

April 5, 2025

Subject: Resignation from the Organ Procurement and Transplantation Network (OPTN) Board of Directors

Dear Dr. Formica and Members of the Board,

With deep regret, we submit our resignations from the OPTN Board of Directors, effective April 15, 2025. We can no longer, in good conscience, participate in the Board of an organization where our voices go unheard and our ability to effect meaningful change has been rendered negligible. The role of this Board has been severely diminished—if not outright disregarded.

Transplant patients, families of deceased donors, and families of recipients deserve representation that can genuinely advocate for their needs. Given the current instability, we believe that remaining on the OPTN Board would make us complicit in the dismantling of the existing transplant system under the guise of modernization. It would signal our implicit acceptance of the erosion of transplant patient and community voices in system operations and policy development. Moreover, it would endorse the politicization of life-and-death decisions traditionally guided by a transparent, patient-centered policymaking process. We cannot, in good faith, be part of this.

Tragically, HRSA's OPTN Modernization Initiative has overlooked a fundamental truth: the strength of the OPTN lies in its volunteers. The insights and expertise of the transplant community—voiced through OPTN committees and leadership—have been essential to both the system's successes and its ongoing improvements. Rather than leveraging this knowledge, HRSA has chosen to dismantle the long-standing public-private partnership in favor of a government-controlled system that has already proven to be less responsive to patient needs and significantly more costly.

Now, as the consequences of these missteps become more apparent, government representatives have belatedly expressed their appreciation for our contributions and their desire for our participation in a so-called "meaningful transition," yet no legitimate transition plan has been presented. Simply transcribing meeting minutes from leadership and OPTN discussions does not constitute an appropriate or effective governance transition for the national transplant system.

We refuse to be scapegoats for the government's failure to manage its own contractors. Rather than ensuring a stable and well-governed system, HRSA has placed activists at the helm of modernization efforts—an approach that has created even greater conflict than the supposed "conflicts of interest" attributed to those of us with past affiliations on a UNOS Board. Moreover, despite many attempts from the OPTN Board and OPTN Finance Committee, we have not been provided HRSA approval of a budget, leaving us without transparency into OPTN's financial operations or those of its contractors. In good conscience, we cannot serve on a Board as a mere rubber stamp for this new system, lacking both the oversight and the accountability necessary to ensure its integrity and effectiveness.

Our concerns in this regard are set forth in greater detail in the attached critical comment filed by several patient and donor advocates who serve on the Board. As of this date, the letter has not

even been acknowledged in writing by HRSA, and there have been questions raised as to if our concerns even qualify as a ‘critical comment.’

We still have trust that the donation and transplant community will keep the system running for the benefit of patients, families, donors, and the public. However, we have no confidence in HRSA’s management of the OPTN and this is the main reason for our resignation.

We are honored to have had the opportunity to serve as volunteers on the OPTN Board, and our focus will remain on advocating for the best possible outcomes for transplant patients, living donors, and ensuring that donor families receive the respect and consideration they deserve.

Sincerely,

Macey Levan, *Living kidney donor*

Jennifer Lau, *Parent of pediatric liver transplant patient*

Kelley Hitchman, *Non-directed living kidney donor*

Julie Spear, *Donor mother/non-directed living kidney donor*

Tara Storch, *Donor mother*

Denise Abbey, *Heart transplant recipient*

Brittany Clayborne, *LVAD & heart transplant recipient/Post transplant lymphoma survivor/Pediatric heart transplant parent/donor family member*

Joe Brownlee, *Parent of two-time pediatric heart transplant recipient (effective 4/1/25)*