Navigating Trisomy 18

A Financial Burden Impact Report

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E.WE Foundation
A Healthcare Advocacy Organization

Overview

Families caring for children with Trisomy 18 (Edwards syndrome) often face overwhelming emotional, medical, and financial challenges. To better understand the hidden costs of this rare condition, The E.WE Foundation conducted the **Financial Burden Impact Project** in partnership with Global Genes (2021).

This study gathered data from families across the United States, highlighting out-of-pocket costs, insurance gaps, and the long-term financial strain of rare disease care. These findings continue to guide our advocacy, family support programs, and professional collaborations.

Study Snapshot

- **Year Conducted:** 2021
- **Led By:** The E.WE Foundation in partnership with Global Genes
- **Participants:** 25 families of children diagnosed with Trisomy 18 (Full, Partial, or Mosaic)
- **Diagnosis Timing:** Majority were diagnosed *prenatally*; some received diagnosis at or after birth
- **Method:** Online survey with quantitative and open-ended questions
- **Focus Areas:**
  - Out-of-pocket medical costs
  - Insurance barriers and denials
  - Indirect impacts (lost income, reduced work hours)
  - Support needs
- **Limitations:** Small, self-selected sample; findings may not represent all Trisomy 18 families

Key Findings

1. Out-of-Pocket Medical Costs

- **92%** of families reported significant out-of-pocket costs for medical care, travel, and adaptive equipment.
- Frequent expenses included feeding supplies, adaptive seating, bath chairs, durable medical equipment, and prescription co-pays.
- One parent shared:

> ***“Therapeutic seat, bath seat, and anything with the word ‘adaptive’ in front of it seems to not be covered by insurance.”***

2. Insurance Barriers

- Families reported **frequent denials of coverage**, often justified by the harmful label “incompatible with life.”
- Many caregivers described spending hours navigating appeals, delaying critical interventions.
- A participant explained:

> ***“Thousands of dollars in medical bills … now it has gone to my credit which made buying a house more complicated.”***

3. Indirect Financial Burdens

- **Over half of families** reported reduced work hours or job loss to provide full-time care.
- Several parents noted loss of employer-sponsored insurance due to leaving work.
- Travel to specialty centers created additional burdens:

> ***“Gas to get to appointments was a struggle.”***

4. Long-Term Impacts

- Families reported medical debt, credit impacts, and the need to rely on charitable support.
- Some bereaved families faced unexpected funeral costs, compounding financial stress.
- Emotional and mental health strain linked to financial pressures was a recurring theme.

Broader Context

The **EveryLife Foundation for Rare Diseases (2019)** estimated the U.S. economic burden of rare diseases at **$966 billion annually** across 379 conditions. Trisomy 18 families experience these same pressures at the household level, where the financial strain is immediate and personal.

Implications

For Families:

- Financial stress is not uncommon and does not reflect a personal failing.
- Support is available through charitable giving, state programs, and nonprofit assistance.

For Professionals:

- Financial strain must be recognized as a **health equity issue**.
- Providers, social workers, and care teams should proactively connect families to resources.

What’s Next

The E.WE Foundation is committed to:

- Expanding **STRIPE**, our charitable giving program for Trisomy 18 families.
- Advocating for **insurance reform** to address diagnosis-based denials.
- Providing **financial literacy resources** tailored to rare disease families.
- Continuing research to measure long-term financial and psychosocial impacts.

Conclusion

The **Financial Burden Impact Project** amplifies the voices of Trisomy 18 families, exposing the hidden costs of rare disease care. These insights inform our advocacy, guide our support programs, and inspire systemic change.

> ***“The burden is more than financial—it affects our mental health, our relationships, and our ability to just be present with our children.”*** **– Parent Participant**