February 24, 2026

Health Resources and Services Administration (HRSA)
Organ Procurement and Transplantation Network (OPTN)

Dear HRSA and OPTN Leadership,

On behalf of the undersigned patient advocacy organizations representing individuals living with advanced lung disease, lung transplant candidates, recipients, caregivers, and families, we are writing to formally request clarification regarding recent policy actions related to the Composite Allocation Score (CAS) and associated lung allocation processes.

As the only national patient advocacy organization dedicated exclusively to lung transplantation, Lung Transplant Foundation (LTF) represents the voices of lung transplant candidates, recipients, caregivers, and families across the country. Our responsibility is to ensure that this community remains informed, supported, and meaningfully included when decisions are made that directly affect access to life-saving transplantation.

Lung transplant recipients face unique and persistent challenges as compared to other solid organ transplants recipients. Lung transplant recipients experience higher rates of rejection and chronic graft dysfunction, and long-term survival outcomes are significantly less than other solid organs. While significant progress has been made across transplantation, lung transplant outcomes have not advanced at the same pace. These ongoing disparities require focused, lung specific policy attention and decision making that meaningfully incorporate both experts and patients.

In November 2025, an OPTN policy decision affecting lung transplant candidates was advanced without clear public communication, patient engagement, or implementation guidance, despite unanimous opposition from the Lung Committee, creating uncertainty for patients and transplant centers. Over the past several weeks, we have received a growing number of questions from patients, caregivers, and transplant centers regarding the process, transparency, and timing of the proposed CAS-related changes. To best support and accurately inform our community, we request clarification on the following:

1. Public Comment Period

OPTN may be proceeding under the "Emergency Actions" (E.7) pathway. If utilized, this mechanism typically includes a public comment period to allow stakeholders to review and provide input. At this time, there has been no clear communication regarding whether a public comment period will occur or when it would begin. Given the significant implications for patients awaiting transplant, a transparent and accessible opportunity for public input is essential. Please clarify your plans for holding a public comment period, including when it will begin, how it will be announced, and how long it will last for.

2. Implementation Timeline for CAS Changes

We have not seen confirmation of an implementation date or defined timeline for the proposed CAS changes. The absence of this information creates uncertainty for transplant candidates and clinical teams and makes it difficult for patients to understand how their scores, waitlist status, or transplant timing may be affected. Clear guidance is imperative to assist patients and programs in preparing appropriately. Please advise on when this change will go into effect for the lung transplant community, and how this change will be communicated to transplant centers and current lung transplant candidates in advance of implementation.

3. Consideration of Expert Committee Recommendations

We are concerned that the unanimous recommendations of the OPTN Lung Committee, comprised of subject matter experts, clinicians, and community representatives, appear to have been overridden. From the patient perspective, it is difficult to understand why expert consensus and available data were not more fully reflected in the final direction. We request greater transparency regarding how expert input and clinical evidence informed the decision-making process.

4. Consideration of the Policy

A thorough review of recent data shows Allocation Out of Sequence (AOOS) does not appear to be aligned with the realities of lung allocation and is in fact a problem that has largely resolved itself. There is concrete statistical modeling (meeting notes from the lung committee on 11/23/25) showing that reweighing the allocation of points to the Travel Efficiency category and pulling them away from biological factors such as blood type and short stature, will negatively impact waitlist mortality for lung transplant candidates, particularly among those who are most difficult to match. Can you please clarify the rationale for advancing this policy change when sufficient data does not yet exist to determine whether AOOS is clinically significant in lung transplantation.

Our intent in raising these concerns is rooted in our responsibility to advocate for lung transplant patients who often feel that policy changes occur without clear explanation or opportunity for engagement. Lung transplant candidates live with significant medical uncertainty. Transparent communication and inclusive processes are critical to maintaining trust and ensuring equitable outcomes.

We respectfully request clarification on the above points and welcome continued dialogue. We stand ready to collaborate constructively to ensure that policies reflect both clinical expertise and the lived experiences of those most directly impacted.

Thank you for your time and for your continued commitment to the lung transplant community.

Sincerely,

Amy Skiba- Executive Director
On behalf of the Board of Directors and Advocacy Committee

Patient Groups in support of this letter:

COPD Foundation

Cystic Fibrosis Foundation

Children's Organ Transplant Association

Transplant Journey, Inc

Pulmonary Hypertension Association

Cystic Fibrosis Research Institute (CFRI)

Allergy and Asthma Network

ARDS Alliance

Right2Breathe

Alveolar Capillary Dysplasia Association

Hermansky-Pudlak Syndrome Network

Alpha-1 Foundation

PF Warriors

Vasculitis Foundation

The PAP Foundation (Pulmonary Alveolar Proteinosis)

Second Wind

Transplant Families