

STAKEHOLDER REPORT

On February 11, 2014, PPTA held its annual stakeholder intake meeting in Washington, DC. The following patient groups were in attendance along with PPTA North America Board members and staff:

Alpha-1 Association/Alpha-1 Foundation
Committee of Ten Thousand (COTT)
GBS/CIDP Foundation International
Hereditary Angioedema Association (HAEA)
Hemophilia Federation of America (HFA)
Immune Deficiency Foundation (IDF)
National Hemophilia Foundation (NHF)

PPTA's Vice President, Legal Affairs referenced the PPTA meeting guidelines and reviewed the antitrust compliance rules.

PPTA's Senior Vice President, North America welcomed participants to the annual intake meeting which provides the Association and the industry 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.

The focus for the roundtable discussion was "Partnering to Overcome Barriers to Patient Access under the ACA." To stimulate the dialogue on the unique effects of the ACA on patients who use plasma protein therapies for their lifesaving treatments, stakeholder groups were asked to present their observations and experiences with ACA the implementation.

Patients seeking insurance in the ACA marketplaces are facing challenges that are similar to those that they have faced in the broader insurance market. Patients continue to face:

- Insurance practices that present barriers to access and detrimental cost-sharing;
- A lack of transparency in insurance offerings, including opaque benefit designs and formularies, as well as confusing provider networks;



PPTA together with its Member Companies is pleased to sponsor the second International Plasma Awareness Week to be celebrated globally October 12-18, 2014.

The goals of IPAW are to:

- Raise global awareness about source plasma collection
- Recognize the contributions of plasma donors to saving and improving lives
- Increase understanding about lifesaving plasma protein therapies and rare diseases.

- Resistance and an inability on the part of insurance issuers to fully inform consumers about the content of their plans prior to purchase;
- Access that varies by region and state.

To address these concerns, all groups have actively engaged with their members to understand the issues facing patients and to enhance advocacy on their behalf. The HAEA, the newest member of the Stakeholders group, presented their approach to patient advocacy. Acting as a platform for public-private partnership, HAEA is leading the creation of the US HAEA Angiodema Center at the University of California San Diego. The center will act as the central point for HAE comprehensive care, research, and advocacy, and will provide HAE patients the opportunity to receive care and work with expert physicians with specialized experience in treating the disease. The center will also serve as a patient-centered leader in establishing best practices for diagnosis, care coordination, and angioedema-focused research.

HAEA, along with NHF and IDF, have conducted surveys to better identify policy concerns and trends in patient access in the plasma protein therapeutics community. NHF is developing a tool to gather grievance reports from their patients to get a better view of any issues regarding insurance coverage. Other patient tools that have been created or are in development are:

- Mobile Apps
- Webinars
- Patient Portals

The stakeholder groups are working hard to make sure their patients can access the best plan for their needs and if they cannot, find a way to get their voice heard. While no extreme cases have been reported, the patients are still trying to navigate their way through a challenging healthcare landscape.

Based on the valuable input from the stakeholders, PPTA staff identified two action areas:

- **Federal Affairs:** Pilot analysis of the state of patient access under the ACA
 - Focusing on how to inform the analysis to benefit patient advocacy and member support, patient stakeholders and member companies engaged in a substantive discussion regarding the most appropriate metrics and factors that should be included in the analysis as it is expanded nation wide. Stakeholders, members, and PPTA agreed to utilize the analysis as a platform for regular collaboration and alignment.
- **State Affairs:** Initiative to address the transparency problems at the state level.
 - After the next State Affairs Steering Committee meeting, PPTA will reach out to stakeholders to get feedback on how to

approach the issue and some options of action.

PPTA will be contacting stakeholders about these action items in March 2014. We look forward to this collaborative effort.

PPTA presented on the following topics:

- Patient Notification System
 - Seeing spikes after PNS presentations at booth
 - Looking to promote the system and increase enrollment

- Health Technology Assessments
 - Patients centeredness must be a priority
 - Personalized medicine will be the new trend

- Patient Access
 - ACA and Patient Access Analysis to help identify areas of focus
 - Areas for alignment between patient organizations and the industry
 - State Affairs Steering Committee activities to increase access to care

- International Plasma Awareness Week
 - October 12-18, 2014

Conclusion

PPTA sincerely appreciates the participation and attendance of industry and patient organizations. If you have any questions, or require additional information, please contact Association staff.

GBS/CIDP Foundation International presentation can be found [here](#).

PPTA staff presentations can be found [here](#).

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