



## Stakeholder Report

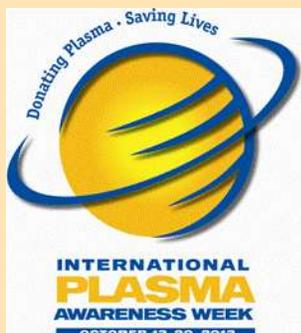


September 25, 2013  
Volume 11, Issue 2

[Avalere Considers Marketplace](#)

[PSI Discusses Patient Assistance Organizations](#)

[Stakeholders and ACA Outreach](#)



Representatives from U.S. based patient organizations, the North America Board, member companies and PPTA staff met on September 18 in Washington, DC. Representatives from the following organizations attended:

- Cavarocchi-Ruscio-Dennis Associates, LLC  
(on behalf of Jeffrey Modell Foundation)
- GBS/CIDP Foundation International
- Hemophilia Federation of America
- Immune Deficiency Foundation
- National Hemophilia Foundation

Invited guests included Avalere Health and Patient Services, Inc.

- A representative from Avalere Health LLC presented "[The Rare Disease Marketplace: Effects of Healthcare Reform](#)". The presentation noted that the goals of healthcare reform are to make insurance more accessible and affordable for all, pay for quality instead of volume of care and find sustainable ways to pay for reform provisions. The Affordable Care Act (ACA) is expected to significantly reduce the number of uninsured Americans through health care exchanges, revised Medicare and Medicaid enrollment eligibility and premium and cost sharing subsidies. Each state is crafting its own implementation to meet Essential Health Benefits requirements leading to a lack of understanding and confusion, particularly with regards to out of pocket expenses. Formularies also vary greatly from state to state. The rare disease community should benefit as out of pocket expenses caps may be met with the first prescription filled. A concern for the rare disease community is whether or not manufacturers will be able to provide assistance for those covered by exchange plans and this may not be decided until January. Patient education and outreach will be key and noted that it appears that CMS is not ready to launch by the October 1 deadline as there are unresolved issues and key personnel staff have not been trained.
- Patient Services Inc. presented "[The Effect of the ACA on Patient Assistance Organizations](#)". An overview of PSI and the assistance they offer was discussed. Several key points relating to the ACA were highlighted. Specifically, does the ACA create an under-insured population and will the benefits in the new plans be sufficient. With respect to the impact of reform patients who rely on plasma protein therapies, the Appeals process may be key to collecting data and a

tracking mechanism to chart access to EHBs. There was general consensus among the group that this was advisable and A-PLUS is working to design a format that is acceptable to relevant stakeholders. PPTA requested that any findings be shared. It was noted that the impact on patient assistance programs is still unclear, as well as how smoothly patients will transition from PCIP and state high-risk pools to exchanges or Medicaid. Additionally, ACA navigators aren't focused on chronic illnesses and access to and cost of specialty tiers remains a key issue. PSI has applied to be a certified application counselor. It is likely that most people will not enroll until November/December and that things may have leveled off by then.

- A-PLUS Perspectives on the ACA were discussed and it was noted that although each organization is working with its own constituency they are collectively working to comment, review and express the needs of rare disease patients via webinars, development and distribution of informational materials and an insurance toolkit. A-PLUS will collect data and information from all patient groups effective in January so that the effect of the ACA on rare disease patients can be evaluated over the next few years. The Hemophilia Federation of America is working to make advocacy personal. They will host a Hill Day on October 22 and a reception on October 23 where Representatives David McKinley (R-WV), Hank Johnson (D-GA) and Lois Capp (D-CA) will be honored. They are using web technologies including a biweekly blog to answer patient questions, as well as Issue Briefs. The GBS/CIPD Foundation International is enhancing its advocacy staff and will explore improving web-based advocacy information. The National Hemophilia Foundation is working to educate consumers and educate payers and social workers via webinars, symposia and a web-based portal with interactive case studies. They have developed a revised toolkit with new fact sheets and will share with other groups. IDF is focused on educational activities and adapting the online toolkit for PID patients. They are also working on to improve staff ability to address questions and collect and analyze data on how the ACA affects patients. The Jeffrey Modell Foundation is not as active on ACA-related patient advocacy issues and refers to information from IDF on this topic.
- PPTA staff also delivered presentations. The Association's key federal issues including preserving access to Medicare Part B reimbursement, advocating for the Annual Pharmaceutical Fee and patient access issues during ACA implementation were discussed. PPTA staff reviewed recent revisions to QSEAL standards which are global and complement regulatory requirements that differ among jurisdictions. An update on International Plasma Awareness Week (IPAW), an inaugural event slated for October 13-20 and expressed appreciation for the support the Association has received from patient organizations in both the U.S. and Europe. PPTA appreciates the support it has received from patient organizations for IPAW.

#### *Related News*

- PSI provided an [NASCHIP chart](#) which includes an up-to-date list of when each state is planning to close their high risk pool post-ACA, as well as those that have yet to decide. Fifteen will close by January 1st or shortly thereafter, five are undecided, and the rest will remain open beyond mid-2014.



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