



February 11, 2020

Thomas Engels
Administrator
Health Resources and Services Administration
U.S. Department of Health and Human Services
5600 Fishers Lane
Rockville, MD 20852

RE: HRSA-2019-0001, Removing Financial Disincentives to Living Organ Donation

Filed electronically at <https://www.regulations.gov>

Dear Administrator Engels:

On behalf of the Cystic Fibrosis Foundation (CFF), we write in response to the HRSA proposed rule *Removing Financial Disincentives to Living Organ Donation*. We thank HRSA for this opportunity to provide feedback on potential changes to allowable reimbursements for living donors.

Cystic fibrosis (CF) is a rare genetic disease that affects over 30,000 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. Over 250 people with CF received transplants in 2018, the majority of which were lung transplants. However, some people with CF also may require liver or kidney transplants due to the disease.

We applaud HRSA for its efforts to increase the pool of available organs by addressing potential financial disincentives for living donors. HRSA's existing reimbursement program provides vital support for individuals who are interested in becoming a living donor but who would otherwise lack the financial means to cover associated expenses. Reimbursement for costs associated with childcare, eldercare, and lost work will help reduce the overall cost burden for interested individuals.

Given the high morbidity and mortality for people in need of a transplant, this small investment has the potential to make a truly impactful change for patients awaiting donor organs. This is a practical solution for making living organ donation more feasible for many potential donors, and it is an important step for addressing the national shortage of donor organs.

Once again, we thank HRSA for this opportunity to provide feedback on potential changes to allowable reimbursements for living donors. We are happy to serve as a resource and look forward to working alongside HRSA in the future on this issue.

Sincerely,

Albert Faro, M.D.

Handwritten signature of Albert Faro in black ink.

Vice President of Clinical Affairs
Cystic Fibrosis Foundation

Mary Dwight

Handwritten signature of Mary Dwight in black ink.

Chief Policy and Advocacy Officer
Cystic Fibrosis Foundation