



September 20, 2022

The Honorable Ron Wyden
United States Senate
221 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Patty Murray
United States Senate
154 Russell Senate Office Building
Washington, DC 20510

The Honorable Mike Crapo
United States Senate
239 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Richard Burr
United States Senate
217 Russell Senate Office Building
Washington, DC 20510

Dear Senators Wyden, Crapo, Murray, and Burr:

On behalf of the Cystic Fibrosis Foundation, we are writing to the committees of jurisdiction on health care to request a meeting and offer our organization's expertise as a resource for members when examining and addressing the systemic issues in organ procurement and transplant. To affect meaningful change, we strongly urge the committees to work with the Department of Health and Human Services (HHS) on a plan to implement the recommendations included in the recent National Academies of Science, Engineering, and Medicine (National Academies) report, *Realizing the Promise of Equity in the Organ Transplantation System*¹. The Cystic Fibrosis (CF) Foundation agrees with the National Academies that there is a need for systematic improvements in the transplant system and believe that many of the reports' recommendations will help address inequity in access, variation and inefficiency in system performance, and underuse of donated organs.

The CF Foundation is heavily dedicated to supporting and advocating for a strong, well-functioning transplant system. Cystic fibrosis is a rare genetic disease that affects almost 40,000 people in the United States; in people with CF, a defective gene causes a thick buildup of mucus in the lungs, pancreas, and other organs. In the lungs, the mucus obstructs the airways and traps bacteria, leading to infections, extensive lung damage, and eventually, respiratory failure. Historically, over 200 individuals with CF have received an organ transplant each year, with CF accounting for ~10-15% of the annual lung transplant volume. Although lung transplants have declined dramatically since 2019 due to an impactful new therapy, people with CF will continue to require transplantation each year. With that in mind, we regularly provide feedback to various entities involved with the transplant system, including HRSA.

Our expertise in transplantation goes beyond our advocacy work. The CF Foundation has invested millions of dollars in research related to lung transplantation; created a multicenter CF lung transplant consortium to share best practices and facilitate transformational research in transplant, launched a lung transplant-specific biorepository and patient registry; and developed new clinical care guidelines. We have formed working groups and sponsored events dedicated to addressing the needs of people with CF and their caregivers before, during, and after transplant—a process for which our CF care teams

provide direct guidance. This work is guided by a steering committee of experts in adult and pediatric pulmonology, lung transplantation, and critical care medicine.

The CF Foundation is dedicated to using this expertise to serve as a resource in the ongoing and much-needed effort to improve the transplant system. We would welcome the opportunity to meet and discuss these issues with you further. To arrange a meeting, please contact David Elin, Senior Director of Policy and Advocacy at delin@cff.org. Thank you for your leadership on this critical issue; we support your efforts to reform the organizational issues of the US's organ procurement and transplant network and look forward to working with you on behalf of people with CF and their families.

Sincerely,



Albert Faro, M.D.
Vice President, Clinical Affairs
Cystic Fibrosis Foundation



Mary Dwight
Chief Policy and Advocacy Officer
Cystic Fibrosis Foundation

CC: The Honorable Chuck Grassley

¹ <https://nap.nationalacademies.org/read/26364/chapter/1>