisomy 18 individuals may not be covered by private payor insurance alone. This is important to note because 40% of those surveyed report not having supplemental coverage like Medicaid. This could potentially lead to care coordination "negotiations" where the cost associated with therapies, equipment, and procedures control the level of care a child receives, even when it may not be the best plan of care. Additionally, patients may be more prone to miss appointments due to unexpected costs or difficulty in accessing medical resources. Sixty-five percent report experiencing this difficulty and another 42.1% report having missed or canceled appointments due to their worry about potential costs.

Though health insurance companies are starting to implement strategies such as managed care plans, cost sharing, tiered-services, and benefit reductions, these strategies tend to save cost for health systems while increasing costs to individuals.

The financial burden associated with caring for an individual with Trisomy 18 includes:

- durable medical equipment needs
- medical travel
- physician costs
- prescription costs
- daycare and childcare needs
- COVID-19

Fifteen percent report having no negative impacts or financial burden since receiving their Trisomy 18 diagnosis.



The E.WE Foundation believes early detection, access to early intervention, and therapeutic treatment solutions can successfully contribute to the overall quality of life of individuals' diagnosed with Trisomy 18. Bridging the gap between diagnosis delivery and care coordination starts with respecting the family's desired health outcomes for their child; which should also include access to social services, and medical and financial awareness. Ninety percent of those surveyed agrees, however only 40% were connected with hospital personnel and subspecialty providers.

The families surveyed believe there is *still* a direct need for the following:

- education & advocacy resources for families living with Trisomy 18 and children with special health needs
- disease education and resource listings for public school systems
- Trisomy 18 studies
- information for accessing SSI
- respite care
- parent/caregiver retreats
- self care programs (for parents)
- counseling
- sibling support group(s)
- economic assistance for parent doctor's appointments
- childcare
- prenatal classes

CONCLUSION



STRIPE PROGRAM

Understanding the financial burden associated with caring for a medically complex individual, the E.WE Foundation created and implemented STRIPE, an economic assistance program for families facing financial hardship due to Trisomy 18. Applications can be submitted from our website. Sixty percent of the families we surveyed report financial hardship due to Trisomy 18 in the past. Fifty-five percent report experiencing financial hardship currently.

LEAP PROGRAM

LEAP is a resource program promoting health literacy, community education, and patient advocacy. This program was developed to eliminate [some of] the challenges that comes with accessing information. LEAP focuses on optimizing health and social service access to improve the overall well-being of individuals, families, and communities. LEAP is an approved Continuing Education Provider.

ZEBRA PROGRAM

ZEBRA is a comfort care & end-of-life solutions program that supports families living with life-limiting diagnoses, medical complexities and special health needs. Our comfort care program addresses physical comfort, daily care, mental, emotional & spiritual support. ZEBRA can assist with resources, intervention, counseling, and bereavement support.

HOW ARE WE HELPING?

NEXT STEPS

**Next step research initiatives will not be publicly shared at this time. This information has been shared with our research partner and project management team but withheld from the published report.*

Post-research objectives:

- All participants will receive compensation for completing the survey.
- All participants will receive an E.WE Foundation participant "thank you" package.
- 55% of the families surveyed report current financial hardship. All of these families will receive an additional monetary gift on behalf of our STRIPE program.
- We will host a financial advocacy & education webinar once the survey results are shared. All participants will be invited to attend.

REFERENCES

Financial Literacy and Navigation In Rare Disease. Global Genes.
<https://resource-hub.globalgenes.org/>

The National Economic Burden of Rare Disease Study. EveryLife Foundation for Rare Diseases.
<https://everylifefoundation.org/burden-study/>.

The E.WE Foundation. A Healthcare Advocacy Organization.
<http://www.theewefoundation.org>

U.S. National Library of Medicine. Medline Plus.
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