

Bridging the Gap and Strengthening Care Through Industry Partnerships

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Disclosures

- Neurelis, Speaker, Advisory Board
- UCB, Speaker
- UpToDate, Reviewer
- Elsevier, Contributor

763
Urinary Catheterizations

97,445
Student Visits



6,984
Insulin Doses

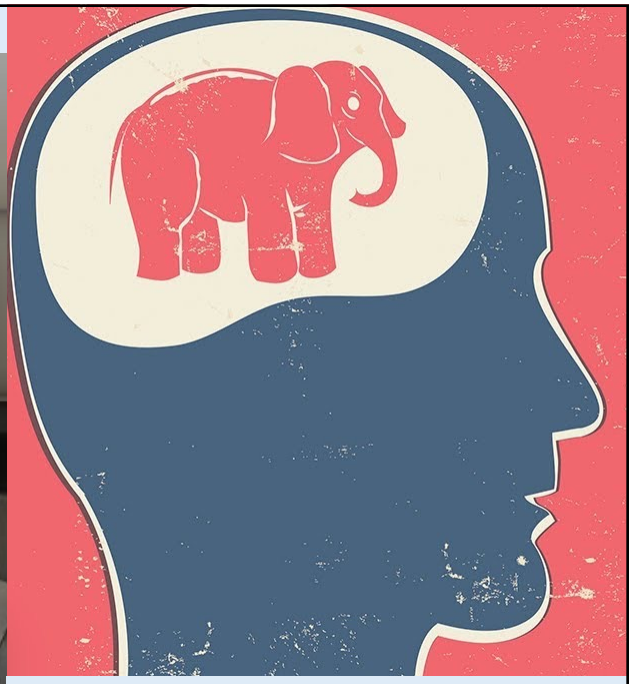
1,848
Tube Feeds

2,258
Staff Visits

Source: MCPS School Nursing Facebook Page; Interview with Diane Alley, Lead RN

The Elephant in the Room…





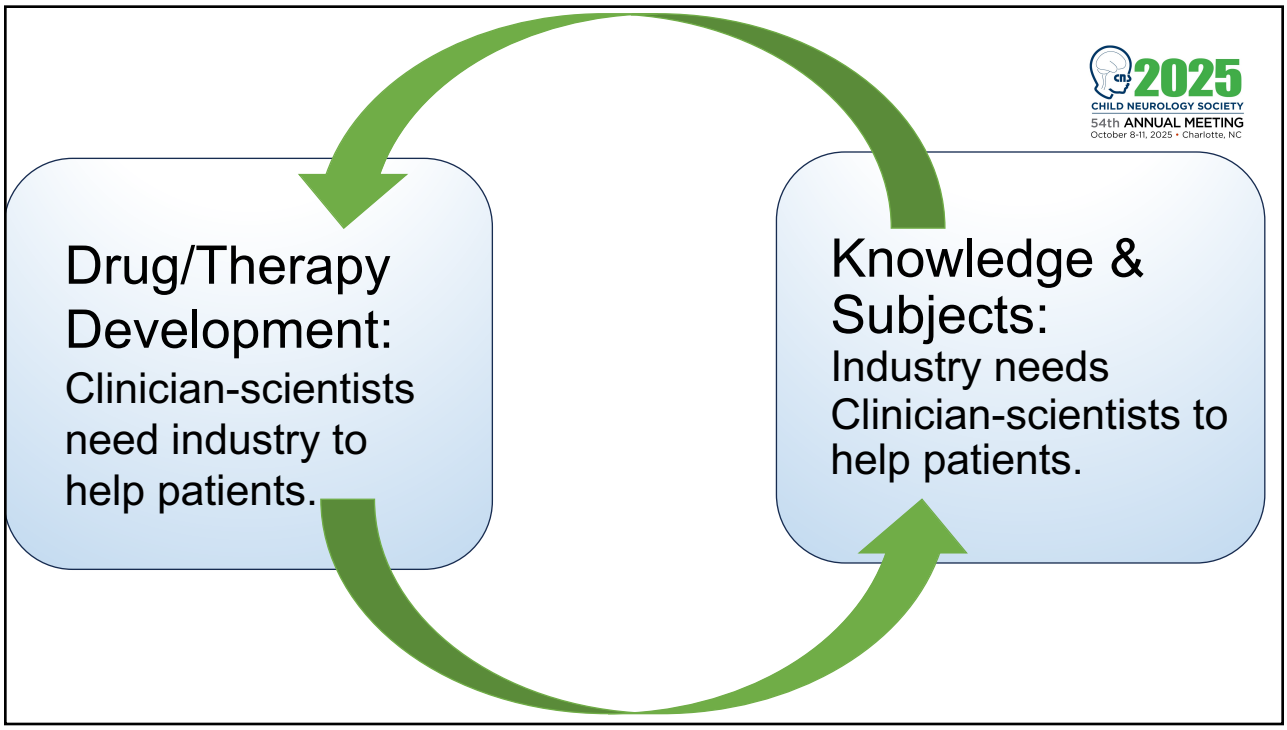
…and the The Elephant in the Brain



2025 CHILD NEUROLOGY SOCIETY
54th ANNUAL MEETING
October 8-11, 2025 • Charlotte, NC

Industry

Clinicians



All in Pursuit of Novel Therapies

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- Patient Advocacy Organizations
- Regulatory Agencies
- Industry
- Academia
- Nonprofit Organizations

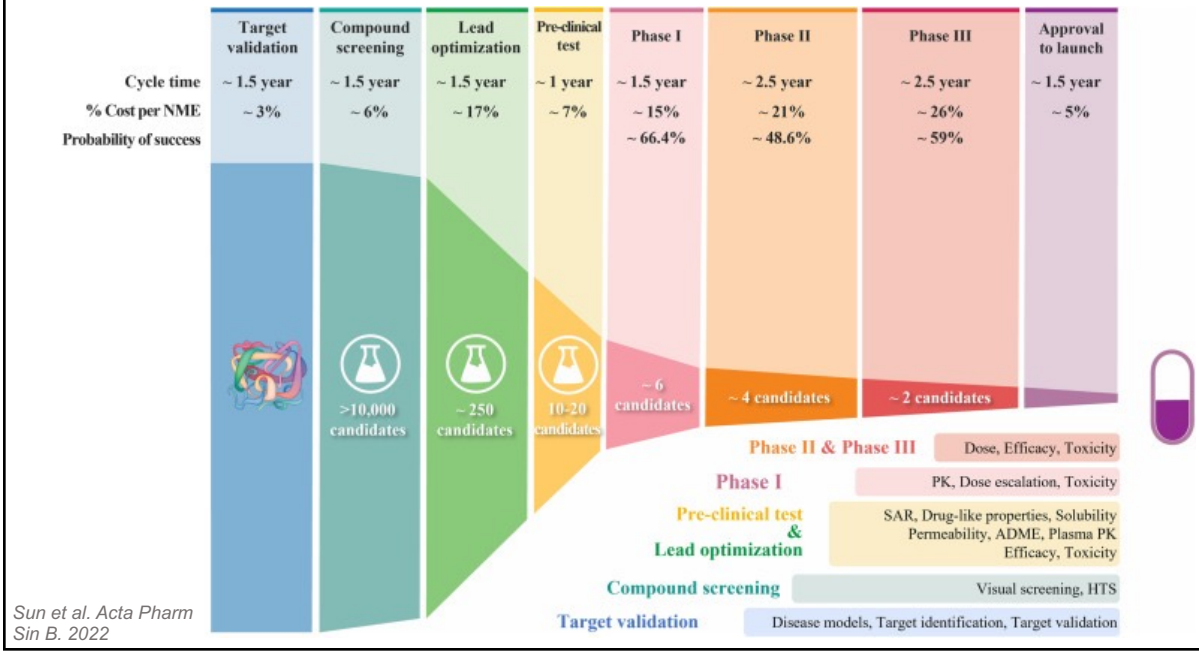
The scale and complexity of today's biomedical research problems increasingly demand that scientists move beyond the confines of their own discipline and explore **new organizational models** for team science…. **novel partnerships**, such as those between public and private sectors, will be encouraged to accelerate movement of scientific discoveries from bench to bedside.

-Elias Zerhouni, NIH roadmap (2003)

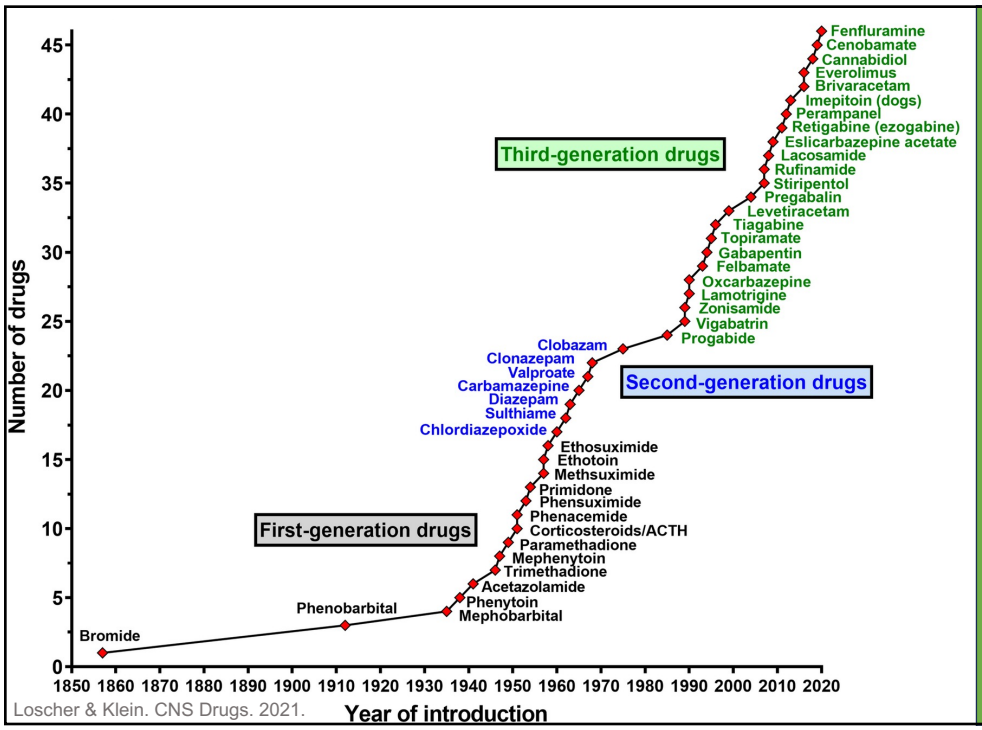
Clinicians Partner Across All Sectors



Drug Development Takes Time & Money

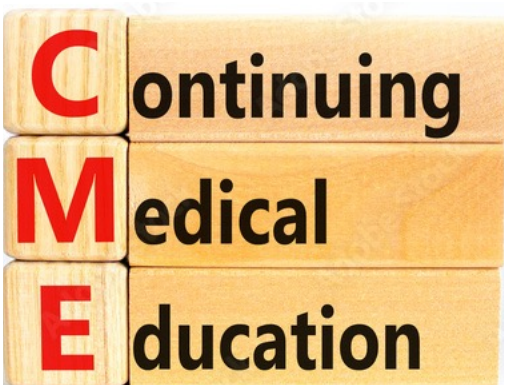


Sun et al. Acta Pharm Sin B. 2022



New seizure treatments increased exponentially in the last four decades.

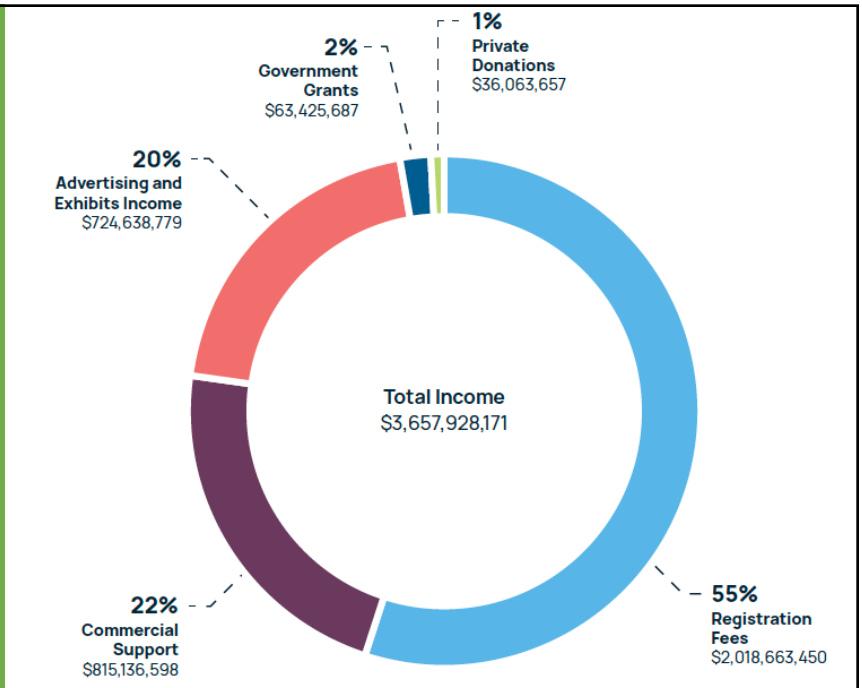
Industry Offsets Cost of CME





CME/CE 2024 Total Income

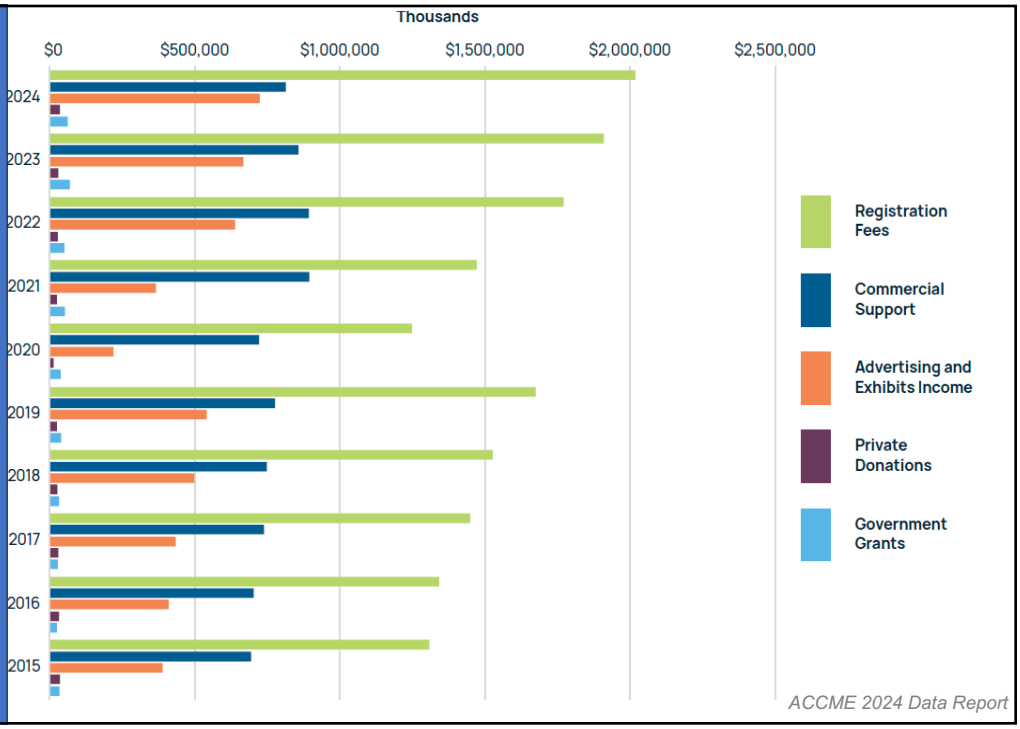
(Providers Accredited in the ACCME System)



ACCME 2024 Data Report

CME/CE Sources of Revenue

2015-2024



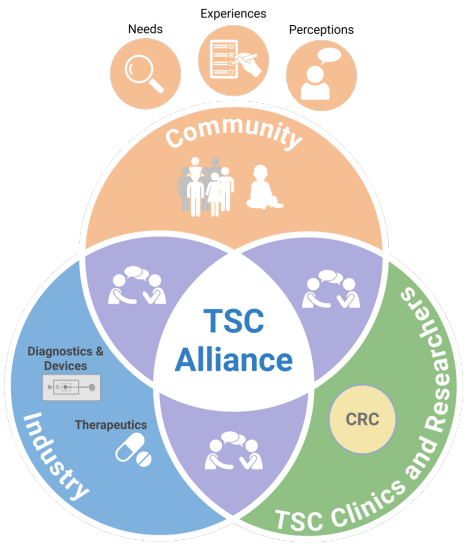
ACCME 2024 Data Report

Consortiums Act as Intermediaries



PEDIATRIC EPILEPSY RESEARCH CONSORTIUM

Advocacy Organizations Connect Industry, Patients, & Clinicians



- Protocol Development
- Participant Recruitment
- Clinical Site Access
- Best Practices
- Common Endpoints
- Results Sharing

TSC clinical research NETWORK

biosample REPOSITORY

natural history DATABASE

CNF & Genetic Testing Awareness Initiative

CNF's Commitment
- Support the disability community through early access and increased awareness of genetic testing

Collaborative Approach
- Co-designed educational content with GeneDx for both families and clinicians
- Partnering with two additional advocacy organizations + GeneDx Director of Marketing
- Expanding resources to fill education gaps across organizations

Key Principles
- Unbranded educational content
- Focus on equity, awareness, and accessibility



Where Do We Go From Here?

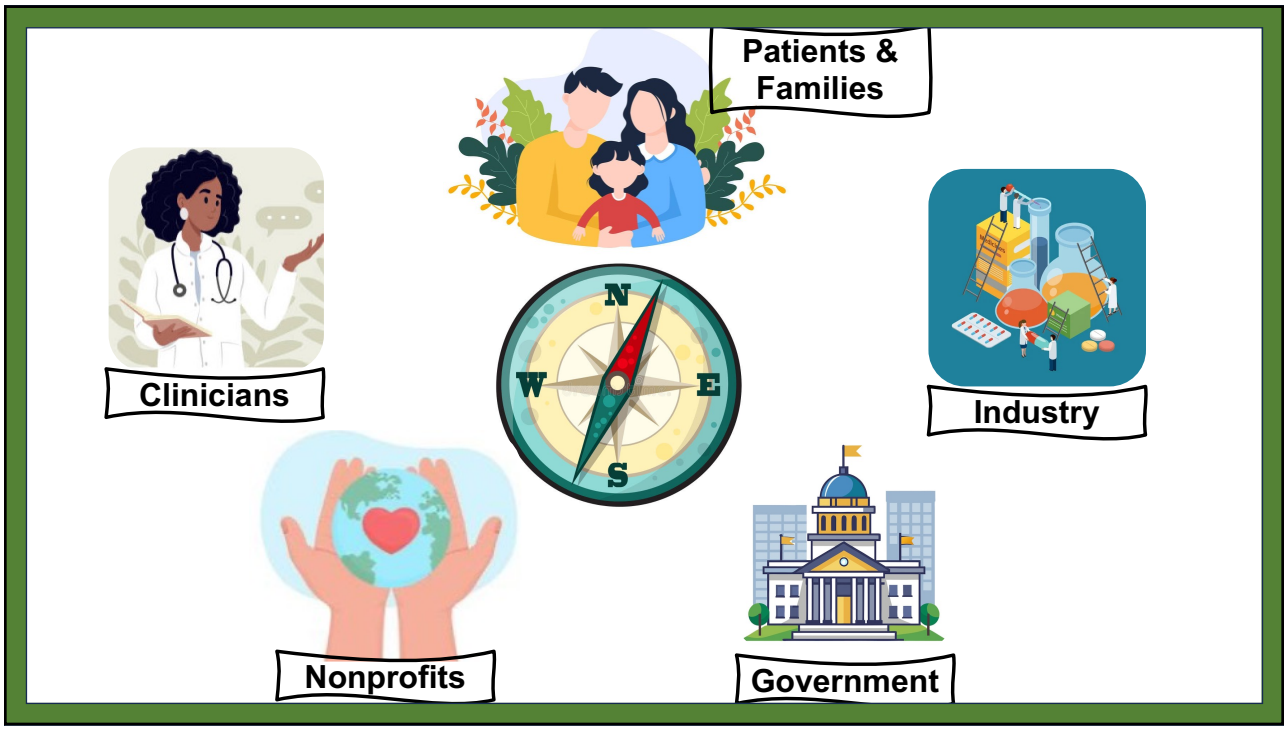
CONNECTION

COLLABORATION

EDUCATION

PATIENT SUPPORT

PROGRESS



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