



ALPHA-1 FOUNDATION Advocacy Agenda

Public Policy Priorities

Research – Advance Alpha-1 research conducted by the National Institutes of Health and other Federal Agencies, including promoting expansion of the Alpha-1 research portfolio and conducting scientific conferences and information dissemination.

New Therapeutics – Work with the U.S. Food and Drug Administration and other agencies to ensure that new therapies are available for the treatment of Alpha-1. Ensure expedited licensure and product availability.

Targeted Screening and Detection – Promote awareness and the recommendations of the *American Thoracic Society, European Respiratory Society. American Thoracic Society/European Respiratory Society statement: standards for the diagnosis and management of individuals with alpha-1 antitrypsin deficiency. Am J Respir Crit Care Med. 2003;168(7):818–900*, to ensure effective targeted Alpha-1 screening and detection initiatives are implemented for the identification of Alpha-1 in population groups at risk, including family testing.

Access to Care – Support legislative and administrative proposals that ensure improved patient access to care. Improve health insurance benefits and reduce restrictions to public programs.

Blood Product Safety and Availability – Work closely with the U.S. Food and Drug Administration, Department of Health and Human Services, Congress, and other agencies where appropriate to promote policies that ensure the safety of blood products. Promote policies that allow the optimal collection of plasma to ensure that there are not shortages that disrupt the continuity of care for patients.

Education, Outreach, and Awareness – Work with the community to support education, outreach, and awareness to elected government officials.

Public Policy Strategies

The Alpha-1 Foundation has identified the following strategies to be employed in order to achieve the above objectives:

- Federal Advisory Committee membership
- Comments in response to proposed Federal Rule Making
- Position statements on specific issues
- Congressional testimony
- Alpha-1 specific legislation
- Strategic alliances in coalitions and membership organizations to reach out to legislators.
- Engagement of the Alpha-1 Community to achieve these goals.

Grassroots Advocacy

The success of the Grassroots Advocacy Network has grown substantially through participation in efforts with other organizations, by holding Alpha-1 Congressional Briefings, bringing patients to Capitol Hill, in Washington DC, for specific Alpha-1 lobbying agendas and by building relationships with key legislators. We will continue to expand and strengthen the effectiveness of this grassroots program and address access to care barriers through the legislative and regulatory process. To be most effective, funding is needed to generate participation in state and federal lobby activities to inform elected officials and state and federal agencies about the critical needs of those with Alpha-1.

Alpha-1 Foundation mission:

The Alpha-1 Foundation is committed to finding a cure for Alpha-1 Antitrypsin Deficiency and to improving the lives of people affected by Alpha-1 worldwide.