Assistor Training:
NY State of Health and the Organ Donation Registry
Implementing Chapter 40 of the Laws of 2016

Date: April 19, 2017
Time: 10:00am
Dial-In Number: 1-855-897-5763
Conference ID: 6001371
TODAY’S WEBINAR

• Dial in to listen to the audio portion of the webinar using the audio instructions on your WebEx control panel.

• All participants will remain muted for the duration of the program.

• Questions can be submitted using the Q&A function on your WebEx control panel; we will pause periodically to take questions.

• A recording of the webinar and any related materials will be available online and emailed to all registrants.
Today’s Training Agenda

- Introductions
- Background
  - Organ Transplantation
  - The Critical Need for Organs
  - The New York State Donate Life Registry
- Implementation of NY State of Health Donor Registry Questions
- Review of NY State of Health Screen Changes
- Questions and Answers
Melanie Evans, Associate Director
Today’s Presenters

Nancey Agard  Director, Organ Donation and Transplant Program, Division of Hospitals and Clinics, NYS Department Of Health

Lisa McMurdoo  Director, Regulation and Special Projects, Division of Hospitals and Clinics, NYS Department Of Health

Michael Thibdeau  Chief Information Officer, NY State of Health
Background: Organ Transplantation

• Many conditions, including end-stage heart, liver and kidney disease, can be treated by organ transplantation
• Advances have been made in preventing and treating diseases that can lead to transplant (Hepatitis C, hypertension)
• But there will always be a need for organs for transplant, as many people waiting have diseases that are not preventable
Background: The Critical Need for Organs

- There is a severe shortage of organs for transplant – making this a critical population health issue.
- 22 people a day in the United States die waiting for an organ.
- Every 10 minutes someone is added to the wait list – over 118,000 people in the U.S. are waiting for an organ.
- Over 10,000 New Yorkers are waiting for an organ.
- One individual can save up to 8 lives by donating organs and improve the lives of many others with donated tissues and eyes.
The New York State Donate Life Registry

• The New York State Donate Life Registry is a database that records a person’s legal consent to donate their organs, eyes and/or tissues at the time of their death
• Individuals may designate which organs/tissue they want to donate and specify use for transplant or research or both
• Information is confidential and only disclosed at the time of death
• Recently enacted state law allows 16 and 17 year olds to enroll, with parents able to rescind if the death occurs prior to age 18
New York State Donate Life Registry Rates

• Most adults are supportive of organ donation, but less than half have registered as donors
• Over 4.4 million people are enrolled in the NYS Donate Life Registry
• This is less than 1/3 of the population eligible to enroll
• New York has made it a priority to address the critical need to improve organs and tissue donation rates
Ways to Enroll in the NYS Donate Life Registry

• NYS Department of Motor Vehicles
  – DMV offices and myDMV website: https://dmv.ny.gov/more-info/register-become-organ-eye-or-tissue-donor
• NYS Board of Elections when registering to vote
• When applying for a New York City Identification Card (IDNYC)
• Through the NYS Department of Health website: https://apps.health.ny.gov/professionals/patients/donation/organ/DonorRegistration.action

• **Through NY State of Health**
Enrolling in the Donate Life Registry through NY State of Health
Chapter 40 of the Laws of 2016

• Requires that every individual applying for coverage through the NY State of Health Marketplace be provided with the opportunity to enroll in the New York State Donate Life Registry

• Specifies the exact questions to be asked and response choices for applicants

• Implementation required changes to NY State of Health on-line and paper applications
Changes to the NY State of Health On-Line Application

• Individuals age 16 and older, completing an application for coverage or making a Life Status Change (LSC), after the date of implementation will be asked the following question:
  – Would you like to be added to the Donate Life Registry?

• Individuals will be presented with two responses to select from:
  – 'Yes' or 'Skip this question'
Changes to the NY State of Health On-Line Application

• Individuals responding “Yes” will be presented with a statement that they should carefully review and they will need to “Agree” or “Disagree”.

![Donate Life Registry]

• After reviewing, if the individual checks “Agree”, his or her enrollment information will be transferred to the Donate Life Registry.
Changes to the NY State of Health On-Line Application

• Whether the consumer checks “Skip this question” or “Yes”, at this point, the requirements of NY State of Health have been met.

• Individuals who mark “Yes” and “Agree” will be contacted by the Donate Life Registry to:
  
  o Verify Enrollment and explain how the person may limit their donation (e.g, transplant only – not for research) or withdraw from the registry.
Let’s Take a Look at the NY State of Health Screens
The organ donation registration question will appear after eligibility is determined.

The individual must select either “Yes” or “Skip this question”.

If selecting “Yes” here.....the consumer will still need to confirm on the next screen.
This pop up box will appear if “Yes” was selected on the previous screen.

If the individual selects “Agree”, they have agreed to be in the New York State Donate Life Registry.
Individuals who receive an Eligibility Determination but do not respond to the question, will be presented with the question again when they return to select a plan.

It is still the same question, just in a different location of the application.
Paper Applications

- Paper applications comprise a small percentage of total applications (less than 1%)
- Paper applications will be modified to include the Donate Life Registry question and responses in the near future.
Assistor Neutrality

• It is your role as an Assistor to read the Donate Life Registry Question as it appears in the application to the consumer so that they may select “Yes” or “Skip this question”.

• If the consumer selects “Yes”, you must read and review the entire confirmation statement with the consumer, so that they may select “Agree” or “Disagree”

• You must remain neutral and not advise consumers in making this decision.

• If the consumer needs more information about Organ and Tissue Donation, or the Donate Life Registry, you must refer them to the resources on slide 27.
Let’s Review
The Donate Life Registry Question will be asked in which of the following situations?

A. Individuals completing a new application.
B. Existing account holders during their next manual renewal or when making a Life Status Change.
C. Account holders age 16 and over.
D. Account holders who receive an eligibility determination and return to select a health plan if the question was not previously answered.
E. All of the above.
The question about being added to the NYS Donate Life Registry must be answered in order to proceed to plan selection.

A. True
B. False
NY State of Health Assistors must be prepared to respond to questions about organ donation and the Donate Life Registry?

A. True
B. False
Where can Assistors refer consumers for more information about Organ and Tissue Donation and/or the Donate Life Registry?

- Information: [www.health.ny.gov/donatelifede](http://www.health.ny.gov/donatelifede)
- Call: New York State Organ and Tissue Donor Registry at: 1-866-NYDONOR (1-866-693-6667)
- Email: [donorreg@health.ny.gov](mailto:donorreg@health.ny.gov)
Questions?