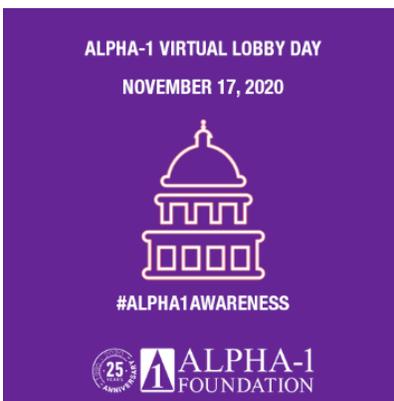


Alpha-1 main priorities and talking points



The Issues

The Alpha-1 Foundation has outlined 3 main priorities that will be presented to members of congress during the Virtual Lobby Day. These issues are:

1. Home Infusions

The Alpha-1 Foundation was among the first to alert the Centers for Medicare and Medicaid Services (CMS) about the need for augmentation infusions to be safe and offer protections to individuals with Alpha-1. The Foundation educated CMS about the detrimental health effects of skipping infusions and the risk of possible exposure to COVID-19 by going to a hospital infusion suite or a physician's office. The administration responded rapidly with the flexibility within the billing and payment system for Alphas to receive home infusions under Medicare Part B or Medicare Part D. To date, we are not aware of any Alpha-1 patients who have been able to obtain home infusions under this special provision. This is due in large part to the practices of specialty pharmacies and distributors of Alpha-1 Antitrypsin augmentation therapy.

ACTION: The Foundation will advocate for a demonstration project with business, manufacturers, and CMS that will demonstrate that home infusions are safe and cost effective under Medicare part B.

2. Make telehealth a permanent benefit for Medicare beneficiaries

As part of the public health emergency determination that was issued in 2020, telehealth services became more accessible due to reimbursement flexibilities. The Alpha-1 Foundation has taken the position of asking Congress to make telehealth a permanent benefit for Medicare beneficiaries, while also ensuring it is adequate, accessible, and affordable. This will protect vulnerable patient communities from having potential exposures to COVID-19.

ACTION: The Alpha-1 Foundation will support HR 7663, the "Protecting Access to POST-COVID-19 Telehealth Act of 2020". This legislation seeks to take critical steps toward ensuring all Medicare beneficiaries have continued access to telehealth services after the COVID-19 public health emergency (PHE) period.



3. Call for NIH to receive adequate funding

During this period of COVID-19, there have been shutdowns and delays in medical research. The Foundation has its own research programs and agenda, which intends to provide investigators with funding so they can go on to receive funding from the National Institutes of Health (NIH) for their research. Without NIH funding, the research conducted for rare disease like Alpha-1 Antitrypsin Deficiency could be in jeopardy. The Alpha-1 Foundation will ask for continued, adequate funding for NIH to continue to support funding for a wide range of medical research that benefits many rare diseases including Alpha-1 Antitrypsin Deficiency.

ACTION: The Alpha-1 Foundation will ask to provide the NIH with \$44.7 billion to the base budget in FY 2021 in order to support opportunities for life-saving medical research.

Talking Points

1. Introductions

Your story is one of the most powerful advocacy tools you can use when meeting with your elected official. It is important to remember that **YOU** are the expert – you are the one living with Alpha-1. At the beginning of each meeting, you will give a brief introduction where you will tell your story. Here are a few points to stick to when telling your story:

- Start with your name
- Tell them where you're from, and if you live and vote in their district. A personal connection strengthens your story
- Describe what it's like living with Alpha-1, or your personal connection with someone who has Alpha-1
- Talk about your personal connections with the issues being discussed today
- Keep it brief so everyone on your team has the opportunity to tell their story

2. Making the Ask

After everyone has made their introductions, your group leader will make the formal ask on each of the three priorities outlined. Following the remarks from the member of congress, your group leader will close out the meeting by thanking everyone for their time and making sure to identify the proper staff member to follow up with. Following the meeting, the Foundation will provide you with a template, which can be used to create a personalized letter which you can send to your member of congress.