

**New York State Transplant Council  
Minutes of the May 23, 2023 Meeting**

**Council Members in Attendance for the Purpose of Determining Quorum:**

Council Members: Lewis Teperman, MD - Acting Chairperson; Leonard Achan; Barbara Breckenridge; Patricia Dahl; Andrew Flescher, Ph.D.; Nancy Gallo, RN; Michael Kerr; Chris Kjolhede, MD; Nancy Metzler; Ronnie Schwartz

**Council Members in Attendance by Video Conference:**

Aaron Glatt, MD and Ernesto Molmenti, MD

**Persons Pending Appointment to the Council in Attendance by Video Conference:**

Liise Kayler, MD

**Invited Guests and Speakers:**

Diane LaPointe Rudow, UNOS President; Dr. Sumit Mohan, Columbia University Irving Medical Center

**Staff:** N. Agard; M. Hennessey; T. Irizarry; M. Morelli; J. Morley; A. Nagy; J. Riegert; K. Salvio; S. Shulman; J. Treacy

**Meeting Summary**

**1. Call to Order, Report of the Chairperson and Review of Rules and Conduct of the Meeting**

Dr. Teperman, Acting Chair for the NYS Transplant Council, called the meeting to order at 1 pm and reviewed the meeting agenda.

Dr. Teperman gave a brief summary of the National Academies of Sciences, Engineering, and Medicine (NASEM) committee meeting in the morning and Members and guests introduced themselves. Dr. Teperman announced that Ronnie Schwartz would be resigning from the Council after over 20 years and thanked her for her many years of dedicated service.

**2. Welcome and Remarks by Dr. John Morley, Deputy Commissioner, Office of Primary Care and Health Systems Management**

Dr. Morley introduced himself and described his position in the Department. He stated he would be attending Council meetings representing the Commissioner and Department Senior leadership. He reminded the group that Dr. James McDonald had been appointed Acting Commissioner of Health in January and was pending Senate confirmation hearings in the upcoming months. Dr. Morley iterated the Department's priorities as working towards increasing access to and equity in healthcare. He discussed how the Department is integrating these goals into all departmental initiatives and activities. He conveyed that increasing access to transplantation was included in the Department's access and equity agenda. Dr. Morley thanked Council Members for their service to the state and the people of New York and entertained questions.

**3. Approval of Minutes**

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Dr. Teperman asked Council members to review the minutes of the May 25, 2022 meeting and asked if there were any questions or concerns about the draft. There were no questions or concerns raised. A motion to approve was made by Ms. Dahl, seconded by Dr. Kjolhede. The motion to approve the minutes was approved, no abstentions, no disapprovals.

#### 4. Staff Report

##### Brief Review of Bylaws and Rules/Conduct of the Meeting

Ms. Agard walked through the rules of the meeting and explained that the order of items on the agenda may shift as speakers and invited guests become available. This meeting was a Hybrid meeting (in person and WebEx). Review of the meeting rules included a brief review of Council Bylaws and Public Officers Law where applicable to Council meetings and member responsibilities.

##### Amendments to the Open Meetings Law (OML)

Jason Riegert, Esq., attorney for the Organ Donation and Transplantation program, provided information about changes that have been made to the OML including those changes made related to use of videoconferencing. Mr. Riegert explained that under extraordinary circumstances members of the Council could participate by videoconferencing in a non-public location if the Council passed a resolution allowing that to occur. Mr. Riegert explained that there must be an in-person quorum, however, an individual with a disability causing a member to not attend in person, can still count toward quorum. Mr. Riegert also explained that DOH can set up multiple physical environments for a meeting and that a video conference must be made public. If a council member is attending remotely, they can vote on a topic, however, will not be counted towards the quorum unless they have been determined meet the extraordinary circumstances ahead of the meeting. Mr. Riegert noted that Council members are all Public Officers and that as such all members of the Council must complete ethics trainings every two years. He explained that generally, Public Officers should complete this training within 30 days of appointment but acknowledged that at this time there are limited classes available. Ms. Agard to follow-up on Council training opportunities and get back to the group.

Additional discussion about voting on matters when there are potential conflicts was had and members were reminded that if they have a potential conflict, it should be recorded in the minutes. Members can from voting if there is a question.

#### 5. Update on Federal, State and Departmental Activities –

##### Federal Updates:

Diane LaPointe Rudow, United Network for Organ Sharing (UNOS) President, spoke to the Council updating them on Organ Procurement and Transplant Network (OPTN) and UNOS matters.

##### a. UNOS Update:

- Maureen McBride, Ph.D. is new CEO of UNOS. Her goal is to increase transparency and communications and foster continuous quality improvement.

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- In 2022, the 1 millionth transplant was performed; with few exceptions year over year donations and organ transplants continue to climb.
  - The implementation status of continuous distribution policies as well as the impact of changes in Glomerular Filtration Rate (GFR) policy and various quality improvement collaboratives underway was given.
  - Recent criticisms of the UNOS and of the organ donation and transplantation system identified by various sources and pressures to improve were acknowledged.
  - The pillars of the UNOS Action Agenda are consistent with those of the Health Resources and Services Administration (HRSA) OPTN Modernization Initiative. These include patient empowerment, equity, data collection, transparency, transportation, IT improvement, oversight, governance.
  - The UNOS contract as the OPTN is currently set to expire 9/30/23.
- b. Health Resources and Services Administration (HRSA) Update –
- HRSA announced their OPTN Modernization Initiative in March 2023 with a focus on accelerating progress in the arenas of technology, data transparency and analytics, governance, operations and quality and innovation.
  - Legislation has been introduced to break up the contract for management of the OPTN by removing barriers in OPTN contracting and giving HRSA statutory authority to improve management of the organ transplantation system in the U.S. If passed it would allow the OPTN to be operated through awards to multiple public and/or private entities, for profit and/or not for profit organizations. In May, HRSA announced its Modernization its Initiative timeline:
    - Phase 1 – Summer 2023: Design and strategy development to include external engagement by contractors to help determine the modernization;
    - Phase 2A --Fall 2023: OPTN transition management and competitive OPTN transition contracts; and
    - Phase 2B -- Spring 2024: OPTN modernization implementation and next generation contracts.
- What this means and how this will happen is still unclear. HRSA promises more detail will be released.

Ms. LaPointe Rudow responded to questions from Council Members.

#### State and Departmental Update

- Ms. Agard updated the Council on the establishment of the Department's Office of Health Equity and Human Rights. This office will address health disparities and work to improve diversity, equity, and inclusion within the Department and throughout the healthcare system. It is comprised of the Office of Minority Health and Health Disparities Prevention, Office of Diversity, Equity and Inclusion, the AIDS Institute, and the Office of Gun Violence Prevention.
- Additionally, an Office of Aging and Long-Term Care was formed and is responsible for long-term care functions related to policy, licensure, survey and surveillance, data collection and analysis. In addition, it will help develop and execute the State Master Plan on Aging to improve the recruitment, retention, and training of long-term care workers, and improve the quality of long-term care.

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Ms. Agard gave a Legislative and Programmatic update.

- Living Donor Support Act (LDSA): Law was signed by Governor in December 2022 with chapter amendments signed off on March 3, 2023. This new law authorizes the establishment of a LD Support Program (LDSP) with the goal of removing financial barriers to LD. Through the program LDs can seek reimbursement for lost wages, travel, lodging, childcare, eldercare, and unreimbursed medical and medication costs. The Program was funded in the state budget. DOH is working to hire staff and meeting with both internal and external stakeholders to gather information and recommendations. Establishment of an Advisory committee is planned. Development of an application, policies, protocols, and regulations are needed. The Department considers implementation of this Program a priority.
- Law requiring inclusion of the Lauren's Law question on applications and portals of certain insurances: This law was also passed late last year and underwent chapter amendments in the first quarter of 2023. The Department has been meeting with stakeholders including the Division of Financial Services, the NYS of Health Marketplace and Medicaid program and representatives of the insurers and plans. We are currently working through their questions about the new law, its implementation requirements, etc.
- The Department continues to work with the Department of Environmental Conservation adding the Lauren's Law question to their licensing applications.
- Adding the Lauren's Law question to the electronic applications of the Office of Temporary Disability Assistance and Higher Education Services Corporation has been delayed at those agencies due to the need for technology updates and contracting delays.
- A brief update on the Registry was given, making reference to a handout in the meeting materials, and informed the Council that a RFP for the next Registry Contract would be published this year for the start of a new contract in May 2024.

## 6. Report of Special and Standing Committees

### Certificate of Need (CON) Regulatory Review Committee Update:

Ms. Agard reported that the Committee would continue its work online by completing a white paper describing its work, its thinking, and its recommendations for reform of the organ transplant CON regulations.

### NASEM Committee – Council Update:

Ms. Metzler, Co-Chair of the TPC-NASEM Committee, noted that the focus of the NASEM report was on the need to improve equity, efficiency and system performance and use more donated organs in the 14 recommendations included in the NASEM report. She gave a brief update of the TPC-NASEM Committee meeting that occurred prior to the Council meeting. She reported that the purpose of the TPC-NASEM committee is to review the report, identify which of the report's recommendations and actions are applicable to NYS and fall within NYS stakeholder abilities to address them and develop an action plan for implementation and recommendation to the Council.

Mr. Achan, Co-Chair of the TPC-NASEM Committee, provided additional information about the Committee meeting and reviewed slides of LiveOnNY data that he presented during the NASEM meeting. He reported that LiveOnNY has been working on accessing and developing their own data to assess and evaluate the state of affairs in their Donor

Service Area (DSA) and he urged other NYS OPOs to work toward being able to carry out this level of analysis for use in determining how best to improve their performance. Mr. Achan stated that all of the data in his presentation is identified by source and is able to be shared.

Presentation, Invited Speaker - Dr. Sumit Mohan, Nephrologist, Medical Director, Kidney Transplant, Professor of Medicine & Epidemiology Columbia University Irving Medical Center

Dr. Mohan provided an in-depth presentation on Transplantation System Challenges, Equity, Utility and Efficiency. Highlights of his presentation included the:

- Increasing prevalence of End-Stage Renal Disease (ESRD) in the U.S. with transplantation being the preferred treatment choice;
- Overall decline in waitlisting of ESRD patients and stagnation in access to transplant;
- Disparities in access to the waitlist (WL); findings show disparities in household income and percent of patients waitlisted or transplanted within four years of diagnosis;
- Disparities in access to transplantation in WL patients; wide variation in probability of transplant after waitlisting; data suggests center organ acceptance practices contribute to this disparity;
- Increasing organ discard rates; discard rates increase with community/residential distress; U.S. discard rate of similar KDRI kidneys much higher than France;
- Most recent kidney allocation policy is more complex; analysis shows it has contributed to increased organ discard rates;
- System inefficient; “work arounds” such as out of sequence kidney placements increasing; organs routinely not going to the person at the top of the list; data not reported until recently and could benefit from increased transparency.

Dr. Mohan responded to questions from Council Members. Council Members voiced appreciation Dr. Mohan’s presentation and would invite him back for future discussions.

**7. New and Other Business**

Dr. Teperman raised that there are a number of ethical issues facing the donation and transplant community at this time and intersecting with our efforts to improve system performance, equity, and use of donated organs. These include the definition of brain death being challenged, increasing interest in and utilization of normothermic perfusion in DCD donors and access to transplantation by persons with disabilities. He suggested it would be helpful to establish an Ethics Committee of the Council.

A motion to establish an Ethics Committee of the Council was proposed by Patricia Dahl. The motion was seconded by Dr. Flescher. The motion passed unanimously.

Dr. Teperman asked Dr. Flescher, an ethicist and member of the Council, if he would Chair the new committee. He enthusiastically agreed to undertake this responsibility.

**Adjourned**

- A motion to Adjourn the meeting was made and seconded.
- The meeting adjourned at 3:46 p.m.