

# Bridging the Gap: A Unified Cross-DEE Strategy to Accelerate Education, Research, and Advocacy for Developmental and Epileptic Encephalopathies

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## A Multidimensional Strategic Framework

To ensure the DEEP strategic plan reflecteutilizedd the true needs of the DEE ecosystem, DEEP a rigorous, 10-month collaborative framework:

•**Strategic Launch (Summer 2025)**

Convened a multi-stakeholder summit including families, clinicians, researchers, and industry leaders to identify urgent community opportunities

•**Multidisciplinary Workgroup (September 2025-June 2026)**

Established a core Workgroup that met monthly to evaluate mission impact and navigate the evolving DEE landscape. Workgroup was composed of clinicians, researchers, caregivers, patient advocacy group leaders, and other DEE relevant topic experts

•**Broad Landscape Outreach**

Engaged leading rare epilepsy and neurodevelopmental organizations to identify gaps, encourage coordination nd collaboration, and minimize duplicative efforts

•**Synthesis of the "Unified Voice"**

Distilled collective insights to develop DEEP's unique value add and landscape role

## Mission and Key Pillars

### Mission

Improve outcomes for those impacted by developmental and epileptic encephalopathies (DEEs) by driving collaborative efforts to educate and empower caregivers and clinicians, accelerate groundbreaking cross-disease research, and advocate for improved quality of life.

### Key Pillars



**1. Education & Empowerment**

Goal: Expand trusted, accessible education for families and clinicians.



**2. Accelerate Research**

Goal: Advance outcome measure development and cross-DEE research.



**3. Advance Advocacy**

Goal: Strengthen DEE representation in policy and industry.

## A Blueprint for Progress

| Expand Education and Empowerment                                                                                                                                                                                                                                                           | Accelerate Research                                                                                                                                                                                                                                                                                                  | Advance Advocacy                                                                                                                                                                                                                                                                                                  |
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| <ul style="list-style-type: none"><li>Construct a unified education front</li><li>Bridge the "Resource Vacuum"</li><li>Precision education</li><li>Cultivate a dynamic learning ecosystem</li><li>Deliver actionable Intelligence</li><li>Architect proactive caregiver advocacy</li></ul> | <ul style="list-style-type: none"><li>Synchronize Cross-DEE Efforts</li><li>Collaborate for Efficiency/Dismantle Research Silos</li><li>Target Shared Mechanisms (phenotypes, symptom clusters, bio pathways)</li><li>Develop Fit-for-purpose Metrics for the DEEs and Construct an Evidentiary Foundation</li></ul> | <ul style="list-style-type: none"><li>Develop a shared DEE Language</li><li>Unify the Collective DEE Voice</li><li>Lead with Lived Experience</li><li>Lead FDA and regulatory engagements</li><li>Establish a permanent DEE influence on the Hill</li><li>Mobilize Grassroots Action and Public Urgency</li></ul> |

## Ways to Get Involved

### Patient Advocacy Groups

Become an official DEEP partner and get involved through our Partnership Participation Pathways:

- DEEP Steering Committee
- Inchstone Steering Committee
- Education and Support Workgroup
- Cross-DEE Research Workgroup
- Advocacy Workgroup
- Co-developed and branded Webinars
- Co-branded DEEP Support Chat
- Co-developed and branded Toolkits, Guides, and Resources
- Moderate community support WhatsApp Groups
- Ecosystem Building
- Partner Proposal

### Want to learn more?

#### Schedule a time

