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STAKEHOLDER REPORT

On March 5, 2015, PPTA held its annual stakeholder intake meeting via teleconference.

The following patient groups participated in the call, along with PPTA North America Board members and staff:

- Alpha-1 Association/Alpha-1 Foundation
- Committee of Ten Thousand
- GBS/CIDP Foundation
- Hemophilia Federation of America
- Immune Deficiency Foundation
- National Hemophilia Foundation
- Patient Services Inc.

PPTA's Vice President, Legal Affairs, referenced the PPTA meeting guidelines and reviewed the antitrust compliance rules. Representatives from the Hereditary Angioedema Association were unable to participate.

PPTA noted that this first meeting of the year is important as it is a key factor in the Association finalizing its 2015 patient access 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.

Several common concerns emerged:

- Importance of data-driven advocacy positions
- Continued need for advocacy at the federal and state levels



Save the Date!

The 2015 Plasma Protein Forum will be June 16-17 at the JW Marriott in Washington, D.C.

Registration will be available soon on the PPTA [website](#).

- Specialty tiers
- Biosimilars
- Hemovigilance
- Patient assistance programs issues
- Support for the PNS

Stakeholder Plans and Priorities

In addition, stakeholders articulated specific plans and priorities:

Alpha-1 Foundation

- Challenges on patients and access to portable liquid oxygen.
- Challenges with patient assistance programs: low on funds; can't accept new patients;
- Increasing awareness on pulmonary diseases;
- Reimbursement.

GBS/CIDP Foundation International

- Ensure GBS is recognized as a condition eligible for study through the Dept. of Defense Peer-Reviewed Medical Research Program in 2016;
- Expand the GBS, CIDP, and related conditions research portfolio at National Institutes of Health through 2016 growth and by increasing awareness in Congress;
- Improve patient access to quality, affordable health care and innovative therapies;
- Participate in community advocacy efforts on improving the drug development pipeline and facilitating treatment development;
- Cultivate a network of grassroots advocates to engage their elected officials;
- Stay current and engaged on relative legislative and public policy issues by monitoring media, participating in advocacy activities and attending Capitol Hill events.

Hemophilia Federation of America

- Specialty tiers legislation;
- Premium Assistance (PSI);
- Continue to support members in third-party payer issues;
- Working to assure adequate funding for CDC
 - 21st Century Cures Initiative
- Working with coalitions to ensure FDA is making biosimilars safe;
- Blood safety vigilance programs;
- Leading a Patient Notification System (PNS) Sign-up Campaign in 2015 that so far has helped increase PNS registrants;
- Continued focus on encouraging patients with bleeding disorders and their families to become strong self-advocates.

- Focus on the campaign, "Honor Our Past & Building Our Future."

Immune Deficiency Foundation

- Shared results from the 2014 IDF Health Insurance Survey. IDF develops data driven advocacy positions and their experience has been that good data makes a difference. IDF will be publishing a report on all results;
- Medicare IVIG Demonstration. For the first time, patients are receiving infusions at home;
- Is involved in six state access to care coalitions that have proposed specialty tier legislation;
- Engages when there are access issues with payers;
- Implementation of the Affordable Care Act;
- Advocating that the patient voice be heard in the biosimilar approval process;
- Newborn Screening for Severe Combined Immune Deficiency—now taking place in 27 states;
- American Plasma Users Coalition (A-PLUS).

National Hemophilia Foundation

- Just completed a Washington Day with 250 attendees advocating on hemovigilance programs, legislation for SNF and specialty tier bill;
- Continues to monitor FDA's announced change in MSM donor deferral;
- Closely monitoring FDA activities on biosimilars;
- Working on updating Guidelines for Comprehensive Care; next set of guidelines will address von Willebrand disease. Future goals include guidelines on aging in hemophilia, prophylaxis, and inhibitors in hemophilia;
- Finalizing an advocacy toolkit for use with state chapters.

Patient Services Inc.

- Number one issue is third party payers
- Working on advocacy at the federal level and also looking to introduce legislation in South Carolina.

Patient Notification System

The Patient Notification was a discussion point on the call. Val Bias on behalf of NHF summarized MASACs recent interest and desire to increase the number of registrants. NHF may consider a pilot program to introduce an Opt-In feature. The difficulty of maintaining a patient's engagement in a system that does not provide regular communications was mentioned. The HFA next shared with participants their recent initiative to reach out to their membership in an effort to raise awareness and provide patients with information on the PNS. HFA launched a significant campaign to empower patients so they can make an informed choice regarding PNS registration. HFA's multi-faceted (symposium, print,

Facebook, Twitter, email push) initiative is geared towards providing information. HFA's Patient Notification Sign-Up Campaign is patient focused and is having a positive impact increasing the number of PNS registrants.

Important dates to calendar are the May 13, PPTA congressional reception and May 14 Capitol Hill Fly-In. In closing the meeting, participants were reminded that a face-to-face dinner meeting will be held in conjunction with the Plasma Protein Forum (PPF) on June 15 from 5:30 p.m. - 8 p.m. at the J.W. Marriott, Washington, D.C.

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