

CHARTER

Working with External Groups

Consumer/patient organizations that represent the interests of individuals living with rare, chronic plasma protein-related diseases and deficiencies have the ability to inform policymakers, from a unique perspective, of the importance of maintaining open access to all plasma-derived and recombinant analog therapies (collectively, “plasma protein therapies”). Consumer/patient organizations and PPTA member companies often can be more effective in their patient access advocacy efforts by working collaboratively within a clear framework.

In pursuit of those common interests, PPTA may undertake specific activities with active patient-led groups. PPTA does so primarily by bringing together external groups that advocate for access to plasma protein therapies. These groups may include members from consumer/patient organizations, physicians and medical specialty societies. Two primary groups currently exist within the Association: the Plasma Protein Users Group, which meets in Europe; and the Stakeholder Group, which meets in North America. Although the names differ, the goals remain the same – to establish common objectives and seek message alignment with external groups on issues related to patient access to plasma protein therapies. Activities undertaken by these groups may include the organization of events and meetings, the publication of educational materials, the development of information campaigns and country- or state-specific health policy activities to improve patient access to care.

The key, underlying principles of this charter are:

- 1) Patient access to all brands of plasma protein therapies in all sites of service; and
- 2) Building relationships based on openness and transparency.

PPTA therefore undertakes to abide by the following conditions when working with all external entities:

- PPTA respects the independence and credibility of consumer/patient organizations, physicians and medical specialty societies;
- Consumer/patient organizations will not be asked to promote or advocate any specific treatments or therapies;
- Any financial and in-kind support of consumer/patient organizations, physicians or medical specialty societies by PPTA will be transparent;
- PPTA encourages external groups to communicate about joint advocacy efforts with PPTA and other stakeholders to external audiences;

- All work with external groups will be conducted through consultation, with mutual respect, and for the purpose of achieving agreed common goals.
- When working with external groups, any third parties acting on behalf of PPTA must agree to abide by the same set of principles; and
- The objectives and scope of any partnership shall be transparent. Examples of areas for cooperation may include:
 - Communications activities;
 - Advocacy activities, such as meetings with policymakers;
 - Mutual participation in meetings and conferences.

Support by PPTA for joint advocacy efforts with external groups has at its core the provision of mutual support and cooperation in the interest of advancing patient access to plasma protein therapies.

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