



# STAKEHOLDER REPORT

**The next Stakeholder Meeting will take place on Monday, June 17 in conjunction with the PPTA Plasma Protein Forum in Reston, VA.**

PPTA held a Stakeholder Intake meeting in Washington, D.C., on January 24, 2019. Representatives from the following stakeholders participated in the meeting, along with PPTA members and staff:

- Alpha-1 Foundation
- GBS/CIDP Foundation International
- Hemophilia Federation of America
- Immune Deficiency Foundation
- Jeffrey Modell Foundation
- National Hemophilia Foundation
- Platelet Disorder Support Association
- U.S. Hereditary Angioedema 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 opportunities to collaborate.

PPTA's new President & CEO, Amy Efantis, introduced herself to the group. She stated she looks forward to the future of the Association and collaboration with patient groups.

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

- Blood safety
- Co-pay accumulators
- Development of a database for patient outcomes
- Education and awareness
- Importance of grassroots advocacy
- Information sharing on advocacy priorities
- Patient access
- 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
- The patient story
- State issues (*PDLs, step therapy, block grants, prior authorization*)

Stakeholder groups are monitoring other federal actions, including:

- PCORI Reauthorization
- Medicare IVIG Access Enhancement Act
- Prescription Drug User Fee Act (PDUFA)
- 340B Drug Pricing Program

### Stakeholder meeting presentations/videos

- [Alpha-1 Stakeholder Meeting power point presentation](#)
- [Immune Deficiency Foundation Stakeholder Meeting power point presentation](#)
- [Co-pay accumulators - Immune Deficiency Foundation](#)
- [Do Something: The Jeffrey Modell Story - Trailer](#)

### SOCIAL MEDIA

PPTA North America continues using its social media channels to increase awareness of plasma protein therapies and the rare diseases they treat. The social media channels have been used to highlight patient conferences and awareness weeks, International Plasma Awareness Week, and to communicate directly with policymakers. PPTA encourages all patient groups to continue their interaction with our social media channels. Please do not hesitate to reach out to Mat Gulick ([mgulick@pptaglobal.org](mailto:mgulick@pptaglobal.org)) to coordinate any upcoming events or campaigns.



**HOW IS  
YOUR DAY?**

MAKING THE DIFFERENCE WITH PLASMA PROTEINS.

The "How Is Your Day?" campaign launched in early 2018 and is a global effort to increase awareness of the diseases impacted by access to plasma protein therapies (PPTs), the importance of donors as the source of the therapies' starting material,

and the unique value provided by PPTs to individuals, their families, and their communities. The campaign exists primarily online via a dedicated website ([www.howisyourday.org](http://www.howisyourday.org)) and on social media (@HIYDglobal on Facebook and Twitter). Meeting attendees were thanked for their support of the HIYD campaign to date and were encouraged to continue engaging with its social media posts and sharing information with their networks.

Get involved and follow "How Is Your Day?" on social media:



### North America Contacts

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