



STAKEHOLDER REPORT

The next Stakeholder Meeting will take place on Monday, June 11 in conjunction with the PPTA Plasma Protein Forum in Washington, D.C.

PPTA held a stakeholder meeting in Washington, D.C., on February 8, 2018. Representatives from the following stakeholders participated in the meeting, along with PPTA members and staff:

- GBS/CIDP Foundation International
- Health & Medicine Counsel of Washington on behalf of US HAEA & GBS/CIDP Foundation International
- Hemophilia Federation of America
- Hereditary Angioedema Association
- Immune Deficiency Foundation
- Cavarocchi Ruscio Dennis Associates on behalf of the Jeffrey Modell Foundation, Alpha-1 Foundation and National Hemophilia Foundation Patient Services Incorporated
- Platelet Disorder Support Association

PPTA's Vice President, Legal Affairs, provided guidance on antitrust compliance.

PPTA's Senior Vice President, North America & Global Health Policy welcomed participants to the annual Stakeholder Intake meeting. The meeting provides the Association an opportunity to interact with stakeholder groups to better understand their advocacy priorities and seek alignment on issues of mutual importance. Access to therapies in all sites of service frames the Association's advocacy priorities, and PPTA looks for chances to collaborate.

Over the course of the day's briefings and discussions, several common objectives and priorities emerged:

- The four pillars of patient protections
 - No exclusion for pre-existing conditions
 - No lifetime or annual caps
 - Ability for dependents to remain on parents plans until age 26
 - Keeping out of pocket expenses manageable
- Essential Health Benefits
- Step therapy legislation
- Use of multiple coalitions for greater advocacy impact
- Blood safety
- FDA coordination
- Patient access
- Research funding
- Orphan Drug Act

- Information sharing

Stakeholder groups are monitoring several pieces of legislation, including:

- Access to Marketplace Insurance Act
- Patients' Access to Treatment Act
- MIPS Part B Payment Technical Correction
- Medicare Part B DME Home Infusion Services Temp Transitional payment "fix"
- Medicare IVIG Access Enhancement Act

NORTH AMERICA SOCIAL MEDIA

PPTA launched three social media channels in October, 2017, with the goal of advocating at the federal level for policies that secure access to PPTs. Target audiences are policymakers at the federal level as well as patients and stakeholder groups. PPTA encourages stakeholders to follow @PlasmaProteins on [Facebook](#) and [Twitter](#) and to promote the content to their respective social networks

GLOBAL COMMUNICATIONS

PPTA will launch a global education and awareness campaign in Budapest in March, 2018. The campaign—"How Is Your Day?"—will utilize a dedicated website, social media channels, and media outreach to emphasize messages that differentiate PPTs from traditional pharmaceuticals and build understanding of the value they provide to patients and their families.

Stakeholder meeting presentations

- [GBS|CIDP Foundation International Legislative and Public Policy Priorities: 115th Congress, 2nd Session](#)
- [Video: Jean-Phillippe's CIDP Story—Journey to Diagnosis](#)
- [Video: GBS CIDP 2018 Rare Disease Day Video](#)
- [Platelet Disorder Support Association \(PDSA\) presentation](#)
- [U.S. Hereditary Angioedema Association Advocacy Priorities 2nd Session, 115th Congress](#)

Additional information

- [IDF 2017 at a glance](#)

North America Contacts

[Julie Birkofer](#), Senior Vice President, N.A. & Global Health Policy

[Bill Speir](#), JD, Senior Director, State Affairs

[Tom Lilburn](#), Senior Director, Government Relations

[Mat Gulick](#), Director, Global Communications

[Chase Thomas](#), Assistant Director, Government Relations

[Brenna Raines](#), Senior Manager, Health Policy

[Kimberly Serota](#), Assistant Manager, Government Relations

