

Patient Voice Initiative: Welcome Webinar

Tuesday, February 4, 2025

6:30PM ET



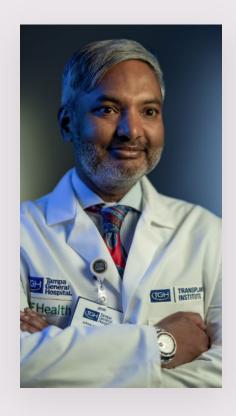
Agenda

- Welcome & Introductions to ASTS Leadership & Staff
- 2. ASTS Mission & Activities
- 3. ASTS Advocacy Landscape
- 4. Patient Voice Initiative

We encourage attendees to submit questions in the Q&A window, and we will answer all of these during the live Q&A at the end.

ASTS Leadership Joining Us Today









Ginny L. PhD **ASTS President**

Tayyab Diwan, MD Bumgardner, MD, ASTS Councilor-at-Large

Kiran Dhanireddy, MD Chair, ASTS Legislative & Regulatory Committee

Maggie Kebler-Bullock, CFRE **ASTS Executive Director**

Emily Besser, MA, CAE ASTS Associate Director, Advocacy & **Professional Practices**

ASTS Executive Committee

President



Ginny Bumgardner, MD, PhD *The Ohio State University*

President-Elect



James Markmann, MD, PhD
Penn Transplant Institute

Secretary



Debra L. Sudan, MD *Duke University Medical Center*

Treasurer



Julie Heimbach, MD Mayo Clinic

DEI Officer



Henry Randall, MD, MBA SSM Health Saint Louis University

Immediate Past President



Elizabeth Pomfret, MD, PhD *University of Colorado*

Past President



William Chapman, MD, FACS
Washington University in St. Louis



ASTS Council



Andre Dick, MD, MPH University of Washington



Tayyab Diwan, MD
Mayo Clinic Rochester



Majella Doyle, MD, MBA
Washington University in St. Louis



Jacqueline Garonzik Wang, MD, PhD, University of Wisconsin Madison



Sunil Geevarghese, MD, MSCI Vanderbilt University



Daniela Ladner, MD, MPH Northwestern University



Matthew Levine, MD, PhD
Penn Medicine



Robert Montgomery, MD, PhD

NYU Langone Transplant Institute

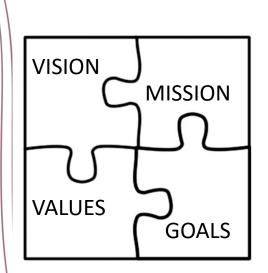


Dinee Simpson, MD *Northwestern University*

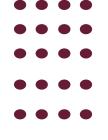


Samantha Halpern, MSN, APRN, FNP-C Washington University, St. Louis





American Society of Transplant Surgeons



- Vision: Saving and improving lives with transplantation.
- Mission: ASTS advances the art and science of transplant surgery through patient care, research, education, and advocacy.
- Values: Integrity, Excellence, Forward Focus, Respect, Diversity, and Compassion.

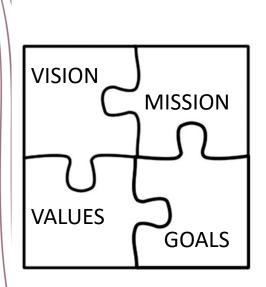












American Society of Transplant Surgeons



Strategic Goals:

- Training & Professional Development
- Research
- Advocacy
- Optimal Patient Care
- Innovation
- Lifelong Learning
- Organizational Excellence





Transplant Accreditation and Certification Optimal Patient Care -> Transplant Surgery Workforce



The Transplant Accreditation & Certification Council (TACC) serves the public, healthcare community, and transplant surgeons by promoting excellence and professionalism through education, accreditation, and certification.

Accreditation

72 Abdominal Transplant Surgery programs are TACC accredited in the US and Canada.

81 fellows started fellowship in 2024.

Optimal Patient Care

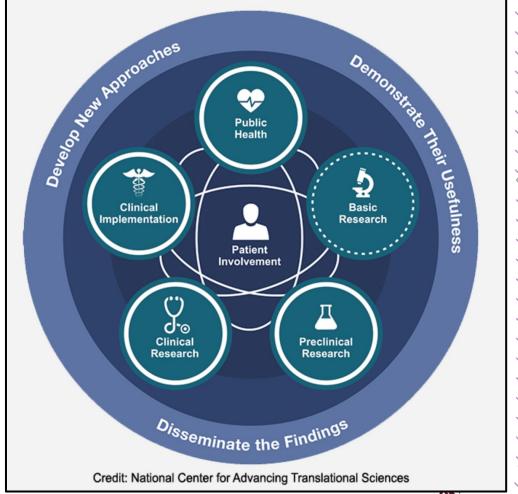




ASTS Foundation: Research

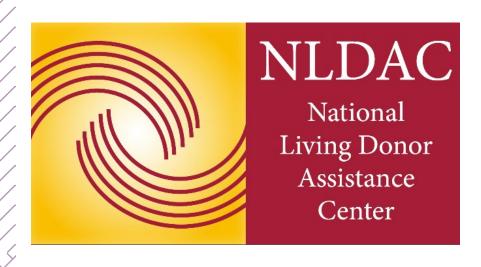


The mission of the ASTS Foundation is to promote **philanthropy** in the field of transplant surgery. Funds support ASTS initiatives such as education, fellowships, scholarships and other training, and **research**.





Living Organ Donation Reimbursement Program: Overview



- Funded through a collaborative agreement with the HHS- Health Resources and Services Administration (HRSA).
- The grant is awarded to Dr. Ojo (KUMC) and ASTS is a subcontractor on the grant.
- ASTS/NLDAC staff run the day-today operations of the program and are supported by an IT & evaluation team at Arbor Research.



Living Organ Donation Reimbursement Program: A Jewel of a Program!



Reimbursement Category	Payment Method	Limits
Travel Expenses	Controlled value card	Covers expenses such as transportation (airfare, gas, rental car, Uber/Lyft), lodging (hotels or Airbnb), food, & incidentals US travel only
Lost Wages	Direct deposit or check	3 days for evaluation 4 weeks for surgery & recovery 2 weeks for rehospitalization or follow-up trips
Dependent Care	Direct deposit or check	Covers expenses such as travel for a family member to come care for donor's dependent(s), a babysitter, a home health aide, or extra hours at daycare Daily maximum allotted (\$60 or \$72)



Living Organ Donation Reimbursement Program: Program Impact









Donor expenses reimbursed: \$38 million

Donation surgeries supported: 10,008

Applications received: 17,913

Donors who report could not have donated without this support: about 80%

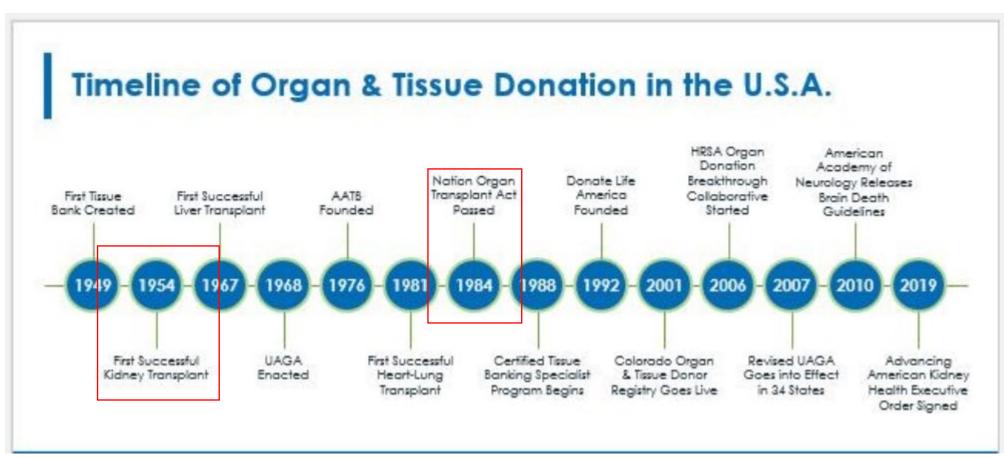


Introduction to ASTS Advocacy

Kiran Dhanireddy, MD Tampa General Hospital Chair, ASTS Legislative & Regulatory Committee



Timeline of US Transplant History

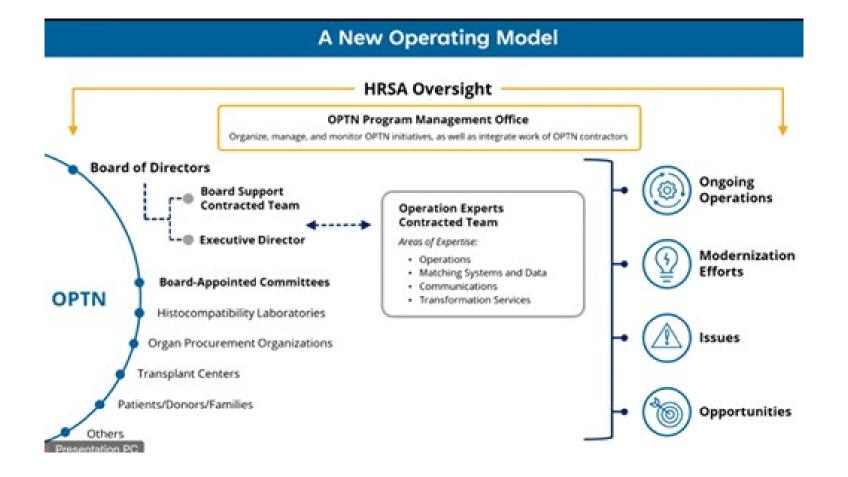


Source: Donor Alliance













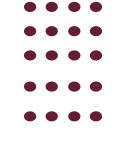
Congress authorizes overhaul of troubled organ transplant system

Updated July 28, 2023

G4min A □ □



Expert witnesses testify at a July 20 Senate Finance Committee hearing about reforming the organ transplant system. (Jahi Chikwendiu/The Washington Post)





The ASTS Supports OPTN Modernization

https://www.asts.org/advocacy/optn-modernization-initiative



ASTS OPTN Modernization: Guiding Principles









Maintain publicprivate partnership OPTN Governance should include stakeholders in transplant system

Priority should be equity and access

Transparency of the process and data are critical



Key Legislation & Opportunities for Advocacy





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•	•	•	•
•	•	•	•

BILLS	SUMMARY	
The Living Donor Protection Act (LDPA) (H.R. 2923/S. 1384)	 Prohibiting life, disability, and long-term care insurer from denying or limiting coverage and from charging higher premiums for living organ donors. Amending the Family and Medical Leave Act to include living organ donation as a serious health condition (private/gov't). Directing HHS to update materials on living organ donation to reflect these new protections, encourage more donors. 	\
The Living Organ Donor Tax Credit Act of 2023 (H.R. 6171)	 Provides \$5,000 one-time refundable tax credit to living organ donors who were not reimbursed for the costs of organ donation by the National Living Organ Donor Assistance Center (NLDAC) or any other entity. 	F
The Honor Our Living Donors (HOLD) Act (<u>H.R.</u> 6020)	 This legislation would no longer limit donor eligibility based on the income of the intended recipient. Currently, a donor can only be reimbursed if the combined income of the recipient and donor is less than 350% of the HHS poverty level. 	\
Living Organ Donation Reimbursement Program Reauthorization Act of 2024 (<u>H.R. 10282</u>)	 Reauthorize the National Living Donor Assistance Center (NLDAC) and allow more organ donors to receive financial assistance to help cover donation-related expenses. Raise the household income eligibility to include more potential donors and increase the maximum reimbursement level to \$10,000, with discretion given to the Secretary to keep payments 	\ (

within the budget provided.

Will be reintroduced in the 119th Congress

Possible re-introduction in the 119th Congress, there are questions about valuable consideration

Will be reintroduced in the 119th Congress

Will be introduced in the 119th Congress



Patient Voice Initiative

Ginny L. Bumgardner, MD, PhD, FACS
President, American Society of Transplant Surgeons
Ohio State University



Why the Patient Voice Matters

From Jan. 2025 ASTS President's message:

Purpose:

Amplify patient perspectives and engage patients in advocacy by sharing their valuable insights and unique stories.

Activities:

Participants in this initiative will join our members on Capitol Hill to meet with legislators and regulators, collaborate on educational content to inform the community about critical issues, and work closely with us to drive awareness and

meaningful change.

Why?

Why now?

Why ASTS?



Patient Voice Initiative Mission, Vision, Objectives

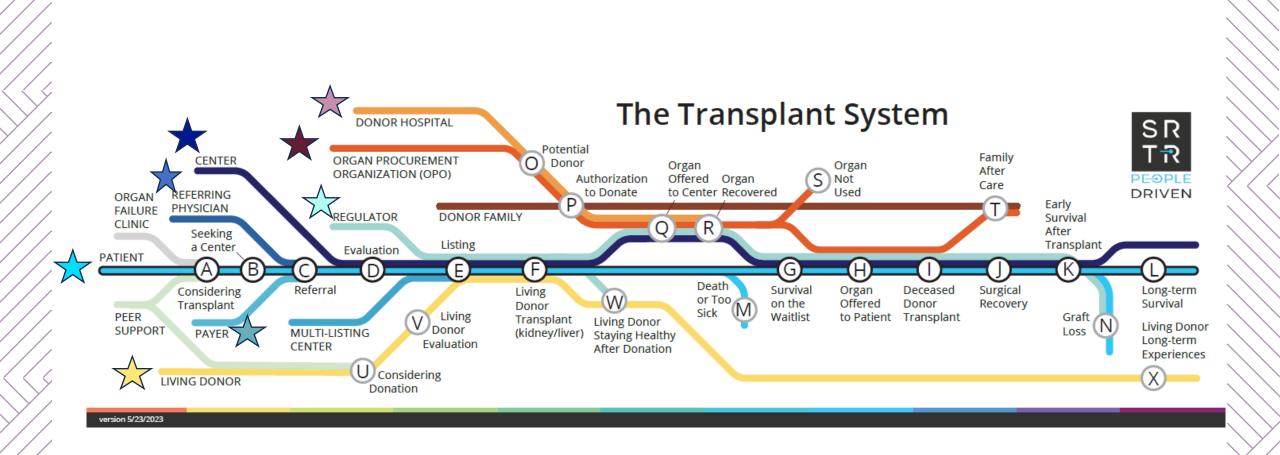
Mission Statement – Engage a diverse volunteer group of patients, donors, and families whose experiences, expertise and voice will enhance the *ASTS mission to save and improve lives through transplantation*.

Vision – Ongoing patient engagement to understand patients' experiences and perspectives and to gather patient ideas is critical to informing and strengthening ASTS led advocacy and other mission-based endeavors.

Goals:

- 1) Increase patients' awareness of transplant legislation, regulations and national initiatives
- Enhance transparency about the national transplant system and provide patients an avenue for input into transplant processes, policies and priorities
- 3) Share patient stories to highlight the impact of federal policy-making on their lives
- 4) Inform ASTS advocacy and other mission-based endeavors in a patient-centric fashion

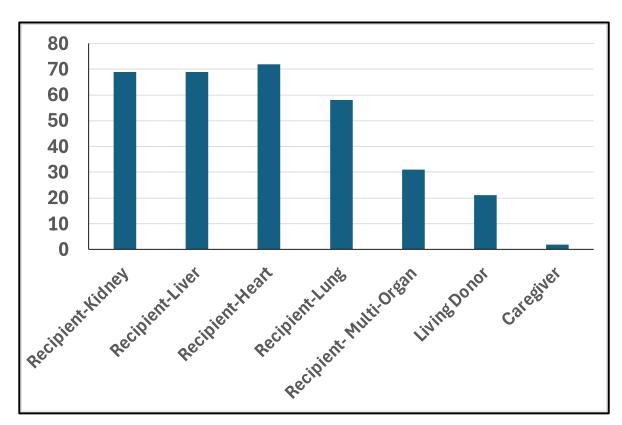
Why the ASTS? Transplant Surgeons Accompany Patients Along the Entire Journey





Joining Us ... October 2024 through January 3rd, 2025, n>300







ASTS Spring Advocacy Day

- April 16 17, 2025
- www.asts.org/advocacy-day







ASTS Advocacy Day Fall 2024

ASTS Supports Modernization of the Organ Procurement and Transplantation Network (OPTN)

ASTS URGES CONGRESS TO ENSURE TRANSPARENCY, CONTINUED STAKEHOLDER INVOLVEMENT, AND DATA ACCESS UNDER THE NEW OPTN STRUCTURE

TRANSPARENCY

 We urge Congress to ensure that the new modernized OPTN, which we understand will be solely controlled by HRSA, be fully transparent to the transplant stakeholders and the public.

STAKEHOLDER INVOLVEMENT

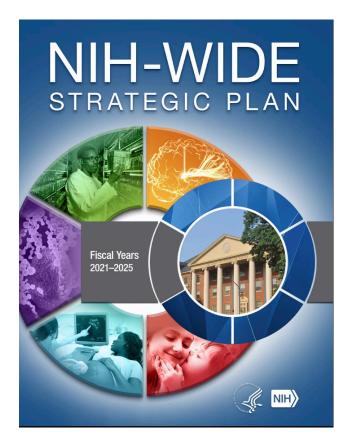
- We urge Congress to ensure that the transplant community elect the OPTN Board and that existing Board nomination procedures be followed (including for any special Board election held by the Secretary).
- We urge Congress to ensure that OPTN policymaking, which involves complex clinical considerations, be conducted without political or administrative interference.

DATA ACCESS

 We urge Congress to ensure that all OPTN data remain accessible to the public; that research directed by the transplant community priorities continue to be conducted to determine the impact of OPTN policies; and that such research be disseminated to the public irrespective of political considerations.



ASTS Advocacy: Transplant Research



2021-2025

NASEM Consensus Report 2022

Achieving Equity in Organ Transplantation: Recommendations for Action Based on the National Academies of Sciences, Engineering, and Medicine Report

Leigh Anne Dageforde, MD, MPH, 1,2 Rebecca A. English, MPH, 3 and Kenneth W. Kizer, MD, MPH4



ASTS->Stakeholder Engagement ASTS Winter Symposium January 16-19, 2025

- Saturday, January 18, 2:30 3:30pm Stakeholder Perspectives & Recommendations for OPTN Modernization
 - Lloyd Ratner MD MPH OPTN Board
 - David FoleyMD AST President-Elect
 - Ryo Hirose MD Chief of Transplant, Univ of Washington
- Sunday, January 19, 10:00am 11:30am

Measuring Progress & Success Towards OPTN Modernization Moderated by: Ginny L. Bumgardner MD PhD, ASTS President

<u>Panelists</u>:

AAKP - President, Edward V. Hickey III JD

AOPO – Councilor-at-Large, Jennifer Prinz

ASHI- President, Cathey Murphey PhD HCLD/CC(ABB)

NATCO- Executive Director, Donna Dickt BS

OPTN Data - Ryo Hirose MD

The Alliance – President, John Magee MD







Live Q&A / Polling Questions for Participants



Questions for the Group





TOPICS YOU ARE MOST INTERESTED IN FOR FUTURE WEBINARS.

WEBINAR FREQUENCY & TIMING

Thank you for joining us!

Questions? advocacy@asts.org

