

If you are having trouble viewing this message, please [click here](#).



Stakeholder Report



April 24, 2012

In This Issue

[Health Care Reform Tops A-PLUS Agenda](#)

[Collaborative Opportunities on Federal Issues](#)

[State managed Medicaid Dominates Agenda](#)

[Advocacy Toolkit Provides One-Stop Resource](#)

Executive Summary

Consumer organizations, industry representatives, and PPTA staff convened in Washington, DC on April 12, for the second Stakeholder Meeting of 2012.

The meeting was well attended with representatives from:

- A-PLUS
- Committee of Ten Thousand
- GBS/CIDP Foundation International
- Hemophilia Federation of America
- Immune Deficiency Foundation
- Jeffrey Modell Foundation
- National Hemophilia Foundation
- National Organization of Rare Disorders
- Platelet Disorder Support Association

Health Care Reform Tops A-PLUS Agenda

- The implementation of health care reform is the top priority for A-PLUS. Specifically, they want to ensure that states are acting equitably in the treatment of persons with rare diseases. They are focusing their advocacy and efforts on State Health Exchanges and Essential Health Benefits. The first of a webinar series, "[Health Care Reform in Your Backyard](#)", designed to train grassroots supporters in basic advocacy skills was held. The next webinar will focus on State Health Exchanges.
- The consumer organizations are also interested in trying to establish an ombudsman position at the Health and Human Services (HHS) Secretary level specific to rare diseases. The National Organization of Rare Disorders has submitted a draft proposal for HHS to consider this. Some states have an ombudsman, but no reporting on activities has occurred yet. Both are needed to represent the needs of rare disease populations with regard to Essential Health Benefits. There has also been outreach to Bio.
- The groups were also concerned with insurance issues, particularly co-pay and co-insurance levels and out of pocket costs for those that require lifelong therapy.
- Finally, as the Food and Drug Administration's (FDA) Blood Product Advisory Committee (BPAC) and other countries begin to consider revising MSM donation restriction policies, a concern was raised about possible safety issues. PPTA staff is holding a follow-up conference call with consumer representatives staff to address this issue.

PPTA

- Staff unveiled the revamped [Advocacy Toolkit](#) designed to provide a one-stop resource for consumers to learn about plasma protein therapies, the disorders, and the Association's patient access advocacy agenda for both the U.S. and Europe. The toolkit provides instant access to the [Patient Notification System](#), the [North America Data Program](#), issue briefs, comment letters, fact sheets, publications and more. Consumer organizations are encouraged to use the toolkit to complement their advocacy efforts, educate grassroots staff and volunteers, and strengthen communications.
- The [Capitol Hill Fly-In](#) will be held on May 9 in Washington, DC. To date, over 100 meetings have been scheduled with legislators and staff. Attendees were invited to participate and submit suggestions for discussion items. All participants are invited to a dinner on the evening of May 8. RSVP to [Danene Goffney](#), 443.433.1111.
- The [Federal Affairs team](#) highlighted opportunities with several issues and solicited feedback and discussion including: greater collaboration regarding the [Annual Pharmaceutical Fee legislation \(see Dobson Davanzo\)](#), potential joint outreach to [Patient-Centered Outcomes Research Institute \(PCORI\)](#) Executive Director regarding rare disease research, the possible financial impact of [Sequestration](#) later this year and the pending Supreme Court decision on health care law this summer.
- The [State Affairs presentation](#) focused on issues related to state managed Medicare and health care reform implementation. State Medicaid programs, which do not have a great track record for transitioning populations from fee-for-service to managed care, are beginning to place Medicaid recipients with rare, chronic conditions in Medicaid managed care organizations. Some of these Medicaid managed care organizations will have little to no experience in coordinating care for individuals that rely on access to plasma protein therapies. It is essential that the patient community become proactive in educating state decision-makers on their needs to have access to certain providers and plasma protein therapies.

Action Items

PPTA will do the following:

- Create a webinar for state level grassroots advocacy
- Prepare a spreadsheet of various options that will facilitate a discussion on reasonable out-of-pocket costs
- Share more information and an agenda for the Capitol Hill Fly-In
- Organize a meeting between patient community representatives and the Executive Director of the National Association of Medicaid Directors (NAMD) at the Plasma Protein Forum (PPF) in June
- Organize a meeting with the PCORI Executive Director

Conclusion

PPTA sincerely thanks everyone for their participation. We hope to see you at the [Capitol Hill Fly-In](#) and the [Plasma Protein Forum](#).

If you have any questions, or require additional information please contact us.

[Julie Birkofer](#), Senior Vice President, North America
[Everett Crosland](#), Manager, Federal Affairs
[Danene Goffney](#), Project Coordinator, North America
[Kym Kilbourne](#), Director, Federal Affairs
[Lisa LoVullo](#), Senior Manager, Communications
[Bill Speir](#), Director, State Affairs

If you have any queries or would like to add a recipient to our electronic mailing list, please contact the association office.

[Forward to a Colleague](#)

Annapolis Office
147 Old Solomons Island Road
Suite 100
Annapolis MD 21401 USA
tel: +1 202 789 3100
fax: +1 410 263 2298
ppta@pptaglobal.org

Washington Office
Washington Harbor
3050 K Street NW Suite 400
Washington DC 20007 USA
tel: +1 202 789 3100

To ensure delivery of *Stakeholder Report*, please add 'ppta@pptaglobal.org' to your email address book or Safe Sender List. If you are still having problems receiving our communications, see our [white-listing page](#) for more details.

If you would like to safely unsubscribe from this email list, [go here](#).