

Coverage, Access, & Advocacy

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Washington Update

- **New Congress (116th) and Split Government**
- **New Tone on Healthcare Policy**
- **New Members of Congress (113+)**
- **New Appropriations Bills (FY20)/Legislation**



Pre-Existing Condition Protections

Current Framework

- Guaranteed issue
- No caps on benefits
- Dependents can stay on family coverage until age 26
- (ongoing effort) Lower out of pocket costs

Potential Changes

- House working on proposals to enhance “Pre-Ex” protections
- Senate working on proposals to lower (not always patient) costs
- Administration rule-making on generic steering and STLDHPs.
- Texas v. US



Emerging Legislative Efforts a Mixed-Bag

- Senate HELP Committee: Focused on ending “surprise” medical billing.
- Senate Finance Committee: Focused on reforming Medicare Part D and lowering out of pocket costs
- Missing from the debate: repeal of the medical device tax and timely reauthorization of PCORI



Patient Access Efforts

- ***Restoring the Patients Voice Act /Safe Step Act***

(88 cosponsors)

- ***Access to Marketplace Insurance Act***

(177 cosponsors) + copay accumulators

- ***Patients Access to Treatments Act***

(35 cosponsors)



Community Advocacy Gains Momentum

- **Growing the Federal Medical Research Portfolio (NIH)**
- **Inclusion in DoD Research (GBS)**
- ***Medicare IVIG Access Enhancement Act (CIDP and MMN)***



Recent Congressional Recommendations

Peripheral Neuropathies.—The Committee is pleased at the continued progress of ongoing research into Guillain-Barre syndrome, chronic inflammatory demyelinating polyneuropathy, and related conditions. The Committee encourages NINDS to work with NIAID and stakeholders on a state of the science conference on evolving research and scientific mechanisms.

Autoimmune Neuropathies.—The Committee continues to encourage NIAID and NINDS to collaborate on a state-of-the-science of autoimmune neuropathies research into conditions like Guillain-Barre syndrome and chronic inflammatory demyelinating polyneuropathy. The Committee is pleased that NIAID and NINDS are working with stakeholders on the importance of the patient perspective.

PEER-REVIEWED MEDICAL RESEARCH PROGRAM

The conference agreement provides \$350,000,000 for a peer-reviewed medical research program. The conferees direct the Secretary of Defense, in conjunction with the Service Surgeons General, to select medical research projects of clear scientific merit and direct relevance to military health. Research areas considered under this funding are restricted to the following areas: acute lung injury, antimicrobial resistance, arthritis, burn pit exposure, cardiomyopathy, cerebellar ataxia, chronic migraine and post-traumatic headache, congenital heart disease, constrictive bronchiolitis, diabetes, dystonia, eating disorders, emerging infectious diseases, epidermolysis bullosa, focal segmental glomerulosclerosis, frontotemporal degeneration, Guillain-Barre syndrome, hemorrhage control, hepatitis B, hereditary angioedema, hydrocephalus, immunomonitoring of intestinal transplants, inflammatory bowel diseases, interstitial

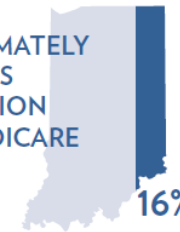


The Medicare IVIG Access Enhancement Act (HR 2905)

- Facilitates access to home infusion for CIDP and MMN Medicare beneficiaries
- Provides the same benefit as PID patients in need of IVIG
- Promotes clinical judgment and allows for patient choice in healthcare
- Ask your members of Congress to support this bipartisan legislation!
- Visit the Foundation's Advocacy Action Center: <https://www.gbs-cidp.org/advocacy/advocacy-action-center/>
- Sign the petition...

GBS & CIDP In Your State

APPROXIMATELY
16% OF IN'S
POPULATION
USES MEDICARE



16%

603
PATIENTS LIVING
WITH THE
AUTOIMMUNE
CONDITION, CIDP



Fast Facts

✓ GBS 6,000 CASES IN THE
US EVERY YEAR

- Treated with IVIG or Plasma Exchange
- Rapid onset of numbness, weakness, paralysis
- Recovery time varies and can take months or years
- Many patients have chronic residuals
- Occurs once; patients usually regain most functionality

✓ CIDP 30,000 ONGOING CASES
OF CIDP IN THE US

- Chronic condition that requires on-going treatment of IVIG; symptoms wax and wane
- A small percentage of patients are treated with plasma exchange or steroids
- Untreated, 30% of patients progress to wheelchair dependence
- With proper treatment, patients' function significantly improves

About IVIG & Home Infusions

IVIG is thought to interfere with the patient's own antibodies that are attacking the myelin coating of nerves.



IVIG treatment can take 4 to 8 hours for each treatment



CIDP patients usually need, and want, IVIG treatment on a regular basis for the rest of their lives



Delaying or stopping treatment increases the chance of the condition declining

Most Importantly...

**Become an advocate
and plan to make your
voice heard!**

just contact: Chelsey at the Foundation

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Questions?

Thank You