



THE EPILEPSIES

TAKING ACTION TOGETHER

SEP 2025 Stakeholder Update

AGENDA

1. Welcome & Update

2. Advocacy Successes from EAN Partners

- Epilepsy Alliance America
- CURE Epilepsy
- PAME
- PERC
- DEE-P/SCN8A
- Epilepsy Foundation

3. How YOU Can Engage in Advocacy

4. Update from National Plan for Epilepsy Committee (NPEC) on Consensus Priorities Development - Jack Parent

5. Closing





2022

2023

2024

2025

Epilepsies Action Network is launched!

- Solicited Stakeholder Inputs
- Stakeholder Letter to Pres Biden
- Onboarded Partners

Building Foundation

- House Caucus Launched
- Solicited Stakeholder Inputs
- National Advisory Board Stood Up
- 2 Congressional Briefings (May & Nov)
- Grassroots & grasstops mtgs
- 6 Advocacy webinars & Trainings
- Grew partners

Momentum Increasing

- Senate Caucus Launched
- Stakeholder Letter to Pres. Biden
- Grew Caucuses & Partners
- Capitol Hill day w/ PERC
- Solicited Stakeholder Inputs
- National Plan Reception
- National Plan for Epilepsy Committee (NPEC) launches
- Secured House & Senate Report Language for CDC and Research
- National Plan intro'd House & Senate**
- National Plan Booth & Campaign @ AES

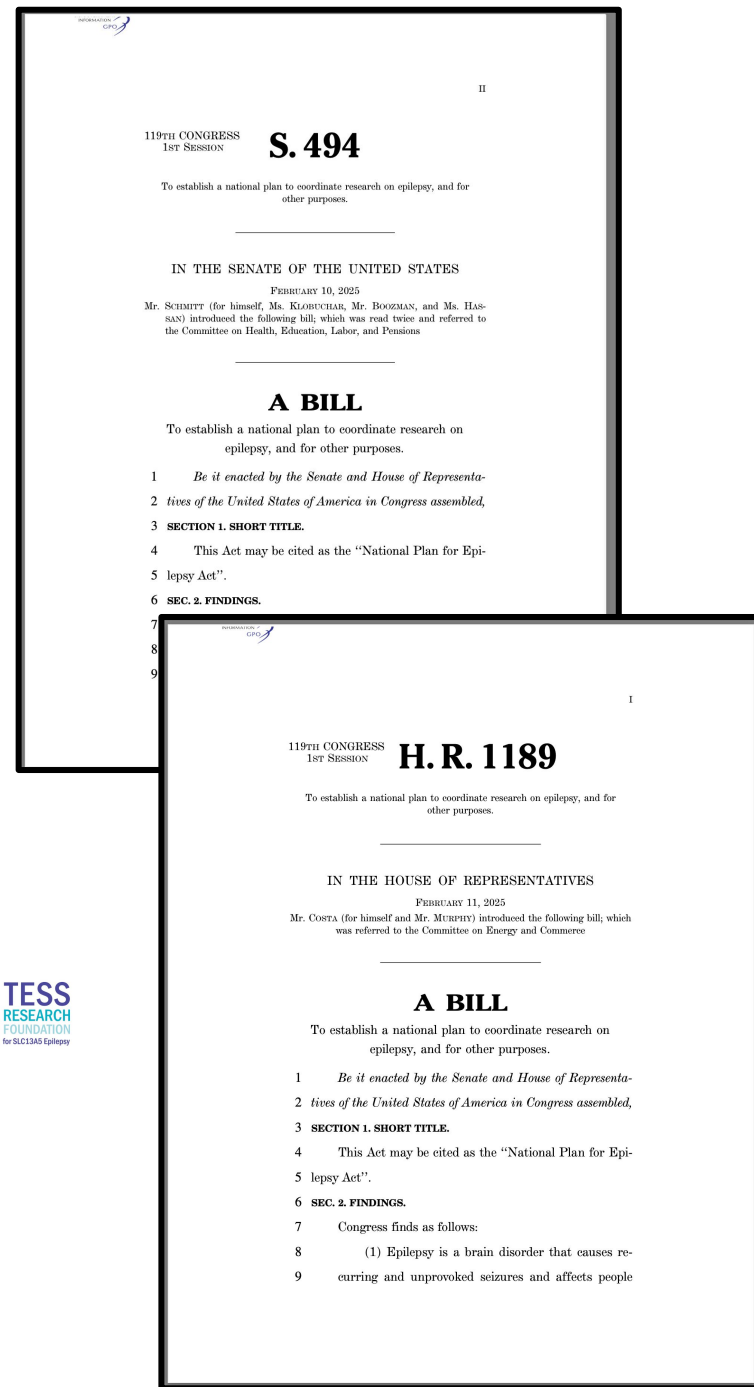
National Plan Re-Introduction!

- National Plan Reintroduction Briefing w/ House & Senate Co Chairs & Epilepsy Leaders (S.494 & HR 1189)**
- NPEC Launches Work Groups to develop Consensus Priorities
- Capitol Hill days w/ Epilepsy Leaders
- Increasing Plan Sign Ons
- Grassroots & grasstops meetings ongoing
- PAME Fly Ins & Briefing
- Testimony at events - 75th NINDS; New Dems Caucus
- Key HELP and E&C Leadership Mtgs**

NATIONAL PLAN “SIGN ON” DASHBOARD: 34 SIGN ONs

S. 494: 7 SENATORS

H.R. 1189: 27 REPRESENTATIVES





SUCCESSES FROM EAN PARTNERS

EMERGING THEMES: **ACROSS EPILEPSY ADVOCACY**

- **Many Epilepsy Orgs Formed Advocacy Committees in 2024**
 - Inspired by National Plan and other advocacy opportunities!
 - Change is afoot across the epilepsies - our advocacy skills, resources, and community are growing!
 - We need every org and every advocate. We need you NOW!
- **Multiple Askers; Single ASK - Works!**
 - In IL & OH - we saw repeated examples of multiple orgs meeting with the same legislators and those legislators signing on to the Plan!
- **Connections and Stories Make the Difference**
 - Legislators hearing from constituents why the Plan matters to them and will improve lives drives sign ons
 - Be authentic to your mission - one ask but many experiences!





HOW YOU/YOUR ORG CAN:
GET ENGAGED!

HOW YOU CAN HELP: ASKS & LINKS

GET YOUR LEGISLATORS TO SIGN ON TO THE PLAN

- Join EAN, DEEP and other virtual Congressional meetings this fall. We will reach out to advocates in key districts and states.
- **Meet/Contact YOUR Members:** in person in DC or during a recess, via zoom mtgs, phone calls, postcards, letters, and emails (voter voice)
- **Organize a post-card or letter writing campaign** with friends, family, constituents
- Carve out advocacy training during your **family and professional conferences**
- **Use your newsletters + social media channels** to rally friends, family and colleagues to action.
- **Write a letter to your local newspaper editor about what the Plan means to and for YOU**

VOTER VOICE ONE STOP TOOL

<https://www.epilepsiescaucus.org/supportplan>

MESSAGE & MATERIALS:

<https://bit.ly/EpilepsyPlanSignOn>

Not yet an EAN Organizational Partner?

<https://www.epilepsiesactionnetwork.org/partners>



PAME on Capitol Hill & Virtual Briefing



National Plan for Epilepsy - Advocacy Stakeholder Update

Join the "Get the Plan Passed" Campaign!

DEE-P Connections is passionately engaged in this effort—and we invite you to join **us**. Here's how you and your organization can take action:

- 1 **Save the Date** – National Advocacy Update on Sept. 25 @ 4 PM ET. [\[Register here\]](#) and spread the word!
- 2 **Complete the "Pass the Plan" form** by Sept. 20 – help **us** map connections and amplify our impact.
- 3 **Activate Now** – Use this [\[Voter Voice tool\]](#) or share your story directly with Members of Congress. Every voice matters—together, we're unstoppable.

DEE-P is here to strategize, share resources, and support your advocacy every step of the way—let's get this plan passed!

DEE-P EMAILS

EAA visits Sen. Booker's office on the hill



ALL MEMBERS MATTER: KEY LEADERS OF HOUSE E&C AND SENATE HELP COMMITTEES

SENATE HELP COMMITTEE



Sen. Bill Cassidy, MD (R-LA)



Sen. Bernie Sanders (I-VT)

HOUSE E&C HEALTH SUBCOMMITTEE



Rep. Brett Guthrie (R-KY)



Rep. Frank Pallone (D-NJ)

HOUSE E&C HEALTH SUBCOMMITTEE



Chairman Health
MORGAN GRIFFITH
Virginia – District 9
R



Vice Chair Health
DIANA HARSHBARGER
Tennessee – District 1
R



Ranking Member Health
DIANA DEGETTE
Colorado – District 1
D

ALL MEMBERS MATTER: KEY TARGETS ON HOUSE ENERGY & COMMERCE (E&C)!

ENERGY & COMMERCE

CHAIRMAN BRETT GUTHRIE

Subcommittee Members (32)



Chairman Health
MORGAN GRIFFITH
R Virginia – District 9



Vice Chair Health
DIANA HARSHBARGER
R Tennessee – District 1



Ranking Member Health
DIANA DEGETTE
D Colorado – District 1



GUS BILIRAKIS
R Florida – District 12



BUDDY CARTER
R Georgia – District 1



NEAL DUNN, M.D.
R Florida – District 2



DAN CRENSHAW
R Texas – District 2



JOHN JOYCE
R Pennsylvania – District 13



TROY BALDERSON
R Ohio – District 12



MARIANNETTE MILLER-MEEKS
R Iowa – District 1



KAT CAMMACK
R Florida – District 3



JAY OBERNOLTE
R California – District 23



JOHN JAMES
R Michigan – District 10



CLIFF BENTZ
R Oregon – District 2



ERIN HOUCHIN
R Indiana – District 9



NICK LANGWORTHY
R New York – District 23



TOM KEAN
R New Jersey – District 7



MICHAEL RULLI
R Ohio – District 6



BRETT GUTHRIE
R Kentucky – District 2



RAUL RUIZ
D California – District 25



DEBBIE DINGELL
D Michigan – District 6



ROBIN KELLY
D Illinois – District 2



NANETTE DIAZ BARRAGÁN
D California – District 44



KIM SCHRIER
D Washington – District 8



LORI TRAHAN
D Massachusetts – District 3



MARC VEASEY
D Texas – District 33



LIZZIE FLETCHER
D Texas – District 7



ALEXANDRIA OCASIO-CORTEZ
D New York – District 14



JAKE AUCHINCLOSS
D Massachusetts – District 4



TROY CARTER
D Louisiana – District 2



GREG LANDSMAN
D Ohio – District 1



FRANK PALLONE
D New Jersey – District 6

ALL MEMBERS MATTER: KEY TARGETS SENATE HEALTH, EDUCATION, LABOR & PENSIONS (HELP)!

U.S. SENATE COMMITTEE ON
Health, Education
Labor & Pensions

Majority



CHAIRMAN
Bill Cassidy, M.D.
(Republican - LA)

VISIT WEBSITE →



Rand Paul
(Republican - KY)

VISIT WEBSITE →



Susan Collins
(Republican - ME)

VISIT WEBSITE →



Lisa Murkowski
(Republican - AK)

VISIT WEBSITE →



Markwayne Mullin
(Republican - OK)

VISIT WEBSITE →



Roger Marshall, M.D.
(Republican - KS)

VISIT WEBSITE →

Minority



RANKING MEMBER
Bernie Sanders
(Independent - VT)

VISIT WEBSITE →



Patty Murray
(Democrat - WA)

VISIT WEBSITE →



Tammy Baldwin
(Democrat - WI)

VISIT WEBSITE →



Christopher Murphy
(Democrat - CT)

VISIT WEBSITE →



Tim Kaine
(Democrat - VA)

VISIT WEBSITE →



Maggie Hassan
(Democrat - NH)

VISIT WEBSITE →

Majority



Tim Scott
(Republican - SC)

VISIT WEBSITE →



Josh Hawley
(Republican - MO)

VISIT WEBSITE →



Tommy Tuberville
(Republican - AL)

VISIT WEBSITE →



Jim Banks
(Republican - IN)

VISIT WEBSITE →



Jon Husted
(Republican - OH)

VISIT WEBSITE →



Ashley Moody
(Republican - FL)

VISIT WEBSITE →

Minority



John Hickenlooper
(Democrat - CO)

VISIT WEBSITE →



Ed Markey
(Democrat - MA)

VISIT WEBSITE →



Andy Kim
(Democrat - NJ)

VISIT WEBSITE →



Lisa Blunt Rochester
(Democrat - DE)

VISIT WEBSITE →



Angela Alsobrooks
(Democrat - MD)

VISIT WEBSITE →



NPEC: CONSENSUS PRIORITIES

JACK PARENT, MD



Q & A