



STAKEHOLDER REPORT

On June 12, PPTA held a stakeholder meeting in Washington, D.C., in advance of the 2017 Plasma Protein Forum. Representatives from the following patient groups participated in the meeting, along with PPTA members and staff:

- Alpha-1 Foundation
- Cavarocchi Ruscio Dennis Associates
- GBS|CIDP Foundation International
- Health & Medicine Counsel of Washington on behalf of US Hereditary Angioedema Association
- Hemophilia Federation of America
- Immune Deficiency Foundation
- Jeffrey Modell Foundation
- National Hemophilia Foundation
- Patient Services, Inc.

PPTA's legal counsel provided guidance on antitrust compliance.

PPTA's Senior Vice President, North America welcomed participants to the annual Stakeholder mid-year meeting which provides the Association and stakeholders an opportunity to give updates on advocacy efforts and identify areas of alignment and collaboration. Senior executives representing patient organizations were welcomed as well as members of the North America Board of Directors and the Federal Affairs Steering Committee.

The American Plasma Users Coalition (A-PLUS) Advocacy Update

On the Hill, A-PLUS is differentiating and highlighting the rare, chronic, nature of the diseases treated with plasma protein therapies. Stakeholders gave a brief overview of the strengths and advocacy capabilities of A-PLUS. PPTA's President thanked the A-PLUS for their leadership and action.

There was discussion about the uncertain challenges of repeal & replace efforts, including the House proposed American Health Care Act (AHCA). Participants agreed that it is important to raise awareness in Congress regarding the value of access to plasma protein therapies, and how proposed changes could affect patients personally. One stakeholder remarked that "we have to galvanize patients; there is some risk if we do nothing."

Stakeholders stressed the importance of advocacy collaboration, particularly regarding preserving patient protections. Participants agreed the "Four Pillars" must remain in any health reform package. These pillars include:

- 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

Even though the Congressional timetable is tight, all agreed that we must work together to try to raise awareness about the importance of patient access to plasma protein

therapies. A-PLUS is considering holding conference calls to share information regarding health reform efforts. PPTA will develop short and long term advocacy plans.

PPTA PATIENT ACCESS ADVOCACY PRIORITIES OVERVIEW

Communications & Advocacy

PPTA gave an update on communications and advocacy projects. A new advocacy folder debuted at the PPTA Fly-In on May 18. The contents of the folder will be made [available electronically](#) to stakeholders, who are welcome and encouraged to tailor and use these materials in their advocacy efforts. PPTA shared that it is also working with outside firms on a white paper and a global communications campaign. The purpose of both projects is to highlight the value of plasma protein therapies and differentiate them from other pharmaceuticals. As these projects progress, stakeholders will continue to be updated. The global educational and awareness campaign will have several touch points with stakeholders.

Federal Patient Access

PPTA's priorities at the federal level are to advocate on behalf of access to plasma protein therapies as prescribed by a physician in the optimal site of care. Staff is actively engaged in the current political environment and abreast of rapidly changing legislative proposals to repeal and replace the Affordable Care Act (ACA). The uncertainty surrounding congressional activities with regard to ACA repeal & replace initiatives struck a chord with stakeholders who indicated a desire to further explore the impact this is having within their communities. In addition to health reform efforts, PPTA is working with stakeholders to remedy the delay of the home infusion benefit for subcutaneous immune globulin.

State Patient Access

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 on a bill in California that would harmonize the state's plasma donation policies. PPTA is also working in New York, Tennessee, and California on various other issues.

The meeting ended on a positive note with a plan to coordinate advocacy efforts to strengthen the impact stakeholders can have on health reform efforts, working together to achieve PPTA's mission of promoting the availability of and access to safe and effective plasma protein therapeutics.

Stakeholder meeting presentations

- [PPTA: Communications & Advocacy](#)
- [PPTA: Federal Update](#)
- [PPTA: State Advocacy](#)

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

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

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

[Rachel Liebe](#), Assistant Manager, Communications

[Kimberly Serota](#), Project Coordinator, North America

