

## Health Policy Update

### **Communications**

#### **Politico Advertorial**

April 28, 2009, PPTA ran the 8-page advertorial in *Politico* newspaper and launched the microsite [www.Politico.com/preservepatientaccess](http://www.Politico.com/preservepatientaccess) that contains the same content as the print piece. This advertorial provides information to policymakers and key stakeholders about plasma protein therapies, the patients and diseases they treat and how they are different from traditional chemical pharmaceuticals. It conveys messages regarding the need to protect patient access and the uniqueness of the patient groups and specialized therapies, and uses rare disease language to enhance our argument. Because Politico.com is one of the most widely read on-line newspapers in the country at nearly 4 million visitors per month, the reach of this information is tremendous.

In addition to raising awareness about the therapies, industry and plasma collection, several national consumer organizations partnered with PPTA on the content to discuss the needs of their communities and advocate for specific legislation. PPTA will have 5,000 reprints of the advertorial for use by members, staff and stakeholders for their advocacy work.

**Please visit the link [www.politico.com/preservepatientaccess](http://www.politico.com/preservepatientaccess) and review the content. I encourage all stakeholders where appropriate to distribute this link to your constituencies and to provide their feedback through the "Tell Us What You Think" link in the**

**left navigation of the microsite** or to email Kym Kilbourne at PPTA at [kkilbourne@pptaglobal.org](mailto:kkilbourne@pptaglobal.org).

We appreciate the collaboration with several patient organizations that are advocating on behalf of their members for this *Politico* advertorial and believe it is a great piece to share with any key opinion leader to help them understand more about the industry and the needs of plasma protein therapy users. If you would like to receive copies please contact Kym Kilbourne.

#### **CIDP Awareness**

When news reports indicated that famed former football player William "The Refrigerator" Perry was battling CIDP, PPTA took the opportunity to build upon that news story by distributing a release that discussed how CIDP is treated with IVIG, how IVIG is made and to note the introduction of the IVIG Access Act.

This news release was distributed via PR Newswire to key reporters who cover health across the country and is posted on [www.pptaglobal.org](http://www.pptaglobal.org) in the News section.

PPTA continually looks for opportunities to promote the need to ensure patient access to plasma protein therapies and to provide information about how plasma protein therapeutics are manufactured, along with their vital role in treating patients with rare, genetic diseases.

#### **Swine Flu**

The Association confirmed that therapies produced by PPTA members remain safe

and available, in response to news reports on the swine influenza virus. Please visit [www.pptaglobal.org](http://www.pptaglobal.org) News section to view the Association's statement.

## **Federal Action**

### **Medicare Patient Access**

#### **New Leadership**

Fearing another difficult primary in his bid for re-election, now former Senate Committee on the Judiciary Ranking Member Arlen Specter (D-PA) switched political parties from Republican to Democrat. While this switch will cost Specter his Ranking Member slots on the Labor, HHS, Education Appropriations Subcommittee in addition to his Judiciary post, it will likely ensure he will win his new party's nomination for re-election as he vies for a sixth term as he approaches 80 years old. More importantly, Specter's April 28<sup>th</sup> announcement will give the Democrats a 60 vote filibuster proof majority if Al Franken is seated as Minnesota's second Senator in the coming weeks, as expected. While it may not be as indicative of a total power shift as many pundits believe because of the fiscally conservative nature of many of the moderate Democrats in the Senate, this additional caucus member should allow President Obama to move his health care reform agenda a bit more easily.

**Kansas Governor Kathleen Sebelius was confirmed by the Senate to be the new Secretary of the Department of Health and Human Services (HHS)** on a largely party line vote. Senators Bond, Brownback, Collins, Gregg, Lugar, Roberts, Snowe, and Specter (whose vote was counted as a Republican vote) were the only Republicans to support her in a 65-31 vote.

#### **Health Care Reform**

On April 29, 2009, Senate Committee on Finance Chairman Max Baucus (D-MT) and Ranking Member Charles Grassley (R-IA)

released set of policy options for reforming the nation's health care delivery system to make sweeping changes in the operation of Medicare, including shifting the program from volume-based purchasing to value-based purchasing. This document should serve as an outline for the Finance Committee's legislation, which would also include a reintroduction of the comparative effectiveness research legislation from Baucus and Senator Conrad, S. 3408 of the 110<sup>th</sup> Congress. Again, this legislation would establish a permanent, independent entity to conduct and manage the conduct of the research. The paper released by Baucus and Grassley makes clear they intend to protect subpopulations of patients by limiting the ability of HHS to "automatically link[] the research findings to coverage or reimbursement decisions in public programs" until proper consideration has been given to the potential effect of the results on patient subpopulations and public comments are evaluated.

With regard to health care reform, the Budget conferees agreed to use the reconciliation process if health care reform is not passed through regular order by October 15, 2009. Using this tool would eliminate the need for a filibuster proof majority of 60 or more votes for passage, as a simple majority is sufficient for reconciliation members.

## **State Action**

### **Market Access**

#### **Minnesota**

Minnesota Senate File 339, a standards of care bill ensuring quality care for individuals with primary immune deficiency, alpha-1 antitrypsin deficiency and von Willebrand disease passed out of the Senate Health, Housing and Family Security Committee on March 26, 2009. The bill was the first of its kind to pass out of any legislative committee in any state, and it could not have been done without the tireless efforts of the

patient community. The community and PPTA will continue to work the bill during the interim between the Sessions in hopes of passing the bill, along with its companion, House File 410, during the 2010 Minnesota Legislature.

PPTA has engaged in with the patient organizations and the State Affairs team on media relations in support of the Minnesota Quality of Care legislation (S.F. 339 and H.F. 410). Two recent news stories ran in support of this bill: the first featuring advocate Kathy Antilla (who also works with the Immune Deficiency Foundation) and her son Isaac, who has primary immunodeficiency disorder in the Isanti County News titled, [Hope for 'Quality of Care'](#) ran on April 1. The second, [Fighting a Rare Disease and Insurance Companies](#), featured alpha-1 advocate Julie Knutson was broadcast on the Minneapolis/St. Paul CBS broadcast affiliate, WCCO, on April 23.

### Washington

In the State of Washington, the House and Senate proposed budget language that would limit the provision of hemophilia services to one 340 B provider in the state. A coalition of patient groups, manufacturers and specialty pharmacy were able to persuade both chambers to place in language that would allow more than one provider of care through a competitive procurement process. Given the budget problems in so many states all parties concerned about patient access to their medically appropriate therapy must remain vigilant about such proposals in the future.

## Calendar



PPTA is hosting the Plasma Protein Forum June 2 and 3, 2009 at the Washington Marriott (1221 22<sup>nd</sup> Street NW; Washington, DC). Program and Registration information can be found at:

<http://www.plasmaproteinforum.com/>.

**Register Now!**  
***A special discount is available to consumer organizations – contact Diana Krueger for details.***

**The Advisory Committee on Blood Safety and Availability (ACBSA)** meetings are tentatively scheduled for April 20 – May 1 and October 1-2 at the Universities at Shady Grove (9630 Gudelsky Drive, Rockville, MD 20850).

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**Visit: <http://www.donatingplasma.org/>**

This PPTA publication aims to keep Stakeholders apprised of evolving state and federal health policy developments. **To provide feedback or to add colleagues to the distribution list, please contact Diana Krueger at the Association.**

*PPTA Staff is always available to attend consumer organization functions, make presentations, and assist in developing advocacy strategies and messages, as appropriate, with consumers. Please contact PPTA Staff at any time to discuss these activities.*

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