

**NYS Transplant Council Special Session: Living Donor Support Program  
Minutes of the April 9<sup>th</sup>, 2025, Meeting**

**Council Members in Attendance:**

Chair-Lewis Teperman, MD; Patricia Dahl; Andrew Flescher, PhD; Chris Kjolhede, MD; Liise Kayler, MD; Kevin Gramlich; Nancy Metzler; Nancy Gallo.

**Council Members Not in Attendance:**

Ernesto Molmenti, MD; Aaron Glatt, MD; Jean Emond, MD; Barbara Breckenridge; Leonard Achan.

**Staff in Attendance:** Dr. Douglas Fish; Mark Hennessey; Jason Riegert; Nancey Agard; Matthew Glannon; Tammy Irizarry; Loretta Mosher; Alia Wager; Vicky Murray; Danielle DeSouza.

**Staff in Attendance by Video Conference:** Dr. Eugene Heslin; Alyssa DeRosa; Nichole Katz; William McKenna; Lori Schillinger; Stephanie Shulman; Marissa Crary; Taffney Wallace.

**Other Attendees:** Samantha Delair; Michael Forti; Sam Mellins; Elaine Perlman; Samantha Taylor; Colleen Flores; Katie Dokus; Valeria Munt; Jayson White; Josh Sturm; Kelsey Denette; Lily Lam; Joy Giampaglia; Mary Nelson; Melanie Evans; Tony Kergaravat Rivera.

**Meeting Summary**

**1. Call to Order**

Dr. Teperman, Chair of the NYS Transplant Council, called the session to order at 11:05 am. Dr. Teperman remarked that the New York State Living Donor Support Program (from here on referred to as Program) was long in coming and congratulated the Department for its work in moving the Program toward implementation in the upcoming months.

**2. Welcome and Remarks by Dr. Eugene Heslin, MD, First Deputy Commissioner, Chief Medical Officer, New York State Department of Health**

Dr. Heslin introduced himself and expressed the excitement about this special session that is specifically focused on the New York State Department of Health Living Donor Support Program. Dr. Heslin referenced that, "It seems appropriate today, during Donate Life Month, to be talking about this." He noted that Donate Life Month helps raise awareness about donation, and honor people who have saved the lives of others and that last week, April 2nd, was Living Donor Day.

Dr. Heslin briefly reviewed the number of people, including children, on New York State's transplant waiting list, and the need for donors. He recounted about his experiences as a physician speaking with patients about organ donation and that he himself has signed up to be a donor. He recognized "that rare group of people that make a living donation" as a special subset of people stating "I think that we all need to be honored and humbled by the group of people that make this type of donation."

Dr. Heslin spoke about the package being brought to the Council at this meeting and that it includes proposed regulations and supporting guidance documents that describe how

the department plans to implement the Living Donor Support Program addressing the needs of donors by reducing barriers to a living donation. He explained that the decision to propose minimum regulations created the opportunity to develop detailed guidance documents that could be revised and updated much easier than regulatory changes could be made.

Dr Heslin went on to review the legislative history of the Living Donor Support Act as having passed signed into law in March of 2023 with an effective date of April 2023. He explained that the Department had been taking active steps to get the Program off the ground and wanted “to get this right.” He noted that building a new Program requires intention and attention to detail. He opined that the team and the department has remained committed to the goal of reducing the barriers and building this Living Donor Support Program.

Dr. Heslin reported that the Department is confident that we're ready to move forward and we're looking forward to feedback of the Council and the public via this meeting, the regular meeting of the Council later today and through public comment. He briefly described the regulatory approval process, the 60 day comment period on the proposed regulations and the Department's goal to have the people receiving money from the state to be able to support their desire to be a living donor and to reduce their barriers to being able to help other people of New York State as soon as possible.

### **3. Living Donor Support Program**

#### **a. Introduction and Review of Proposed Regulations-Nancey Agard**

Ms. Agard gave a brief introduction to the Program and its goal to reduce financial barriers to living donation. She reviewed the different sections of the Living Donor Support Act and proposed regulations drafted in Section 1010 of Title 10 of the NYCRR. Ms. Agard reported that a “minimum necessary” approach was taken when drafting the proposed regulations and that guidance documents were developed to educate and provide clarity on how the Department planned to implement the regulations. She invited meeting attendees to provide feedback to the Department on the proposed regulations as well as the guidance documents which were all posted to the Council's website.

Ms Agard reviewed the draft regulations noting that they state that eligible living donors may submit for reimbursement of eligible expenses up to \$14,000 after applying to the Program and receiving in notification of their eligibility and acceptance. In addition, the proposed regulations delineate the types and limits of living donor expenses that are eligible for reimbursement by the Program, Reimbursement categories include lost wages, travel, (to include meals and lodging), dependent care, (to include child, child with a disability, dependent adult and elder care), medications and medical care not covered by insurance, and a flat daily rate for a support person to accompany the living donor throughout their experience, up to a maximum number of days.

Ms. Agard reported that this package is brought to the Council for review, questions and feedback. She noted that the next stage will be to submit the proposed regulations to the Division of Legal Affairs for processing through the Department of Health, Department of State and the Governor's office with the goal of getting them published in the State Register as soon as possible. The State Administrative Procedures Act requires an initial posting of proposed regulations for 60 days, during which time the Department will be receiving and reviewing comments. If comments submitted are assessed to require revisions to the proposed regulations, revisions will be made and the revised proposed regulations will be published for an additional 45 days. Eventually an assessment of public comment, final regulations and a Program effective date will then be published. The Department's goal is to be able to launch the Program by late summer or early fall.

### **Questions & Discussions**

Question: Just for clarification, \$14,000 is everything, lost wages, travel?

Response: Correct. We decided to allow the donor to make their own differential.

Question: Is the \$14,000 cap subject to revision?

Response: It would require a statutory change because the limit of \$14,000 is in the statute.

Question: Do you expect there will be phases of reimbursement to the donors?

Response: Yes, they will incur expenses during each phase of the donation process, and we could pay them after each phase up to \$14,000 total.

Question: Why don't we have them get or try to get funded through NLDAC first and then New York State second?

Response: We are precluded from doing that. We initially thought we were going to do that and have New York State be the payer of last resort, but federal law does not allow NLDAC to reimburse any living donors if there is an existing state program from which they could have received reimbursement. NLDAC has been paying because our program is not yet operational, but as soon as it is operational, NLDAC they will no longer accept living donors that are eligible for the New York State Living Donor Support Program.

Question: Would a living donor that lives in another state donating to someone who lives in NYS be eligible for the NY Living Donor Support Program?

Response: They would not be eligible for our Program in that eligibility for our Program requires that both the donor and the recipient are NYS residents. In this instance, NLDAC would be an option.

## **b. Review of Associated Guidance Documents**

### **i. Eligibility and Program Application-Alia Wager**

To be eligible for the New York State Living Donor Support Program both the living donor and the ultimate intended recipient must be New York

State residents. Those who ultimately make a living donation, as well as those who incur expenses as part of the evaluation process, but due to no decision of their own and based on the transplant center determination, don't end up making a living donation are eligible for reimbursement by the Program.

The eligibility application package requirements include completed applications, associated forms, attestations, and two acceptable proofs of residency from the donor and the recipient as well as a completed Center Review Form. The plan is for applications to be initiated, reviewed and submitted to the Program by the transplant center before the surgery occurs. Similar to what is done now, the transplant professional will assess the living donor's potential need for financial assistance and the residency status of the donor and recipient. If the transplant center determines that the living donor-recipient pair are likely going to meet the criteria of our Program the center will proceed with the initiating the application process. Except in extremely limited emergency situations, eligibility applications and materials must be submitted and approved prior to the living donation being made.

The eligibility guidance document identifies acceptable proofs of residency and notes that these documents must be dated within the 90 days of the surgery and contain the donor and recipients full name and address of current residency, respectively.

Determination of Program eligibility will be made by Program staff and communicated to both the living donor and the transplant center. Living donors will receive notification of acceptance into the Program and a welcome packet that outlines next steps. If the living donor was not accepted, they would receive notification of denial that will clearly indicate reason(s) for the denial.

Ms. Wager reminded the group that she had given an overview of the Program's current policies and procedures and referenced the eligibility guidance documents where there is much more detail. She urged members and attendees to review the documents.

## ii. Questions & Discussions

Question: Are the reimbursements taxable?

Response: Yes, some categories of expenses eligible for reimbursement by the Program are taxable, e.g., lost wages. Further details on this topic are provided in the reimbursement guidance and something that the Department urges Program participants receiving reimbursement of expenses to speak with a tax professional about.

Question: What is the mechanism for submitting the documentation?

Response: The method of submission of documents has not yet been determined. However, Program staff will enhance the guidance documents and make that information known when we get closer to Program launch.

**c. Review of Associated Reimbursement Guidance**

**i. Reimbursement Guidance-Loretta Mosher**

Ms. Mosher reported that the Department feels it is very important to consider Program eligibility for any living donor that donated after the effective date of the Living Donor Support Act, April 1, 2023, through Program launch as well as those donating after Program launch. The Department is referring to these early donors as Legacy Donors. Current Program policy requires that Legacy Donors submit an eligibility application within 90 days of Program launch. Upon receipt, staff will review their application and determine their eligibility for the Program. If determined to be eligible, the donor will be notified and sent information about next steps—including how to submit for reimbursement. Legacy Donors accepted as eligible for the Program must submit claims for reimbursement within 90 days of Program acceptance. Program staff will review submitted claims for reimbursement and supporting documentation, documentation associated with reimbursements the donor may have already received or should have received and determine if and/or how much reimbursement the donor is eligible for from the NYS Living Donor Support Program.

Ms. Mosher reports that a single living donor's reimbursement can be up to \$14,000 and reviewed the expenses eligible for reimbursement under the Program. These include:

- Lost wages, in general up to four weeks will be reimbursed or up to 8 weeks in special circumstances. Ms. Mosher explained that the reimbursement guidance goes into more detail on what is considered a special circumstance and includes such things as having a job that requires physical labor.
- Travel reimbursement will be based on the current GSA rates; accompanying guidance appendices are available that will outline these rates. It is expected the donor will utilize the most economical route of travel that they can. Program policy is that travel more than 75 miles from home, one way, would be eligible for the overnight reimbursement.
- Dependent care includes childcare, elder care, care of a disabled child and care of a dependent adult. Childcare reimbursement rates reference the Office of Children and Family Services childcare assistance market rates modified to meet Program needs. Reimbursement rates for the other forms of dependent care identified above were researched and considered. However, the Department ended up determining Living Donor Support Program specific reimbursement rates for these groups. Ms. Mosher reports there is additional information on dependent care reimbursement in the guidance.
- Unreimbursed medical care and medication reimbursement is a category of expenses eligible for Program reimbursement that is not expected to be sought very often because generally these are covered by the recipient's health insurance. Ms. Mosher reports

that if there are medical care and/or medication expenses incurred related to the living donation process above and beyond what is covered by the recipient's health insurance, including co pays, that the Living Donor Support Program may be able to reimburse for them.

- Support person expenses will be reimbursed at a flat rate of one hundred dollars per day, for up to 20 days. Program expects that donors may want the presence of a support person primarily during the surgical phase of the living donation.

Ms. Mosher explained the reimbursement process and policies, including that in order to receive reimbursement, living donors will be provided a form they will need to complete and submit, and information needed to create an account for them in the Statewide Financial System (SFS) account. The living donor must submit their claims for reimbursement within 90 days of incurring expenses. A living donor may seek reimbursement of expenses in any or all the reimbursement categories. Documentation requirements include submission of forms that were developed and approved by the Department specifically for this Program. If a person undergoes an evaluation to be a living donor but they are deemed ineligible by the transplant center to make a living donation they can still be reimbursed for expenses incurred in that phase. Each claim for reimbursement will be evaluated and a determination will be made regarding the amount to be dispersed. The Program will not reimburse expenses that were required to be paid or were paid by other 3rd party payers.

Examples of 3rd payers are employers that offer benefits to living donors, critical illness insurance coverage, state disability or unemployment compensation, and others. Requests for reimbursement of expenses should be submitted as soon as possible after being incurred and we anticipate living donors submitting request at different phases of the living donor process. Program has not yet been able to establish policy or procedure regarding pre-authorization of payments, but it is understood that it is a priority for the community important for us to try to figure out a solution to.

Internal controls will include tracking and monitoring to ensure compliance with New York state laws and regulations and prevention, detection, and resolution of any findings. Good faith efforts by donors seeking reimbursement of eligible expenses will not be subject to recovery of funds.

As a final point, Ms. Mosher reported that reimbursement received for lost wages is taxable. Program does not anticipate that other categories of reimbursed expenses be taxable but are advising living donors to discuss this with their tax preparer for guidance on this.

## ii. Questions & Discussion

Question: Does the Program cover instances in which there are post-surgical complications?

Response: Yes, there is more detail in the reimbursement guidance about how the Program will take complications into consideration when reimbursing donors. Documentation must be provided by the provider to support the need.

Question: Does NLDAC get around the tax issue for wages by using the debit card?

Response: No, the debit cards NLDAC uses are for travel. NLDAC also provides a W9 to their living donors seeking wage reimbursement.

Question: Can you clarify whether the department has completed drafting the regulations necessary to implement the program?

Response: The proposed regulations necessary to implement the program are included in today's meeting materials. The next step is for the proposed regulations to be published and go out to public comment for 60 days. Depending on the public comments received we will either need to revise the proposed regulations and republish for 45 days or, if no substantial changes are needed to the proposed regulations they will be sent to the Commissioner for approval and published as final regulations including a Program effective date. Guidance documents that provide information about how the Department plans to implement the regulations and the Program are available on Transplant Council webpage for review. Ms. Mosher iterated that the Department felt that it was important to present the proposed regulations and guidance for implementation of the Living Donor Support Program to the Transplant Council and engage stakeholders as we move forward. It is felt that feedback from these groups, is key to the Program's success.

Question: Can you lay out the timeline to the degree that you're able to at this point? That is, when do you expect to post the regulations, start accepting applications? Also, when you expect to start reimbursing donors?

Response: Dr. Heslin responded that this is all subject to change, but the Program staff expect to submit the regulatory package into the approval process within days of this meeting if no significant concerns are raised. Department anticipates that the regulations will be published somewhere over the following 2-4 weeks after that. There is a 60-day public comment period required under the State Administrative Procedures Act. If there are no substantial comments, we anticipate the regulations being signed by the Commissioner shortly thereafter. We are hopeful that the regulations will not need revision nor additional public comment. If this proves true, we would anticipate the regulations being signed by the end of June.

Program launch would include putting up a website that contains all program materials, educating the transplant center and starting a public education and promotional campaign soon after the regulations are signed.

Program goal is to begin accepting applications immediately thereafter, because of the way both the regulations and the guidance were designed. The regulations contain minimum necessary language that will hopefully not require revision while the guidance was designed to include the details of program implementation. The Department plans on continuing to evaluate and refine the guidance documents throughout the public comment period based on comments and questions received. If the regulatory package stays substantially as is, we will refine guidance in parallel moving the regulations through the final approval process. This will allow Program to move faster than we might typically during this process.

In regard to reimbursement, it is Program's expectation that once we receive supporting documentation from a living donor determined to meet program eligibility criteria, that we expect payment to be made within a few weeks' time.

Question: Is the program funded on a recurring basis, or does it need to seek new funding through the budget process each year?

Response: The Program is funded in the budget each year.

#### 4. Adjourned

Dr. Teperman thanked the Department for their work on the Program and adjourned the meeting at 12:20 p.m.