



STAKEHOLDER REPORT

On Feb. 28, 2017, PPTA held a stakeholder meeting in Washington, D.C. It was noted that this meeting coincided with Rare Disease Week.

Representatives from the following patient groups participated in the meeting, along with PPTA members and staff:

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

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

PPTA's Senior Vice President, North America welcomed participants to the annual Stakeholder Intake meeting which provides the Association with an opportunity to listen to stakeholder advocacy priorities. Access to therapies in all sites of service frames the Association's advocacy priorities and PPTA looks for alignment on issues and opportunities for collaboration. Senior executives representing patient organizations were welcomed as well as members of the North America Board of Directors.

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

- Impact of ACA "Repeal and Replace"
 - Patient groups all agreed on four pillars that must remain:
 - 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
- Use of multiple coalitions for greater advocacy impact
- Blood safety
- FDA coordination
- Patient access
- Research funding
- Information sharing

The Rare Disease Caucus meeting held Thursday, March 2nd was mentioned. The meeting is expected to be well attended and the event will be moderated by Caroline Kruse. Also, several patient organizations are holding awareness months.

PPTA PATIENT ACCESS ADVOCACY PRIORITIES OVERVIEW

Federal

PPTA's priorities at the federal level are to advocate on behalf of access to plasma protein therapies (PPTs) as prescribed by a physician in the optimal site of care. PPTA staff is engaged and utilizes various techniques to keep abreast of rapidly changing healthcare issues. A major focus of the North American Division is to educate decision makers on the value of life-saving plasma protein therapies. Access to PPTs is important to patients because of their life-saving nature and in addition there is value to the health care system when patients receive appropriate treatment.

The date for PPTA's 2017 Washington Fly-In is Thursday, May 11. We welcome and encourage everyone to participate.

State

PPTA's goals at the state level are to maintain open access to all plasma protein therapies within Medicaid and other state funded healthcare programs, address threats to the industry, and assist patients with their advocacy goals. PPTA is currently working in California, Maryland, and New York on various issues.

The importance of telling the patient experience of a life before treatment and after diagnosis and treatment was highlighted. Also expressed was the willingness to conduct a joint Capitol Hill briefing that captures the patient experience, stresses the importance of access to care, and differentiates the plasma protein therapeutics industry from traditional pharmaceuticals.

The meeting ended on a positive note with a recap of our accomplishments that demonstrate our strength when working together. The quote "Alone we are rare, together we are strong" symbolizes our ability to advocate on behalf of patient access.

Stakeholder meeting presentations

- [Alpha-1 Foundation](#)
- [GBS | CIDP Foundation International](#)
- [U.S. Hereditary Angioedema Association](#)
- [Platelet Disorder Support Association](#)

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

[William Murray](#), Director, Global Communications

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

[Kimberly Serota](#), Project Coordinator, N.A.