



THE EPILEPSIES

TAKING ACTION TOGETHER

September 2026 Stakeholder Briefing on the National Plan

AGENDA

- 1. Welcome & Overview- Ilene Miller, JD, LLM**
- 2. Plan the Plan Update - Jack Parent, MD**
- 3. National Plan Progress - Katie Collins**
- 4. Pass the Plan Strategy - Ilene Miller, JD, LLM**
- 5. Community Inputs & Feedback**

MULTIPLE EFFORTS CONVERGING

Pass the Plan

Plan the Plan



PLAN THE PLAN

NPEC Update

Jack Parent, MD, FAES

President, American Epilepsy Society

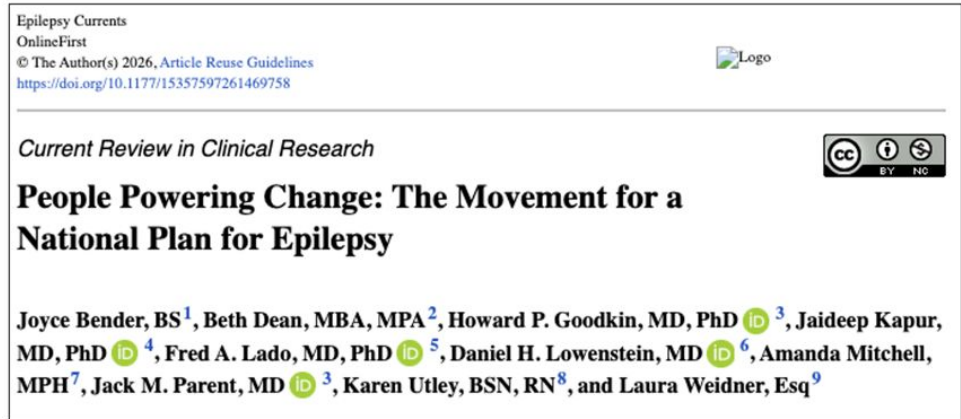
IGAP Session at European Epilepsy Congress

- IGAP is at the midway point
- Presented an update on the National Plan for Epilepsy Act as well as the community consensus priorities
- Received positive feedback from ILAE/EEC leaders on US progress
- Several European countries presented their IGAP/National Plan progress – experiencing challenges similar to ours



NPEC Publication in *Epilepsy Currents*

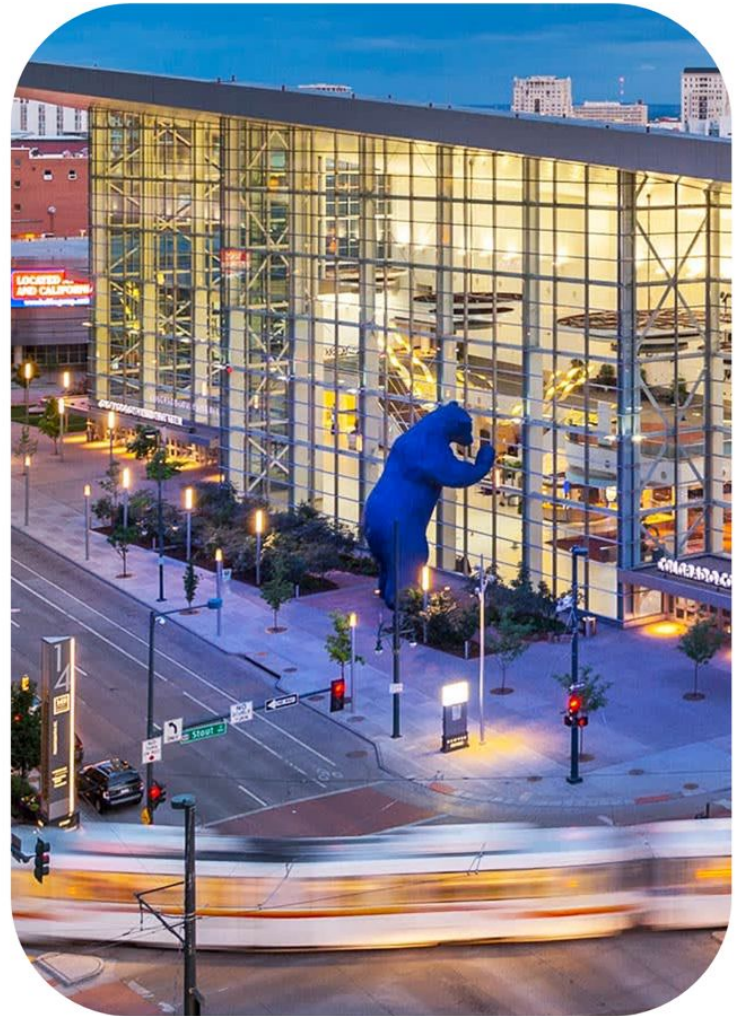
- Article has been officially published and is available via open access
- Outlines the work of the many dozens of people who contributed to these priorities



View and sign on to the consensus priorities here

NPEC at AES 2026

- Organizations can have materials at their respective booths on the National Plan
 - EFA taking lead on developing
 - Distribution plan TBA
- AES will have signage at various points across the convention center
- AES will be launching a new Advocacy Hub where attendees can learn more about AES' advocacy pillars, one of which is the National Plan



MULTIPLE EFFORTS CONVERGING

Pass the Plan

Plan the Plan



PASS THE PLAN: ON THE HILL, AT HOME, AROUND THE US & THE WORLD



AES & EAN
on CAPITOL HILL



Back Again!



Epilepsy Action Alliance
@ August Recess Mtg



Dr. Koh
Former HHS Sec
& EAN NAB
Cheering us on!



EAN Summer INTERNS
@ Capitol Hill



Ilene Miller, JD, LLM @
IMPRES (Austin, TX)



Jack Parent, MD
@ EEC (Athens, Greece)



Kim Hindery
@ CNF CAB (Cincinnati,
OH)

PASS THE PLAN: MANY VOICES - ONE ASK



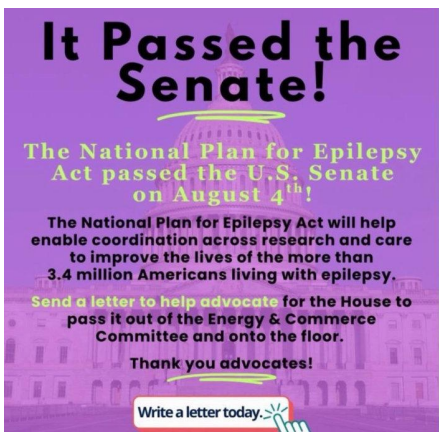
EXCITING UPDATE!

The U.S. Senate has passed the National Plan for Epilepsy Act (S. 494) by unanimous consent.



UPDATE:

Senate Committee Passes the Bipartisan National Plan for Epilepsy Act!



It Passed the Senate!

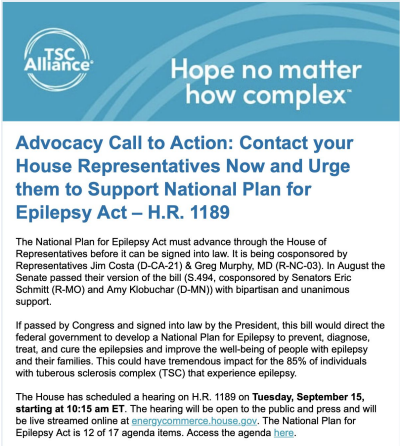
The National Plan for Epilepsy Act passed the U.S. Senate on August 4th!

The National Plan for Epilepsy Act will help enable coordination across research and care to improve the lives of the more than 3.4 million Americans living with epilepsy.

Send a letter to help advocate for the House to pass it out of the Energy & Commerce Committee and onto the floor.

Thank you advocates!

Write a letter today.



Hope no matter how complex™

Advocacy Call to Action: Contact your House Representatives Now and Urge them to Support National Plan for Epilepsy Act – H.R. 1189

The National Plan for Epilepsy Act must advance through the House of Representatives before it can be signed into law. It is being cosponsored by Representatives Jim Costa (D-CA-21) & Greg Murphy, MD (R-NC-03). In August the Senate passed their version of the bill (S.494, cosponsored by Senators Eric Schmitt (R-MO) and Amy Klobuchar (D-MN)) with bipartisan and unanimous support.

If passed by Congress and signed into law by the President, this bill would direct the federal government to develop a National Plan for Epilepsy to prevent, diagnose, treat, and cure the epilepsies and improve the well-being of people with epilepsy and their families. This could have tremendous impact for the 85% of individuals with tuberous sclerosis complex (TSC) that experience epilepsy.

The House has scheduled a hearing on H.R. 1189 on **Tuesday, September 15, starting at 10:15 am ET**. The hearing will be open to the public and press and will be live streamed online at energycommerce.house.gov. The National Plan for Epilepsy Act is 12 of 17 agenda items. Access the agenda [here](#).

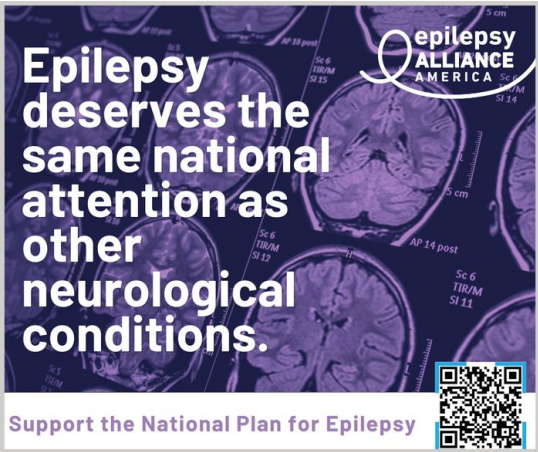


AES
AMERICAN EPILEPSY SOCIETY

NATIONAL PLAN FOR EPILEPSY

UPDATE

SENATE HELP COMMITTEE ADVANCES S. 494
NATIONAL PLAN FOR EPILEPSY ACT



Epilepsy deserves the same national attention as other neurological conditions.

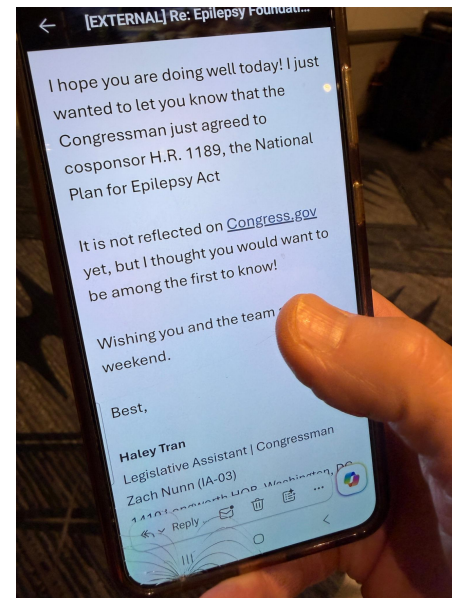
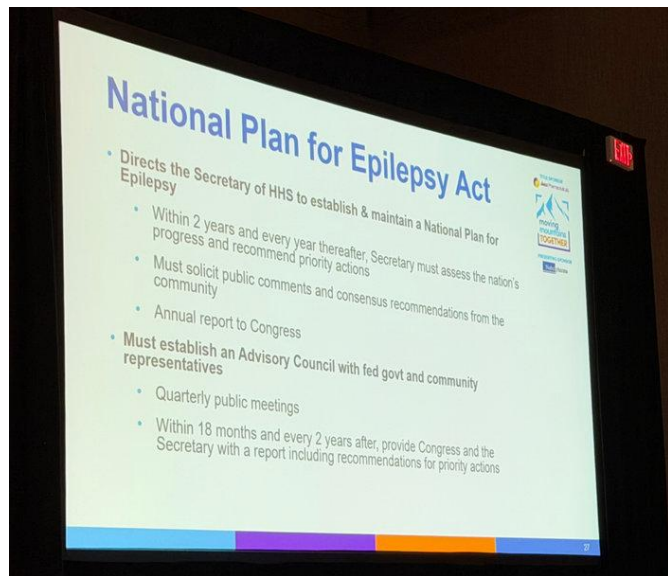
Support the National Plan for Epilepsy



BIG NEWS!

The National Plan for Epilepsy Act (S. 494) just

PASS THE PLAN: FAMILY & PROFESSIONAL CONFERENCES THIS SUMMER!



JUST A FEW MINUTES - ENORMOUS IMPACT!

PASS THE PLAN: THANK YOU LANDIS & WHAT THE EF

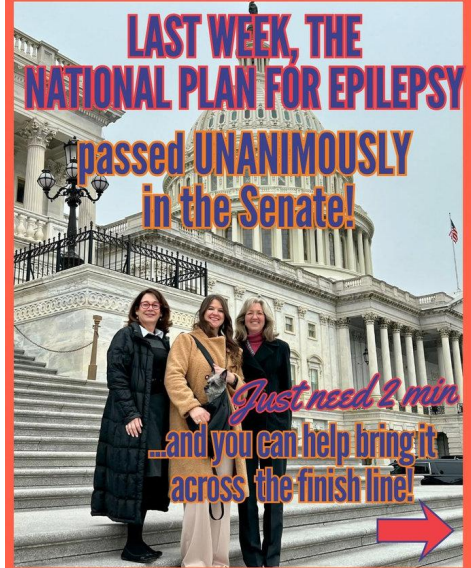
LET'S DO THIS!

Give your 2 minutes.
Bring it across the line.
Be a part of history.



**ALL HOUSE
COMMITTEE MEMBERS
TAGGED IN THIS POST!**

Repost THIS so they know
we want a National Plan
for Epilepsy



PASS THE PLAN: 190 ORGS BAND TOGETHER IN A LETTER TO CONGRESSIONAL LEADERS

September 29, 2026

The Honorable Mike Johnson
Speaker
U.S. House of Representatives
H-232, The Capitol
Washington, DC 20515

The Honorable John Thune
Majority Leader
U.S. Senate
S-230, The Capitol
Washington, DC 20510

Dear Speaker Johnson, Minority Leader Jeffries, Majority Leader Thune, and
Minority Leader Schumer:

The undersigned 190 organizations strongly support the National Plan for
Epilepsy Act (S. 494/H.R. 1189) and respectfully urge that Congress work
together to pass this important, bipartisan, and zero cost legislation before
the end of the year. We were delighted to see the Senate pass S. 494 with
amendment by unanimous consent on August 4th and the House Energy &
Commerce Committee include H.R. 1189 in a September 15th hearing. This
progress is monumental and shows Congress's widespread support of the
legislation. Passage this year is necessary to improve the lives of the nearly
3.4 million Americans living with epilepsy, make care more affordable, reduce
the significant economic burden of epilepsy on our country, and ensure
healthcare providers have the knowledge and resources to deliver safer,
faster, more effective, and cost-efficient care.

About Epilepsy

Epilepsy is a neurological disorder characterized by a predisposition of the
brain to produce seizures, which are sudden abnormal bursts of electrical
energy that disrupt brain functions. It can affect people at any age and is
often lifelong. There are multiple types of seizures and many underlying
causes of epilepsy, including an ever-growing number of rare epilepsies. Many
of these are severe and medically complex, causing relentless seizures,
developmental and cognitive impairment, loss of independence, significant
caregiver burden, and, for some, life-threatening complications and premature
death. In addition to seizures, epilepsy can also cause fatigue, learning and

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
H-204, The Capitol
Washington, DC 20515

The Honorable Chuck Schumer
Minority Leader
U.S. Senate
S-221, The Capitol
Washington, DC 20510

American Academy of Neurology
American Epilepsy Society
Angelman Syndrome Foundation

BAND Foundation
BDSRA Foundation
CACNA1A Foundation
Care and Cure Institute
CASK Gene Foundation
CFC International
Child Neurology Foundation

Coalition to Cure CHD2
COMBINEDBrain, Inc.
CSNK2A1 Foundation
CSNK2B Foundation
CTNNB1 Connect & Cure
Cure CLCN6, Inc.

CURE Epilepsy
Cure GABA-A Variants
CureSHANK
Developmental and Epileptic
Encephalopathy Project/DEE-P
Connections

Dravet Syndrome Foundation
Dup15q Alliance
Empowering Epilepsy
Epilepsies Action Network (EAN)
Epilepsy Advocacy Network
Epilepsy Agency of the Big Bend
Epilepsy Alliance America
Epilepsy Alliance Louisiana
Epilepsy Alliance North Carolina
Epilepsy Alliance Ohio

Epilepsy Association of Western and
Central PA
Epilepsy Center of Northwest Ohio
Epilepsy Foundation Alabama
Epilepsy Foundation Alaska
Epilepsy Foundation Arizona
Epilepsy Foundation Arkansas
Epilepsy Foundation Central & South
Texas

Epilepsy Foundation Eastern Pennsylvania
Epilepsy Foundation Florida
Epilepsy Foundation Greater Orange
County
Epilepsy Foundation Indiana
Epilepsy Foundation Iowa
Epilepsy Foundation Long Island

Epilepsy Foundation Los Angeles
Epilepsy Foundation Louisiana
Epilepsy Foundation Maryland
Epilepsy Foundation Metro D.C.
Epilepsy Foundation Mississippi
Epilepsy Foundation Montana
Epilepsy Foundation Nebraska
Epilepsy Foundation Nevada

Epilepsy Foundation New England
Epilepsy Foundation New Jersey
Epilepsy Foundation New Mexico
Epilepsy Foundation North Carolina
Epilepsy Foundation North Dakota
Epilepsy Foundation of America
Epilepsy Foundation of Delaware
Epilepsy Foundation of Georgia
Epilepsy Foundation of Greater Chicago

Epilepsy Foundation of Greater Southern
Illinois
Epilepsy Foundation of Hawaii
Epilepsy Foundation of Kentucky
Epilepsy Foundation of Michigan
Epilepsy Foundation of Minnesota
Epilepsy Foundation of Missouri and
Kansas

Epilepsy Foundation of Northeastern New
York, Inc.
Epilepsy Foundation of Northern California
Epilepsy Foundation of San Diego County
Epilepsy Foundation of Texas
Epilepsy Foundation of Virginia
Epilepsy Foundation of Wisconsin
Epilepsy Foundation Ohio

Epilepsy Foundation Oklahoma
Epilepsy Foundation Oregon
Epilepsy Foundation South Carolina
Epilepsy Foundation South Dakota
Epilepsy Foundation Utah

Epilepsy Foundation Washington
Epilepsy Foundation West Virginia
Epilepsy Learning Healthcare System
Epilepsy Services of New Jersey
Epilepsy Wellness Advocates
Fairfax County Parents Association
FAM177A1 Research Fund
Foundation for Angelman Syndrome
Therapeutics

GABA-A Alliance
GluT1 Deficiency Foundation
GNB1 Advocacy Group, Inc.
GRIN2B Foundation

HardyHandz Foundation
Henry's Heroes Foundation
HNRNP Family Foundation
Hope for HIE
Hope for ULD
International Foundation for CDKL5
Research

International SCNBA Alliance
Joanna Sophia Foundation
Joey's Song
JoshProvides Epilepsy Assistance
Foundation, Inc.
KCNQ2 Cure Alliance
KCNT1 Epilepsy Foundation
KIF1A

Koolen-de Vries Syndrome Foundation
KPTN Alliance
Landon's Legacy
Lennox-Gastaut Syndrome (LGS)
Foundation

Little Friends of Epilepsy
My Epilepsy Story
My Kool Brother
National Association of Epilepsy Centers
NORSE Institute

Partners Against Mortality in Epilepsy
(PAME)
Paul's Purple Warriors
Pediatric Epilepsy Research Consortium
Pediatric Epilepsy Surgery Alliance
Phelan-McDermid Syndrome Foundation
PPP3CA Hope Foundation
Project CASK, Inc.
PURA Syndrome Foundation

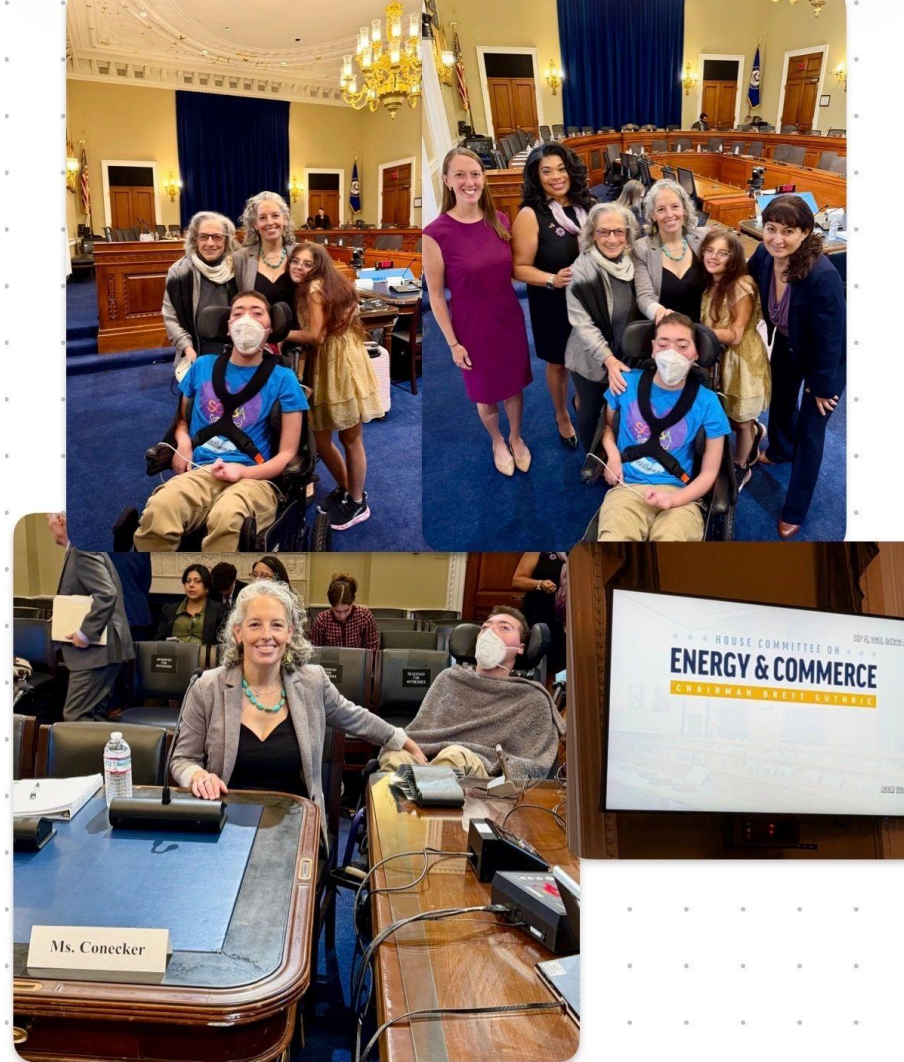
PVNH Support & Awareness
Rare Epilepsy Network (REN) Coordinating
Committee
RASopathies Network
Rea of Hope for a Cure Foundation
Ring14 USA
SLC6A1 Connect
SNAP25 Foundation
Sociedad Puertorriqueña de Epilepsia
South Carolina Advocates for Epilepsy
STXBP1 Foundation
SynGAP Research Fund, dba curesyngap1
SynGAP1 Foundation
Tatton Brown Rahman Syndrome
Community

TBC1D24 Foundation
TESS Research Foundation
The Charlie Foundation for Ketogenic
Therapies
The Danny Did Epilepsy Foundation
The Epilepsy Foundation of Metro NY
The Familiesc2A Foundation, Inc.
The LCC Foundation
The MED13L Foundation
The Rory Belle Foundation
The Sturge-Weber Foundation
(PAME)
Tough Genes
TSC Alliance
Valley Children's Healthcare
v-ATPase Alliance
What the EF
Young Adults with Epilepsy
YWHAG Research Foundation

PASS THE PLAN: ALL EYES ON THE HOUSE

- Aug. 4 - Senate passes S.494 - Bipartisan, Unanimous Consent
- Sep. 15 - House Energy & Commerce Committee Hearing
 - 17 items on the agenda
 - 6 Witnesses
 - Gabi Connecker testifies for National Plan

28 SENATE Sponsors
99 HOUSE Sponsors
127 TOTAL Sponsors



2026 FALL STRATEGY: TACTICS & ENGAGEMENT OPPS

- Time intensive collaboration with Congressional Leadership re:
 - Traditional Committee paths
 - Potential fast-tracking paths
- Meanwhile, continue to build support and obtain co-sponsorships, focusing on key committees with jurisdiction
 - House Energy & Commerce Health Subcommittee
 - Senate HELP Committee
- Add every other Senator & Representative not represented nationwide!
- Fall/Winter Patient & Professional Conference “Advocacy Take Five”
- Plus targeted Fundraisers, Hill Days, Virtual Meetings, Push during AES



2026 FALL STRATEGY:

KEY TARGETS

KEY TARGETS:

HOUSE LEADERSHIP

Rep. Mike Johnson (LA-04)

Rep. Steve Scalise (LA-01)

Rep. Jay Obernolte (CA-23)

Rep. Frank Pallone (NJ-06)

Rep. Diana DeGette (CO-01)

ENERGY & COMMERCE COMMITTEE

Rep. Brett Guthrie (KY-02)

Rep. Morgan Griffith (VA-09)

Alabama

Gary Palmer — AL-06 —
E&C

California

Jay Obernolte — CA-23 —
Both
Raul Ruiz — CA-25 —
E&C
Pete Aguilar — CA-33 —
Leadership
Nanette Diaz Barragán —
CA-44 — E&C

Colorado

Diana DeGette — CO-01
— E&C, Health
Subcommittee Ranking
Member
Joe Neguse — CO-02 —
Leadership
Gabe Evans — CO-08 —
E&C

Florida

Neal Dunn — FL-02 —
E&C
Kat Cammack — FL-03 —
E&C
Laurel Lee — FL-15 —
E&C

Georgia

Rick Allen — GA-12 —
E&C

Idaho

Russ Fulcher — ID-01 —
E&C

Indiana

Erin Houchin — IN-09 —
E&C

Iowa

Mariannette Miller-Meeks
— IA-01 — E&C

Kentucky

Brett Guthrie — KY-02 —
E&C Chair

Louisiana

Steve Scalise — LA-01 —
Majority Leader
Troy Carter — LA-02 —
E&C
Mike Johnson — LA-04 —
Speaker of the House

Massachusetts

Katherine Clark — MA-05
— Democratic Whip

Michigan

Lisa McClain — MI-09 —
Republican Conference
Chair
John James — MI-10 —
E&C

Minnesota

Tom Emmer — MN-06 —
Majority Whip

New Jersey

Frank Pallone — NJ-06 —
E&C Ranking Member
Rob Menendez — NJ-08 —
E&C

New York

Hakeem Jeffries — NY-08
— Democratic Leader
Alexandria Ocasio-Cortez
— NY-14 — E&C
Nick Langworthy — NY-23
— E&C

North Carolina

Richard Hudson — NC-09
— E&C

North Dakota

Julie Fedorchak — ND-At
Large — E&C

Ohio

Bob Latta — OH-05 —
E&C
Michael Rulli — OH-06 —
E&C
Troy Balderson — OH-12
— E&C

Oregon

Cliff Bentz — OR-02 —
E&C
South Carolina
Russell Fry — SC-07 —
E&C

Texas

Dan Crenshaw — TX-02
— E&C
Lizzie Fletcher — TX-07 —
E&C
August Pfluger — TX-11 —
E&C
Craig Goldman — TX-12
— E&C
Randy Weber — TX-14 —
E&C
Marc Veasey — TX-33 —
E&C

Virginia

Jennifer McClellan — VA-
04 — E&C
Morgan Griffith — VA-09
— E&C Health
Subcommittee Chair

URGE YOUR MEMBERS OF CONGRESS: TO PASS THE NATIONAL ACT FOR EPILEPSY



INDIVIDUALS

- **Use your social media channels** to rally friends, family and colleagues to action - ask members to pass the plan!
- **Use the action alert or organize your own letter or email writing campaign** with friends, family, and other people who live in the district or state (constituents)
- **Meet YOUR Members:** in person or virtual with D.C. staff or when members are home during a congressional recess



PAGS/501c3s INDUSTRY

- **Carve out “Advocacy Take 5”** during your family and professional conferences and urge all participants to ask their Members to Sign On (voter voice)
- **Organize a letter or email (voter voice) writing campaign**
- **Use your newsletters + social media channels** to rally friends, family and colleagues to action.



EPI INSTITUTES & CENTERS

- **Invite Your Legislator to visit your center** and see the impact of your care and research
- **Write a letter to your local newspaper editor** about what the Plan means for YOUR patients

ADVOCACY
TOOLKIT >>>>



Scan me

— THE CLOCK IS TICKING —

2026
Congress must act
before the end of 2026.

**Help Pass The
National Plan For
Epilepsy Act**

→ Contact Congress Today! ←

**You Can Help Pass the
National Plan For
Epilepsy Act**

**We've never been closer to a
National Plan for Epilepsy**

**But we need Congress
to act before
the end of 2026.**

ACT TODAY!



THE EPILEPSIES

TAKING ACTION TOGETHER

Questions, Answers & Actions: What Will YOU DO?