

Testimony of Donate Life New York State
Before the Joint Legislative Public Hearing on the SFY 2024-2025 Executive Budget
Proposal:
Topic Health
January 23, 2024

Thank you, Senator Krueger, Assemblymember Weinstein, Senator Rivera, Assemblymember Paulin, and all the committee members for the opportunity to testify on Governor Hochul's proposed Health and Medicaid budget for State Fiscal Year 2022-2023.

Donate Life New York State is dedicated to increasing organ, eye, and tissue donation in New York State and ensuring a life changing transplant for every New Yorker in need. We do this as the State's contractor operating the Donate Life Registry, conducting education and awareness campaigns, and engaging in collaborative partnerships to increase the number of New Yorkers as registered organ and tissue donors. **Donate Life NYS needs the Legislature's continued support to meet an ever-increasing need for this work and seeks a legislative add of \$725,000, which is an increase of \$225,000 from last year's legislative add.**

Accomplishments and Growth. The Legislature's enduring commitment to improving organ and tissue donation rates in NYS through fiscal and policy support has been instrumental in achieving significant impacts over the past decade:

- NYS Donate Life Registry enrollments more than doubled, increasing by 4.2 million registrations, with over 7.5 million New Yorkers now enrolled.
- State population enrolled in the Registry increased from 22% to 48%.
- Deceased organ donors reached a record-breaking 706 in 2023, up from 352 in 2013.
- Lives saved by deceased donor transplants increased from 1,176 in 2013 to a record-breaking 2,996 in 2023.

In SFY23, funds generously provided by the Legislature supported many of our key initiatives. Our primary objective was to expand our outreach by focusing on communities with low enrollment, particularly those disproportionately affected by health issues leading to organ failure and the subsequent need for transplants. These initiatives encompassed the operation of the NYS Donate Life Registry, support for strategic partnerships, an extensive engagement effort involving over 1,000 DMV employees, and orchestrating a multilingual "Be the One" campaign in New York City. The NYC campaign created impactful advertisements in seven languages, executed a targeted media-buy campaign, and strategically utilized 200 LinkNYC kiosk screens and targeted digital ads to maximize outreach and engagement with the public.



Continued Need. Notwithstanding these accomplishments, significant need remains. Few places in the US experience a need for donation as heightened as that observed in New York State (NYS). Statewide, approximately **8,000 patients** in need of organ transplants are candidates on the national transplant waitlist, accounting for approximately **8% of national need**, ranking NYS third behind Texas and California. Complicating this public health crisis is the fact that NYS lags significantly behind other states in terms of the proportion of its residents who have documented their consent to be organ and tissue donors upon their passing by joining their state's Donate Life Registry.

As of January 19, 2024 the donor designation share (DDS), the proportion of the state's population over age eighteen represented on the Registry, stood **at just 48.3%**, which lags significantly behind the **national average of 64%**.

Accordingly, there is a critical need to continue improving the performance of the Registry to align with national standards, and, more importantly, to meet the needs of the thousands of New Yorkers in need of lifesaving organ transplants, and we need the Legislature's help.

State Funding Actions. In this legislative budget cycle, we are asking for a total of **\$725,000**. While this is an increase of \$225,000 from last year, it is consistent with previous legislative commitment to Donate Life NYS (see chart). This funding level will allow us to do two things:

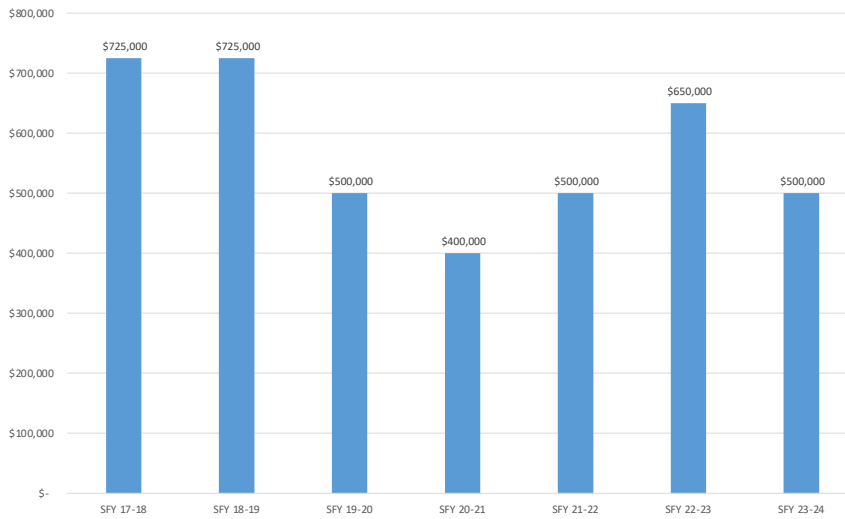
- (1) **Focus on Downstate Engagement.** This funding will allow us to generate more activity in the downstate region of New York. Bronx (28%), Kings (35%), Nassau (40%), Queens (29%), Richmond (33%), and Rockland counties (41%) all have donor designation shares below the New York State average. This region presents a significant opportunity to increase donor registration rates, as 68% of those residents have not yet enrolled in the New York State Donate Life Registry. Our downstate plan includes conducting community-based participatory research in collaboration with community-based organizations serving hard-to-reach populations, with a focus on increasing donation registration among Blacks/African Americans in the Greater New York City area; and
- (2) **Expanding Donate Life NYS's partnership with DMV.** This funding will allow us to further strengthen our donor registry through expanded and culturally sensitive DMV through a multifaceted approach, including culturally sensitive messaging and inspirational events within DMV offices to promote donor registration. Additionally, we plan to collaborate with the NY State Automobile Dealers Association to promote donor registration in 950 auto dealerships statewide; and



With this \$725,000 funding level, we can continue this critical work of growing our percentage of registered donors across the state. Accordingly, we ask that this appropriation be included in the one-house Aid to Localities Appropriations bill.

Thank you for consideration.

Legislative Contract Amount by State Fiscal Year



Of the \$4,000,000 generously provided to Donate Life NYS by the Legislature over the past seven years, nearly half (\$1,856,790) had to be spent on operating the NYS Donate Life Registry.

Just 54% of funds appropriated by the Legislature were able to be dedicated to mission-moving activities.



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