Donate Life New York State 2025 Legislative Education Event Issue Briefing Webinar



Register as an organ, eye, and tissue donor today at donatelifenys.org

Donate Life New York State Aisha Tator, Executive Director atator@dlnys.org www.donatelifenys.org 518-326-3237



Donate Life New York State is the statewide non-profit organization dedicated to increasing organ, eye, and tissue donation in New York State.

Our goal is to ensure a life changing transplant for every New Yorker in need.

Since 2002, we've served as the voice for New York's organ, eye, and tissue donation community, bringing together recovery organizations, health professionals, community organizations, and people whose lives have been touched by our mission.

Donate Life New York State operates the New York State Donate Life Registry for the NYS Department of Health under contract with the State of New York, and advances organ, eye, and tissue donation through public and professional education, Registry enrollment campaigns, legislative advocacy, social and behavioral research, strategic partnerships, and collaborative forums with the greater donation and transplantation community.

2025 Corporate Members and Affiliate Sponsors



Corporate Members

















Affiliates



Artivion, Inc. NYU Langone Transplant Institute

Erie County Medical Center RTI Donor Services

LifeCell, an AbbVie Affiliate Stony Book Medicine

Lion's Eye Bank for Long Island University of Rochester Medical Center

Montefiore Einstein Center for Transplant Weill Cornell Medicine

NY Presbyterian Hospital Westchester Medical Center





Today's Agenda

- Annual Legislative Education Event
- 2025 Legislative Priorities
- Role of the Volunteer
- 4 Other Important Information
- Questions





Annual Legislative Education Event

Tuesday, April 8, 2025, 9:00 a.m. – 4:30 p.m. "Home Base": Legislative Office Building Room 711A/B

During this annual event, we will educate lawmakers on important donation relevant legislation being advanced in 2025.

This year's event is fully in-person! Meetings with lawmakers and staff are team-based.



Parking Information



Empire State Plaza Visitor Parking

oarking.management@ogs.ny.gov 518-474-8118



Parking Information

- Empire State Plaza Visitor Parking Info: https://empirestateplaza.ny.gov/parking. Card payments only - cash not accepted.
- 2. Albany Parking Authority offers parking garages, lots, and meters. Locations and rates can be found at https://www.parkalbany.com.
 - For meter parking, download ParkAlbany app.
 - Garages are cashless and accept payment via credit card, Apple Pay, and Google Wallet.
- 3. Hotel Garages:
 - <u>Hilton Albany:</u> 40 Lodge St.
 - Renaissance Hotel: 67 Howard St.





Downstate Bus Information

7:00 a.m. Departure | Manhattan

Location: 5 Times Square by Red Lobster Building (Southwest corner of 7th Ave and 42nd St.)

Location is convenient to the following subway lines which stop at **42**nd **Street**: 1, 2, 3, 7, N, R, Q, A, C, E, F, B, D, & M.

Manhattan bus team leaders:

- Maria Chelko, Eye-Bank for Sight Restoration
 Email: mchelko@ebsr.org | Cell (814) 880-6538
- <u>Chad Shank</u>, Eye-Bank for Sight Restoration
 Email: cshank@ebsr.org | Cell: (212) 603-9426

7:45 a.m. Departure | Tarrytown

Location: Westchester Marriott, 670 White Plains Road, Tarrytown, NY 10591 (IMPORTANT: park in back of hotel)

Westchester bus team leader:

Paulina Kaczmarczyk, Eye-Bank for Sight Restoration
 Email: pkaczmarczyk@ebsr.org; Cell: 917-515-5252

3:30 p.m. Departure | Albany (returning to Tarrytown and Manhattan) UPPER SWAN STREET LOWER SWAN STREET STREE CORE 1 CORE 2 CORE 3 CORE 4 AGENCY POLICE MEMORIAL AGENCY KOREAN OFFICE BUILDING AFETERIA YMCA BUS PARKING NYS DEPT. OF HEALTH **BUS TERMINAL** CULTURAL BUS PICKUP MUSEUM INFORMATION 0 POST OFFICE ALBANY RM MUSEUM POLICE **GIFT SHO** DEPT. OF HEALTH LABORATORIES PERFORMING CONVENTION SELEVATOR TO SIGN OF TREE ARTS CENTER VISITOR CORNING TOWER WALKWAY TO KNICKERBOCKER ARENA TO 1-787 **ELEVATOR TO**

Event Agenda



9:00 a.m. - 9:45 a.m. - Pick up materials, name tags, & lunches in Legislative Office Building (LOB) Room 711A/B

9:45 a.m. - Quick review of logistics and event

10:00 a.m. – Depart for group photo and press conference in "The Well" of the LOB

10:15 a.m. – Group photo

<u>10:30 a.m.</u> – Donate Life Month press conference

11:00 a.m. – 4:30 p.m. – Team-based meetings with legislators



Team Leaders



0

Aisha Tator

2

Melanie Evans

3

Meredith Cohn

4

Jayson White

5

Maria Chelko

6

Paulina Kaczmarczyk

7

Jeremy Morlock

8

Chadwick Shank

9 Angela Hadfield



Press Conference

9

Time: (10:30 AM)

Location: Legislative Office Building "Well" in Albany

If you have a Donate Life NYS t-si please wear it to the event!



Assembly Majority Leader Crystal Peoples-Stokes





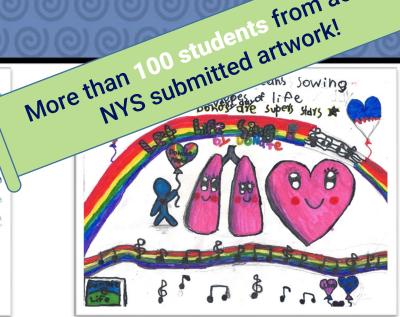
Assemblymember Phil Palmesano



2nd Annual Donate Life Month Student Art Contest





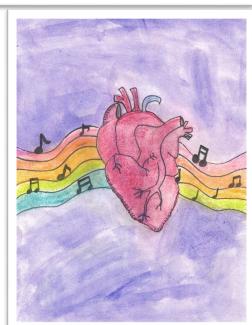


from across













THANK LAWMAKER FOR THEIR BUDGETARY AND POLICY SUPPORT OVER THE YEARS

GET CONTACT INFORMATION FROM STAFF

"ICE BREAKER"- GO AROUND THE ZOOM/ROOM AND MAKE INTRODUCTIONS

VOLUNTEERS SHARE THEIR PERSONAL CONNECTION TO DONATION

DONATE LIFE NYS TEAM MEMBER WALKS THE GROUP THROUGH MATERIALS

TAKE A GROUP PHOTO

THANK LEGISLATOR/STAFF FOR THEIR TIME

COMPLETE CAPITOL VISIT SUMMARY FORM

New York State Budget Request

restore \$1 million in funding in the Aid to Localities in the final enacted New York State budget

HEART Act | Helping Equal Access to Registration for Transplant A.7617 (Peoples-Stokes)/S.TBD (Baskin)



Background

The proposed legislation repeals NYS' ban on multi-listing (NYS PHL Section 4363) to allow patients to register at multiple transplant centers in the State of New York simultaneously, aligning with national standards and improving access to lifesaving organs.

Medicaid coverage generally does not permit non-emergency care outside New York, creating unequal access to lifesaving transplants.

- Medicaid patients represent 27% of transplant waitlist candidates but only 15% of recipients.
- Privately insured patients account for 35% of transplant candidates and 37% of recipients.

Key Benefits

Bill Introduced in Assembly 4/01/2025

Expanded Access: Multi-listing allows patients to register at multiple transplant centers, significantly increasing their chances of receiving a transplant.

Improved Outcomes: Multi-listing boosts transplant rates, lowers waitlist mortality, and reduces graft failure risk, enhancing long-term health outcomes.

Equity and Fairness: The current ban disproportionately affects low-income and minority populations who cannot afford out-of-state listings due to financial barriers and Medicaid's lack of portability.

Alignment with National Standards: Repealing the ban ensures New York meets ethical and evidence-based practices recommended by OPTN policies 3.2 (Notifying Patients of Their Options) and 3.4 (Multiple Transplant Program Registrations).

Multi-Listing Significantly Improves Patient Outcomes

Higher Transplant Rates

times more likely to receive a transplant; liver candidates see increases of **1.8 to 7.4 times**.

Reduced Wait Times

Median wait times for multi-listed kidney candidates **drop from 6 years to 3.5 years**, with similar reductions for liver candidates.

Lower Mortality and Graft Failure Rates

Multi-listed kidney candidates have a 19% lower mortality rate while waiting and a 10% lower risk of graft failure.



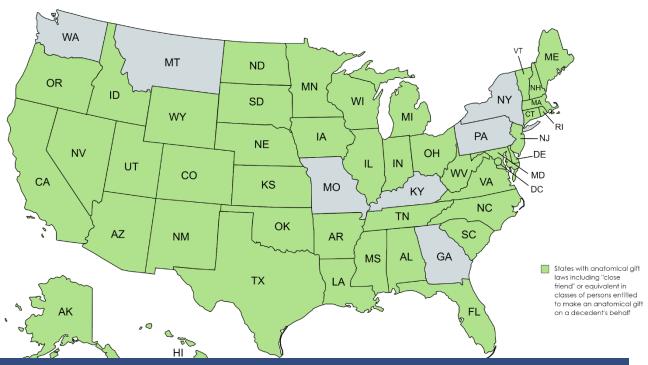
Amend New York Gift Act A.1395 (Paulin)/S.3360 (Rivera)

Passed Assembly

In Senate
Health
Committee



Addition of "Close Friend" into New York State anatomical gift law's hierarchy of surrogate decision-makers



New York is one of only seven states that do not include close friends in the classes of persons authorized to make an anatomical gift in instances when a deceased individual has not documented their decision.

Key Points

- The anatomical gift laws of 43 other states as well as that of Washington D.C. contain language allowing a close friend or equivalent to make this important decision.
- New York's Family Health Care Decisions Act (FHCDA) recognizes the importance of including close friends among the surrogates authorized to make healthcare decisions on behalf of a living individual.
- Incorporating the same class into New York's
 anatomical gift law is a common sense approach in
 circumstances where a deceased individual has not
 named a health care agent and has no relatives, but
 does have a close friend who is willing to act as a
 surrogate.
- The FHCDA defines "close friend" as a person age 18+ who has maintained such regular contact with the patient as to be familiar with the patient's activities, health, and religious or moral beliefs, and who presents a signed statement to that effect to the attending practitioner.



2025 Doorways to Donation | Personal Income Taxes A.TBD (Tapia)/S.TBD

Bill Awaiting Introduction



Voter Registration

In 2010, New York became the **first state in the nation** to pass legislation incorporating the opportunity to enroll in the Donate Life Registry into its voter registration application. Since then, Donate Life New York State has continued to advocate for **new Doorways to Donation**, resulting in numerous new and convenient opportunities for our residents to enroll as organ, eye, and tissue donors.

These innovative 'Doorways to Donation' have generated over 1.2 million registrations.

Continuing this successful approach to improving New York's donor registration rates, Donate Life NYS is advocating for legislation which will provide New Yorkers with another convenient, secure opportunity to **document their decision to be an organ and tissue donor when filing their personal income taxes.** The enrollment system mirrors secure state interactions—only minimal personal data is collected, with no financial details exchanged—thus safeguarding privacy while facilitating donor registration.

This approach is already proving successful elsewhere. In 2023, Michigan became the first state to integrate donor registration into tax filings, setting a precedent that New York can follow to give more residents the chance to leave a lasting legacy of hope.

Doorways

to

Donation



The Vital Role of the Volunteer

Personal journeys are far more compelling than numbers and statistics. Stories from transplant recipients, donor families, living donors, and those on the waitlist play a vital role in educating others and inspiring action.

By sharing your story, you help communicate the Donate Life mission and highlight the life-changing impact of organ and tissue donation and transplantation.

Your voice matters, and your story has the power to make a difference.





How to Effectively Tell Your Mission-Connected Story (in 3 Minutes or Less)





Your Stories Inspire Lawmakers to Action!

Focus on Three Key Messages:

- 1. Life/Challenges before Donation/Transplantation
- 2. Lives Saved and Healed, Legacies Left Behind
- 3. What Donation and Transplantation Means to You

Time is limited so please be concise

Let lawmakers walk in your shoes through your story

Avoid medical jargon and acronyms

Practice! Practice! Practice!

Pictured: The children of NYC Firefighter William "Billy" P. Moon II holding his picture. Billy's organs were donated after he passed away due to a training accident in 2022.



Capitol Visit Summary Form



A note taker should be assigned for each meeting who will be responsible for completing Capitol Visit Summary Form which will be handed out at the event.

- Forms should be handed in to team leaders prior to departure.
- Team leaders can scan and email summary forms to <u>info@dlnys.org</u> or submit information via online form located at <u>https://donatelifenys.org/LegEdEvent-Summary</u>



Visit

https://donatelifenys.org/legislative-event-resources

to access

Issue Briefing Slides

Issue Briefing Webinar Recording Tips for Sharing Your Story of Hope



Spread the Message



Text pictures to Donate Life NYS at **518-326-3237** or email to <u>info@dlnys.org</u> for sharing on web and social media

Upload pictures to social media with tag **#DonateLifeNYS**

Share our social media posts throughout the event





Join Us On May 14, 2025 for "A Breakfast with Champions" Event



HOSTED BY DONATE LIFE NEW YORK STATE

Join us for a morning of inspiration and impact as we gather to champion the lifesaving mission of organ, eye, and tissue donation. This special event will bring together community leaders, advocates, and supporters to celebrate the power of giving the gift of life.

Register Today!

DONA LIF

For more information, contact Meredith Cohn,
Director of Development & External Relations
mcohn@dlnys.org | (518)326-3237



2025 Breakfast with Champions Registration

Register Today:

https://donatelifenys.networkforgood.com/ events/84130-a-breakfast-with-championshosted-by-donate-life-new-york-state



May 14, 2025 | 8:00AM - 10:00AM The Renaissance Albany Hotel























June 26, 2025

































Questions?



