



STAKEHOLDER REPORT

PPTA held a stakeholder meeting in Washington, D.C., on June 17, 2019. The following stakeholders participated in the meeting, along with PPTA members and staff:

- GBS|CIDP Foundation International
- U.S. Hereditary Angioedema Association
- Immune Deficiency Foundation
- National Hemophilia Foundation (Cavarocchi-Ruscio-Dennis Associates)
- Hemophilia Federation of America
- Jeffrey Modell Foundation

The antitrust statement was acknowledged by all.

PPTA's Senior Vice President, North America & Global Health Policy welcomed participants to the Stakeholder meeting which provides the opportunity for the Association to interact with stakeholder groups and better understand their advocacy priorities and collaborate on patient access to care advocacy.

Industry Overview

PPTA's President & CEO welcomed attendees and presented an overview of the plasma protein therapeutics sector, including topics regarding access and industry actions such as plasma collection and plans to expand facilities. (See attached presentation)

North America Data Program

PPTA's Vice President, Legal Affairs offered a presentation about PPTA's North America Data Program. PPTA and its member companies work with an independent, third-party firm provide anonymized, historical, aggregate information to PPTA every month (on a three-month lag) illustrating distribution data for a range of plasma protein therapy products. Data provided adheres to the industry's standard operating procedures to avoid any issues with antitrust law. PPTA makes historical, aggregate information available via its website every month. The charts that are currently posted on PPTA's Web site, which show monthly distribution plotted against a rolling 12-month average, are supplemented with the underlying spreadsheets. The spreadsheets do not present new information, but rather present the same information in a second format (i.e., the distribution figures presented in the spreadsheets are the figures used to generate the charts).

It is hoped that this format change will provide program stakeholders with an even clearer understanding of what the data represents (particularly stakeholders that access the data via PPTA's Web site - e.g., patients, physicians, pharmacists, etc.). The spreadsheets will provide the aggregated data itself, with the charts providing a clear trend line for use as an interpretive aid. (See attached presentation)

IDF 2017 National Patient Survey

John G. Boyle, President & CEO of the Immune Deficiency Foundation, gave a presentation containing highlights and data from IDF's most recent national patient survey. Findings include information about the age at which people are diagnosed as having a PI, the delivery route of their prescribed immunoglobulin product, and tolerance of their prescribed product, among others. (See attached presentation)

PPTA Access to Care Priorities

Federal activities

The Senior Director, Government Relations presented the current activities and priorities for Federal Relations at PPTA. Foremost is preserving access to all plasma protein therapies, particularly in Medicare and Medicaid federally funded programs. First among the priorities was protecting the "four pillars" as demonstrated during the recent PPTA Capitol Hill Fly-in. One of the goals of PPTA advocacy is to demonstrate and educate decisionmakers concerning the value and differences of non-interchangeable biologic PPTs. Regulatory initiatives from Health & Human Services were discussed along with PPTA's position on each. Finally, congressional activity and legislation was highlighted along with "IPAW on the Hill" and a collaborative briefing effort. (See attached presentation)

State activities

PPTA's Senior Director of State Affairs began his update by thanking the APLUS for meeting with him to discuss advocacy efforts that could help improve plasma donation in the United States. He also shared concerns with issues in the states that may impact Medicaid recipients' access to plasma protein therapies. There are the known issues with state cost-containment strategies such as preferred drug lists with step therapy requirements. Additionally, there are emerging issues that may impact access. (See attached presentation)

The emerging Medicaid issues that could negatively impact patient access include:

- Block Grants;
- Work Requirements;
- Closed Formularies;
- Value-Based Purchasing, and
- State's Declining to Reimburse for 340B.

"How Is Your Day?":

Opportunities to Engage

The Director, Global Communications shared an update regarding PPTA's "How Is Your Day?" campaign, noting a new FTE will soon join the Association and will focus primarily on HIYD's social and traditional media outreach.

Additionally, the Global Board recently approved a revision to the campaign's tagline; the new tagline will be "Plasma Donors Save Lives," expanding the focus of the campaign to reflect the importance of plasma donors as the unique source of many PPTs, while also remaining focused on the therapies themselves and the impact they have on patients and communities. He also expressed gratitude to the Stakeholder groups in the room for their efforts to amplify the campaign's messages and encouraged dialogue about ways in which the HIYD campaign and Stakeholders could continue partnering to bring awareness to the campaign, plasma donors, and the patients who rely on access to these therapies.



Stakeholder meeting presentations/videos

- [Presentation by Amy Efantis, PPTA President & CEO](#)
- [North American Data Program Overview and Operational Update](#)
- [IDF 2017 National Patient Survey](#)
- [Federal Priorities](#)
- [State Patient Access](#)
- [Presentation by Mathew Gulick, PPTA Director, Global Communications](#)

North America Contacts

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