OPTN Modernization





@astschimera

@astsconnect

#ASTSadvocacy

ASTS URGES CONGRESS TO PAUSE AND REASSESS THE DIRECTION OF OPTN MODERNIZATION

OPTN LAW SHOULD NOT BE UNDERMINED BY AGENCY OVERREACH

- Federal government regulation of organ transplantation is wisely structured as a public-private partnership between the <u>Organ Procurement Transplant Network (OPTN)</u> and the Health Resources and Services Administration (HRSA) to prevent politicization of organ allocation.
- The OPTN's patient-centric vision is to "promote long, healthy, and productive lives for persons
 with organ failure by promoting maximized organ supply, effective and safe care, and equitable
 organ allocation and access to transplantation."
- OPTN's stated goals are to be "transparent, inclusive, and enhance public trust in the national organ donation system" as it seeks to "increase opportunities for transplants, optimize organ use, enhance OPTN efficiency, and support OPTN modernization."

AGENCY ACTION ON OPTN MODERNIZATION IS TAKING A GIANT STEP IN THE WRONG DIRECTION

- In 2023, Congress enacted the OPTN Modernization Act that authorized HRSA to contract with multiple best-in class contractors to modernize OPTN operations.
 - In two years time, HRSA has hired multiple, expensive contractors whose work is not apparent or transparent to the transplant community and it began to dismantle OPTN's public-private partnership in favor of full government control of organ allocation.
- ASTS and our patient and provider allies have been trying to work with HRSA for two years, with very little success in having HRSA understand the dangers of undermining OPTN's public-private partnership that is driven by OPTN's Board and hundreds volunteers representing patient and transplant community organizations. See our communications HERE.
 - <u>ASTS strongly supports the law</u>; but believes that HRSA has strayed too far from OPTN's mission and vision of patient-centric, clinically driven, and ethically sound organ allocation.
- Transplant patients, their family members, and donor families are –and always have been—fully
 engaged at many levels in OPTN policymaking, including as Board representatives and
 Committee members. We are no longer seeing them valued as such, as evidenced by...
 - Eight (8) of ten (10) Patient & Donor Family Representatives <u>RESIGNED</u> from the OPTN Board of Directors THIS MONTH citing HRSA as not addressing patient, donor, and family concerns.

OPTN Modernization





@astschimera

@astsconnect

#ASTSadvocacy

EXCERPTS FROM OPTN PATIENT GROUPS RESIGNATION LETTER

- ...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.
- ...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.
- 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.
- 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.

PATIENT RESIGNATION LETTER

REQUEST

Because, the current OPTN Modernization effort has not been transparent, inclusive, or enhanced the public trust in our transplant system, we fear that its current path will result in fewer transplants and less opportunity for maximal organ use. Our nation's transplant system can and should continue to operate as a collaborative effort between the OPTN, representing the transplant community, and HRSA, exercising effective public oversight.

PLEASE CONTACT THE ADMINISTRATION, HOUSE AND SENATE LEADERSHIP, OR HOUSE ENERGY AND COMMERCE OR SENATE HELP COMMITTEE LEADERS TO ASK THEM TO PAUSE AND REASSESS OPTN MODERNIZATION.