



# THE IMPORTANCE OF STAKEHOLDER MEETINGS IN THE U.S.

PPTA recognizes the importance of working with Stakeholders. But, what does this really mean? How do we “work” with Stakeholders and what are they? Let’s take a look.

**A**CCORDING TO MERRIAM WEBSTER’S DICTIONARY, the word stakeholder dates back to 1708 and is associated with a person who is “entrusted with the stakes of bettors.” Now, this strict definition is interesting because of its use of the word “entrusted.” As we know, trust is a basic building block of which most successful relationships are built. I think it is important to broaden how the term is used today in the context of an advocacy. After an Internet search, I came across an article titled, “Identifying health care stakeholders: a key to strategic implementation.” The Abstract from this article states:

*“As the number and complexity of stakeholders for health care organizations has increased, health care managers have become more aware of the ability of these groups to thwart or facilitate the implementation of strategic plans. Most stakeholder models have focused on identification of groups within the usual, global definition of affecting or being affected by an organization’s actions. The authors argue that stakeholders management is critical to the implementation of strategic plans... The situational evaluation of stakeholders is critical to successful implementation of strategy.”*

The above definition reflects the purpose of PPTA’s outreach to stakeholders. Since the early 1990’s, PPTA has each year regularly convened with consumer organization representatives, regulatory agency representatives, representatives from the U.S. Department of Health and Human Services, industry experts and Association staff. Central to our legislative and regulatory successes are developing unifying action plans for common goals such as patient access to plasma protein therapies and alignment on advocacy issues. The single largest benefactor of Stakeholder Meetings are the patients who rely on life-sustaining plasma protein therapies. Stakeholder meetings help PPTA establish rapport with patient organizations to better understand the concerns of the patient community. PPTA can help individuals identify state legislative priorities and how these priorities affect strategic issues of patient access, while explaining important safety developments and industry standards programs.

## Stakeholders are mission critical to PPTA

Two elements of the Association’s Mission Statement are: “Educating all stakeholders about the value of the therapies” and “Supporting government reimbursement practices that reflect the unique nature of plasma protein therapies.” These two provisions are the foundation of the Association’s state and federal based advocacy programs. PPTA has a wealth of information available on its web site, [www.pptaglobal.org](http://www.pptaglobal.org). Click *Patient Resources* and it will bring you to a page with a menu of options applicable to both the U.S. and Europe. There are several items of interest posted, such as comprehensive Fact Sheets and the informative “Plasma Protein Therapies Stakeholder Toolkit.” This informative advocacy tool is chock-full of documents that

can be used in visits with legislators and policymakers.

Stakeholder Meetings are important because they promote an understanding of where the Association's concerns and those of stakeholders align. Knowledge of this alignment allows us to coordinate messages to decision-makers. This is essential because decision-makers care more about the impact of public decisions on constituents than corporations. Therefore, Stakeholder Meetings are a vital component of our public advocacy strategy.

In the states, decision-makers are asked to balance their state budgets. Often this involves reductions in Medicaid spending. Limiting patent access to pharmaceuticals through various cost-containment strategies is a common technique for Medicaid savings.

When decision-makers are considering strategies that limit patient access to pharmaceuticals, it is important that the Association and our stakeholders educate the decision-makers with a similar message on the need for patient access to the medically appropriate plasma protein therapy because of high impact, lifesaving nature of these therapies. The Stakeholder Meetings allow for the necessary dialogue to prepare for these threats.

#### Coalitions Enhance Patient Access Priorities

Stakeholder meetings provide an important forum for industry

and patient advocacy organizations to learn more about each entity's legislative and regulatory priorities. The result is a coalition approach to address threats to patient access to care and to identify solutions with a shared voice. For instance, there are a number of provisions in the health care reform legislation representing positive steps for individuals with rare, chronic diseases treated with plasma protein therapies. Consumer organizations representing users of plasma protein therapies did an outstanding job working with Members of Congress to eliminate lifetime and annual limits on insurance benefits and to end the practice of denying coverage based on pre-existing conditions. PPTA came out in strong support of these initiatives and worked hard to secure the rare disease advisory panel in the comparative effectiveness research provision in health reform. These reforms will help all Americans access and maintain the medical care they need for future generations.

PPTA, its staff and members value the participation of stakeholders in these meetings and are committed to continuing to facilitate an open forum for patient groups and industry to address challenges with accessing plasma protein therapies and other critical issues important to patient health.

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