

One Mother's Journey Toward Advocacy and Leadership

**Amplifying Patient
Voices to Shape
Journalism and Justice**

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Our Story: Speaking for Elijah

- Diagnosis with Trisomy 18
- Early prognosis and family challenges
- How personal experience sparked advocacy



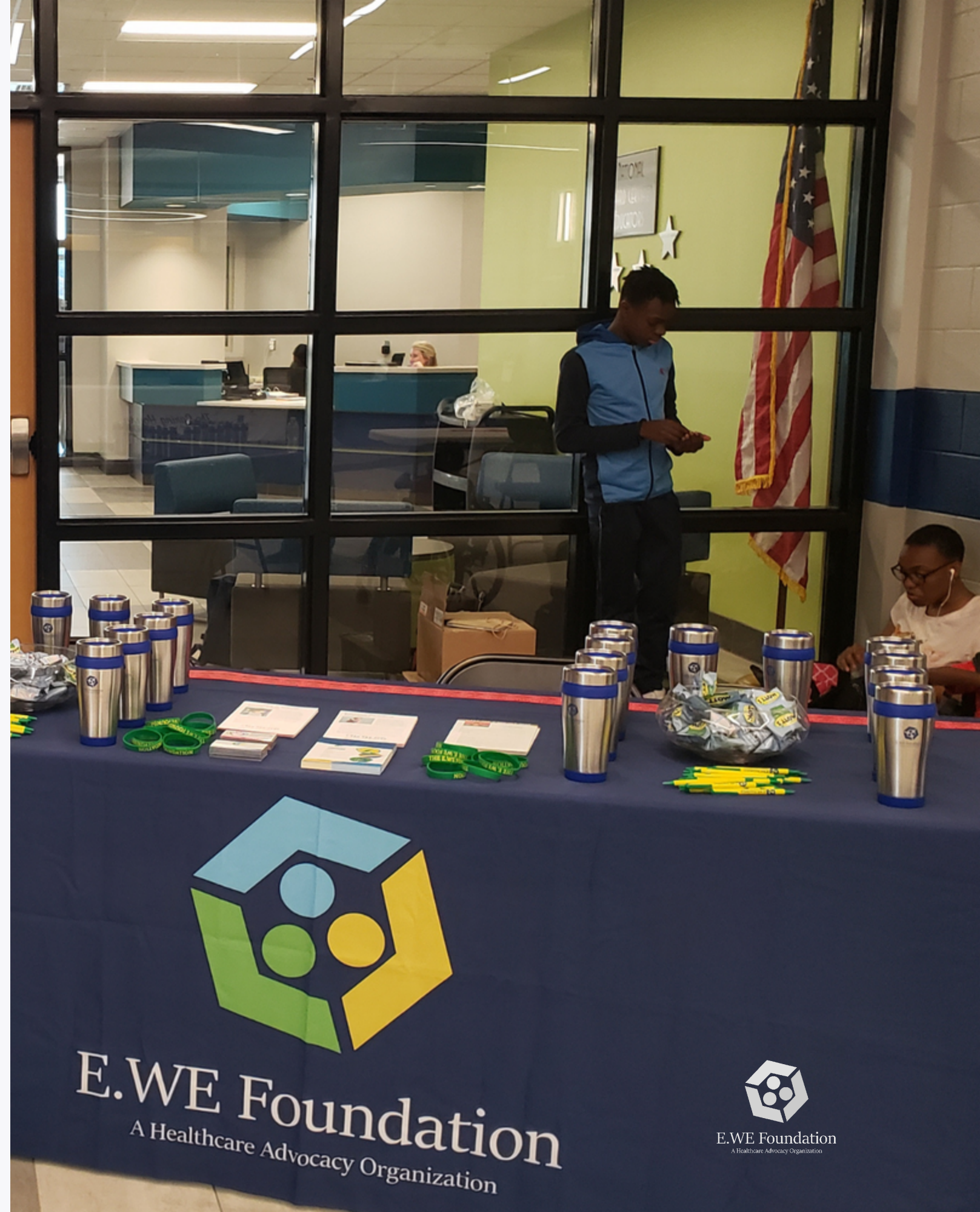
Why Patient Stories Matter

- Humanize data and statistics
- Illuminate disparities in healthcare and society
- Inspire action in policy, research, and clinical care



Advocacy as Leadership

- Advocacy evolves into leadership
- Leading through lived experience
- Lived experience builds credibility
- Leadership is about service and impact



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Journalism's Role in Amplifying Patient Voices

- Center patient experiences in reporting
- Amplify voices responsibly
- Balance empathy with accuracy



Stories Influence Clinical Decisions

- Patient voices guide care
- Stories provide context beyond charts
- Inform personalized treatment decisions
- Example: Elijah's care decisions shaped by storytelling

Stories Drive Research

- Lived experience shapes scientific inquiry
- Identify gaps in rare disease research
- Influence research priorities
- Engage the public to support studies and funding

Stories Inform Policy

- Journalism as a catalyst for justice
- Media coverage shapes legislation and funding
- Amplified stories reach policymakers
- Example: Newborn screening legislation in Alabama

Technology, AI, and Storytelling

Enhancing Reach Without Losing Humanity

- AI and technology accelerate research and reporting
- Identify trends and patterns in large datasets
- Patient stories contextualize AI insights and maintain empathy





Equity and Access

- Address disparities in healthcare and research
- Represent marginalized and underserved communities
- Ensures every voice is heard
- Journalists act as equity leaders through inclusive storytelling



Lessons Learned from Advocacy

- Storytelling fuels leadership
- Leadership grows from lived experience
- Stories inspire systemic change in care, research, and policy
- Collaboration amplifies impact

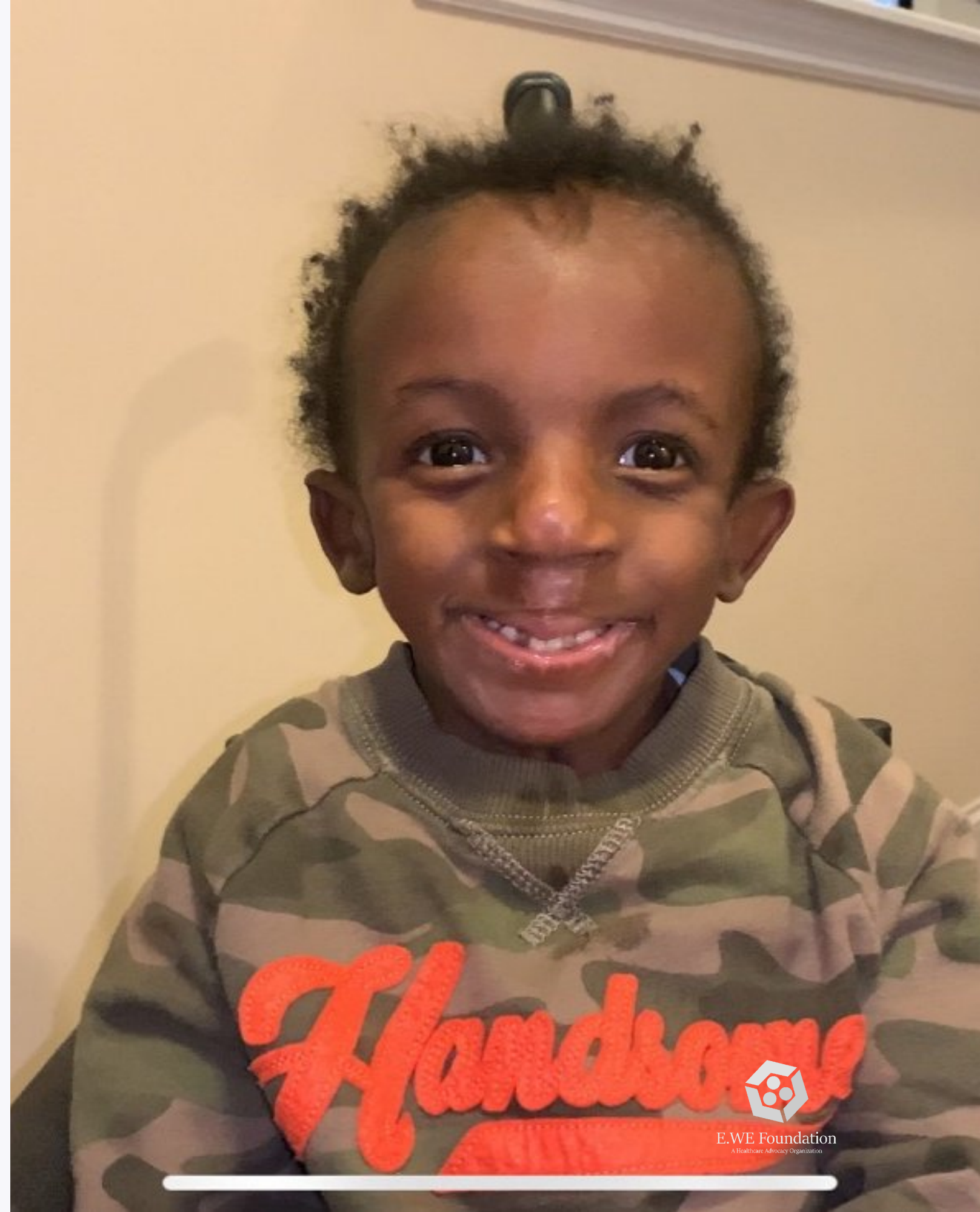
Practical Tips for Journalists

- Amplify patient voices responsibly
- Build trust and long-term relationships with patient communities
- Center patient priorities and context
- Balance impact with ethics
- Stories inform clinical care, research, and policy



Every Story Has the Power to Drive Justice

- Patient voices shape care, research, and policy
- Journalists help the public understand the human stakes
- Stories transform awareness into action



Thank You

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