DEE-P CONNECTIONS

Core premise of DEE-P advocacy since launch in 2019:

Poor state of care and outcomes across rare epilepsies requires political advocacy to improve focus, funding, and impact of federal programs

EAN Stakeholder Briefing
September 25th, 2025

Advocacy Initiatives

- Early engagement through **ELC Advocacy** and formation of independent **REN**
- Major commitment to embed patient advocacy in **Curing the Epilepsies 2021**
- Co-authored **2021 Editorial of ELC Advocacy workgroup** advocating for National Plan and more strategic federal programs
- Founding partner in formation of **Epilepsies Action Network** to unite community around advocacy for the rare epilepsies
- Promote direct organizational and community engagement advocating for members to join **Epilepsy Caucus** and co-sponsor **National Plan** bill in both House and Senate

Insights from Cross DEE research Workshop and SCN2A/8A Researcher and Family Meeting

WHAT WORKED WELL

- ✓ Dedicated discussion across stakeholders of advocacy priorities and urgency for collaboration
- ✓ Focus on opportunities for action
- ✓ Dedicated background sheet on initiatives, contacts, simple ways to make a difference

<u>At exhibit table:</u>

- ✓ Personal conversations; meet people where they are
- ✓ Simple guidesheet for action/engagement

CHALLENGES/OPPORTUNITIES FOR IMPROVEMENT

- ○ Predominant interest in more local, practical advocacy
- ○ Limited knowledge of EAN/collaborative advocacy efforts for National Plan

<u>At exhibit table:</u>

- ○ Anxiety, frustration, and hopelessness about Medicaid and other loss of federal programs
- ○ Importance of linking calls for advocacy for National Plan with immediate care and coverage issues families are confronting

WE NEED TO ACT

The decades-long effort to build federal infrastructure to advance research and provide care for those impacted by epilepsies IS BEING DISMANTLED.

→ NIH FUNDING SLASHED

The Trump administration has proposed significant cuts to the NIH budget, including a roughly **40% reduction** in its overall funding ($18 billion) and summarily consolidating or eliminating institutes/centers without congressional hearings or public input. Cuts at these levels will significantly reduce grant funding for scientific innovation.

A recent report estimates that a **permanent 10 percent budget cut to the NIH** along with a nine-month drug review delay at the FDA (due to staffing cuts) would result in an estimated 53 drugs not coming to market over the coming decade.

→ CDC EPILEPSY PROGRAM ELIMINATED

The epilepsy community has long depended on the Centers for Disease Control and Prevention (CDC) to fund research and patient-support efforts to help people living with epilepsy. Without Congressional approval, the President **abolished the CDC Epilepsy Program** established by law and appropriated funds, including firing all of the people who work in epilepsy at the CDC. The CDC's Epilepsy Program has collected data and funded research aimed at finding new epilepsy treatments, as well as supporting programs providing services and education for people living with epilepsy. Congress has, in effect, approved this action.

→ $1T Medicaid cuts likely to reduce care access for medically fragile children

Medicaid funding was just reduced by **over $1 trillion** over the next 10 years. A recent Congressional Budget Office (CBO) report estimated this would result in an estimated **11.8 million more people becoming uninsured** nationwide. Families with medically complex children will likely be impacted in multiple ways, jeopardizing their access to essential healthcare services, potentially leading to coverage loss, reduced benefits, and decreased access to specialized care. These cuts could also affect the financial stability of families, increase healthcare costs, and disrupt the support systems that enable these children to live at home.

Disability Rights Programs

The Trump administration has taken actions **rolling back disability rights and protections**, particularly through proposed budget cuts and policy changes related to Social Security (including Social Security Disability Insurance and Supplemental Security Income) and Medicaid. The administration has rolled back important health care protections for people with disabilities and chronic health conditions, making it harder to enforce rights and access healthcare, exempting private health insurance plans from nondiscrimination provisions, and potentially deterring people from seeking necessary assistance.

Congressionally Directed Medical Research Program (CDMRP)

Congress singled out and **slashed the CDMRP budget by 57 percent**, from $1.5 billion in FY2024 to $650 million in FY2025. These cuts are anticipated to **significantly disrupt research and development** of new therapies for conditions impacting military personnel, veterans, their families, and the wider public. This deep cut to the CDMRP would severely impact the progress made in understanding and treating epilepsy, especially post-traumatic epilepsy (PTE), funded through the CDMRP.

A NATIONAL PLAN FOR THE EPILEPSIES

Let's get new legislation passed!

Passage of a National Plan for the Epilepsies will spotlight the critical role of federally sponsored research and coverage through Medicaid and the ACA for the epilepsy community. A National Plan will give us a **clear, shared path toward a better future for people living with the epilepsies.**

Passed by Congress and signed into law by the President, a National Plan could get everyone moving in the same direction by developing a framework for collaboration, providing vision, ensuring efficient use of resources, promoting sustainable, equitable progress, and fostering good governance.

Despite this Congress slashing both research and access programs, our community is working closely with bipartisan leaders of the House and Senate Epilepsy Caucuses who have provided leadership to **get this legislation enacted this year**. United advocacy for this small but important step forward can set the stage for restoring the devastating cuts already put into law.

WHAT CAN I DO TO HELP?

1. Tell your Congressperson to **sign on to the first National Plan for the Epilepsies**; ask them to join the House or Senate Epilepsy Caucus to track legislation impacting the epilepsies.
2. Join as an individual or organization to partner with the Epilepsies Action Network
3. Learn more about legislative advocacy priorities; check out EF advocacy page, details on advocacy priorities, and sign up for Advocacy Alerts
4. Join the DEE-P Health Economics Advisory Group to gather and share data on how new treatments, reduced access and research impact the epilepsies.

Click here for more details & links!

Epilepsies Action Network

Decoding Developmental Epilepsies

DEE-P CONNECTIONS

Reach out to us at **info@deepconnections.net** to get involved!

Direct DEE-P Family Advocacy

This Fall - scheduling meetings with key Capitol Hill staffers

- Targeting key congressional leaders who can help support the National Plan legislation
- Virtual meetings 20-30 minutes
- Training will be provided to families to prepare them to share about their lives with DEE and the need for better care & treatments

Interested in participating? Email kcollins@g2gconsulting.com