

# 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



New York Alliance  
for Donation, Inc.

Melanie Evans, Associate Director

## Today's Presenters

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

*And*

Lisa McMurdo      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

By checking yes, you are certifying that you are 16 years of age or older; consenting to donate all of your organs and tissues for transplantation and research; authorizing NY State of Health to transfer your name and identifying information to the NYS DOH for enrollment in the Registry; and authorizing NYS DOH to allow access to this information to federally regulated organ donor organizations and the NYS-licensed tissue and eye banks and hospitals, upon your death. You will receive a confirmation from NYS DOH, which will also provide you an opportunity to limit your donation.

Please note that your response will not affect your eligibility or the assistance you will be provided by NY State of Health.

- 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:
  - 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.

New York State State Agencies Search NY.GOV site

nystateofhealth The Official Health Plan Marketplace ABOUT RESOURCES FORMS GET HELP 1-855-355-5777 ESPANOL LANGUAGES

Logged in as cr1420\_47 Account Sign Out

- ACCOUNT INFORMATION
- Contact Information
- BUILD HOUSEHOLD
- Household Members
- Relationships
- Residential Address
- Household Summary
- COVERAGE PREFERENCE
- Public MEC
- INCOME INFORMATION
- Income Details
- Income Details
- Income Summary
- OTHER INFORMATION
- APPLICATION SUMMARY
- FIND A PLAN

### Donate Life Registry

Thank you for completing your application. Your eligibility determination is below.

**Charles Pac**  
Would you like to be added to the NYS Department of Health's Donate Life Registry?

Your response will not affect your eligibility or the assistance you will be provided by NY State of Health.

### Eligibility Determination

Below are the eligibility results for health coverage for everyone on the application. This tells you what program each person qualifies for and the amount of help paying for health coverage the person can receive, if any.

Please call NY State of Health at 1-855-355-5777 (TTY 1-800-662-1220) if:

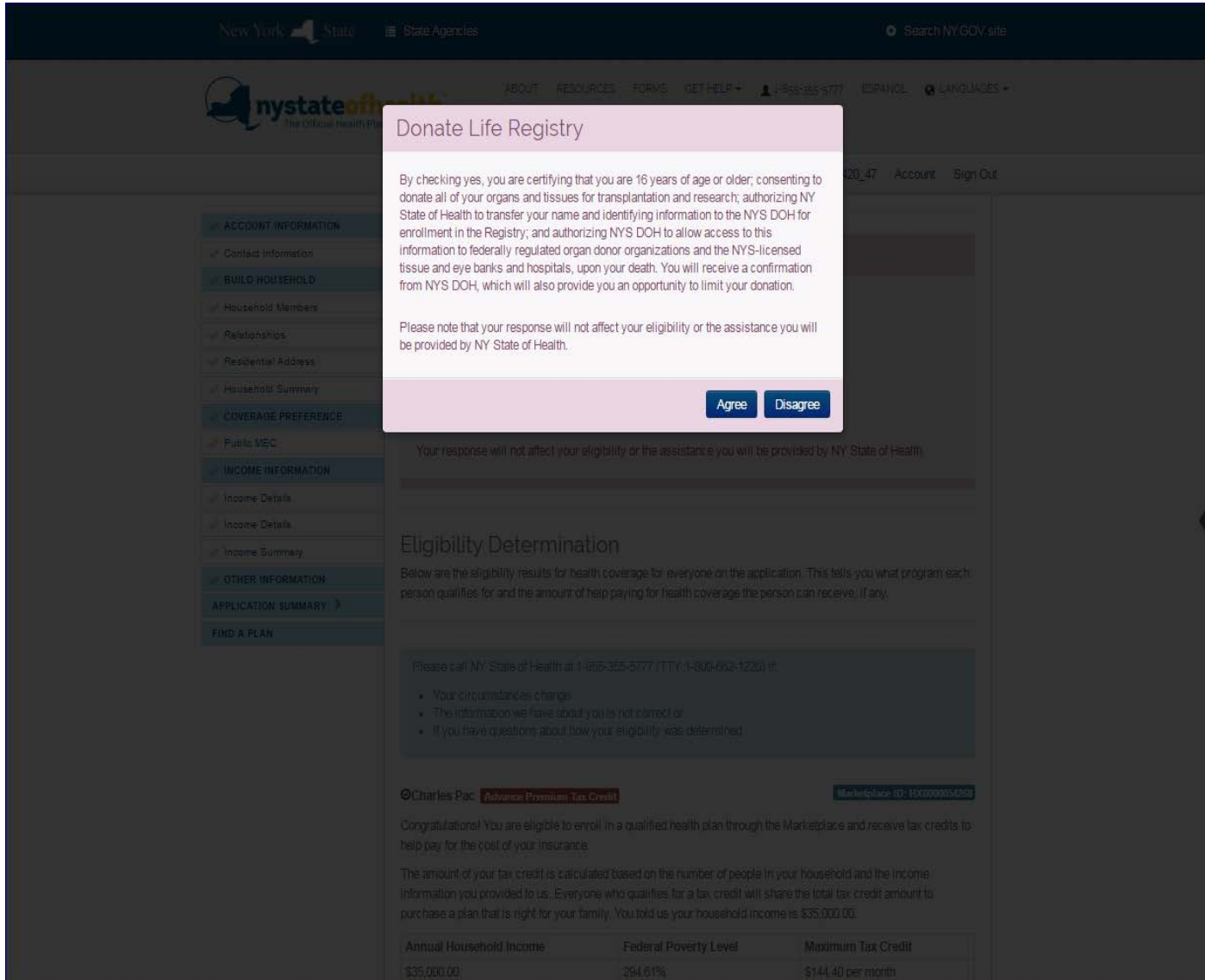
- Your circumstances change
- The information we have about you is not correct or
- If you have questions about how your eligibility was determined

©Charles Pac **Advance Premium Tax Credit** Marketplace ID: HX0000054268

Congratulations! You are eligible to enroll in a qualified health plan through the Marketplace and receive tax credits to help pay for the cost of your insurance.

The amount of your tax credit is calculated based on the number of people in your household and the income information you provided to us. Everyone who qualifies for a tax credit will share the total tax credit amount to purchase a plan that is right for your family. You told us your household income is \$35,000.00.

Annual Household Income	Federal Poverty Level	Maximum Tax Credit
\$35,000.00	294.61%	\$144.40 per month



The screenshot shows a web application interface for the New York State of Health. A central pop-up dialog box titled "Donate Life Registry" is overlaid on the page. The dialog contains the following text:

By checking yes, you are certifying that you are 16 years of age or older; consenting to donate all of your organs and tissues for transplantation and research; authorizing NY State of Health to transfer your name and identifying information to the NYS DOH for enrollment in the Registry; and authorizing NYS DOH to allow access to this information to federally regulated organ donor organizations and the NYS-licensed tissue and eye banks and hospitals, upon your death. You will receive a confirmation from NYS DOH, which will also provide you an opportunity to limit your donation.

Please note that your response will not affect your eligibility or the assistance you will be provided by NY State of Health.

At the bottom of the dialog are two buttons: "Agree" and "Disagree".

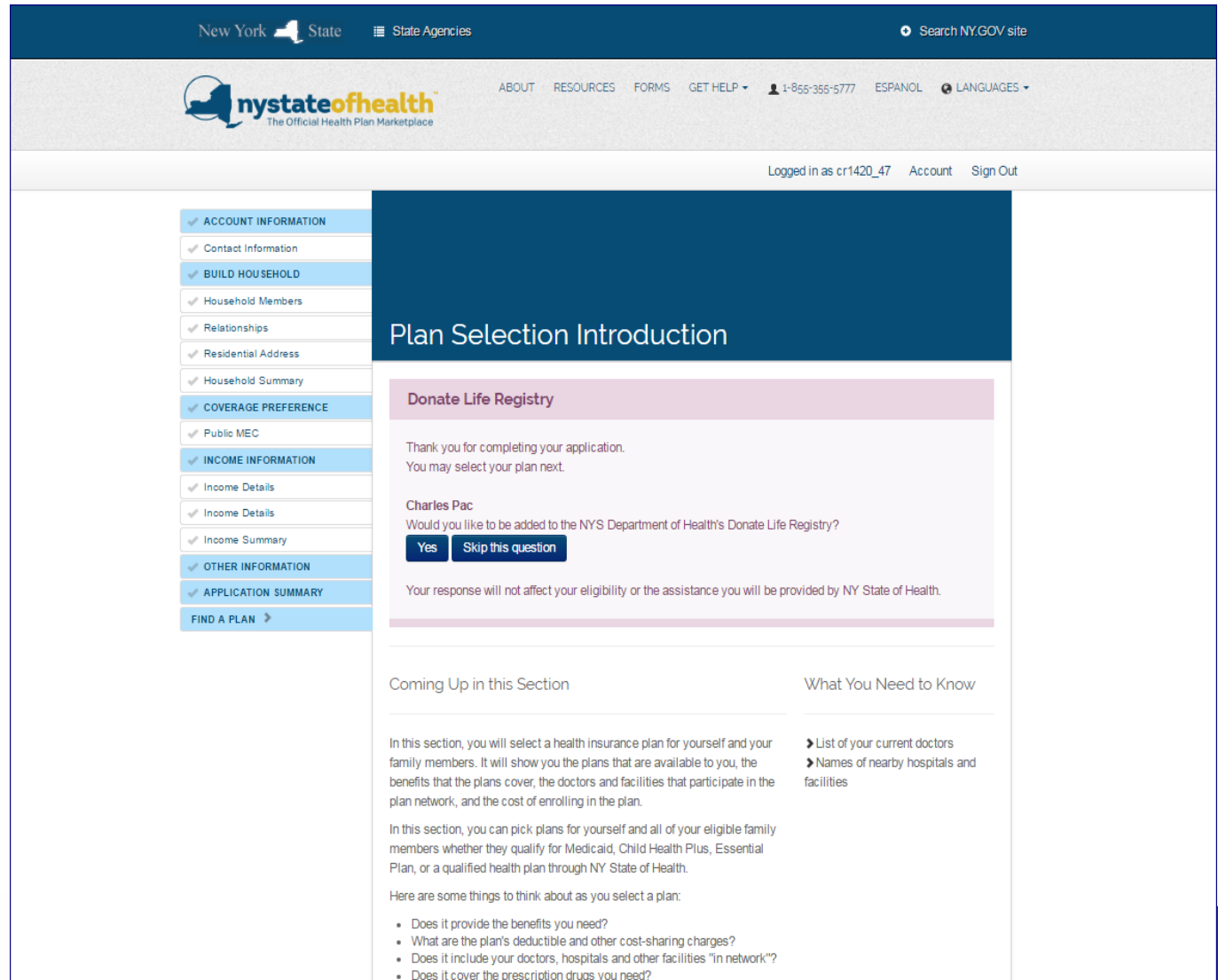
The background page shows a registration form with a sidebar menu on the left containing sections like ACCOUNT INFORMATION, BUILD HOUSEHOLD, COVERAGE PREFERENCE, INCOME INFORMATION, and OTHER INFORMATION. The main content area is partially obscured by the dialog box but shows sections for "Eligibility Determination" and "Charles Pac" with a "Marketplace ID: 14000004256".

**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.**

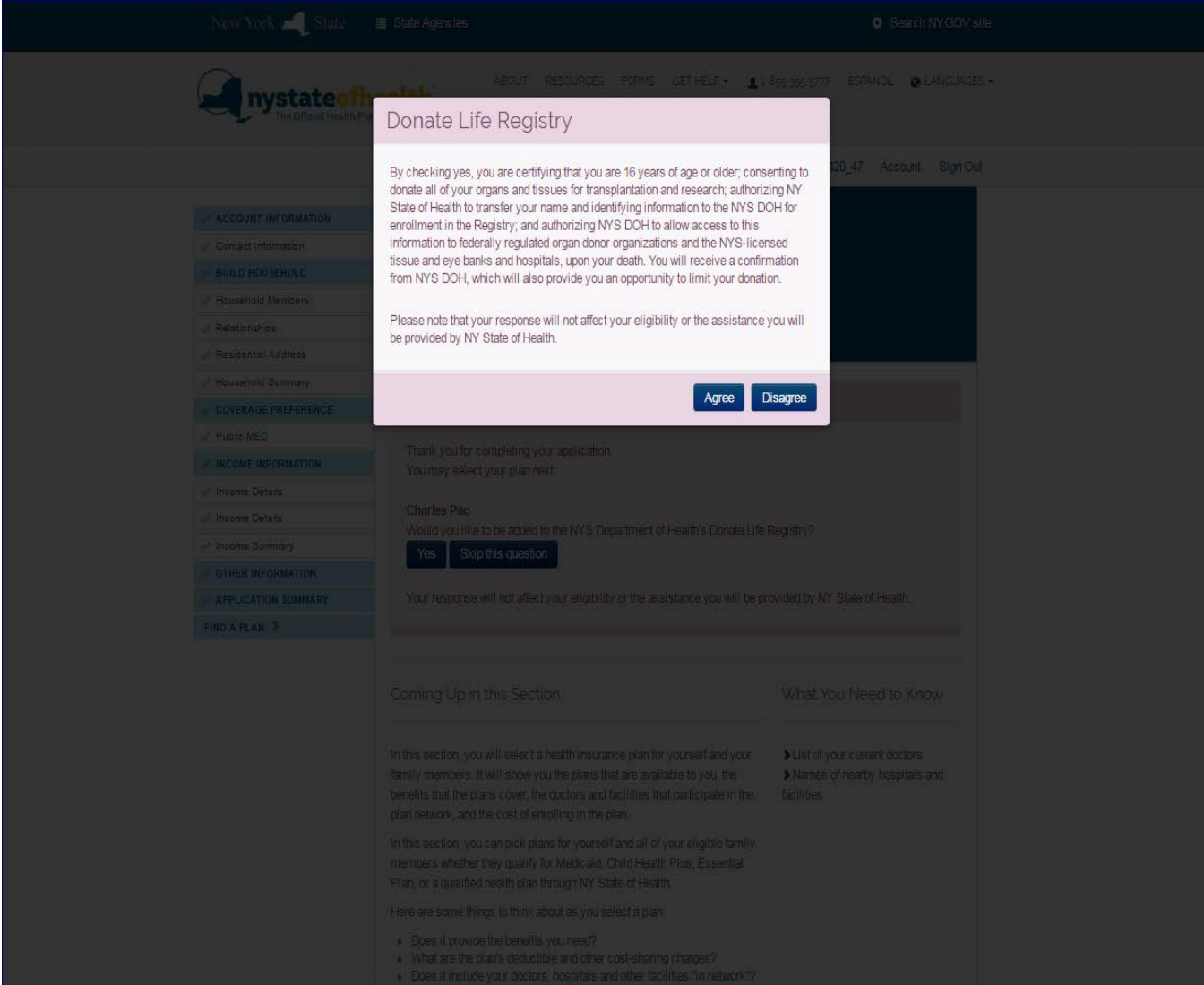
Individuals who receive an Eligibility Determination but do not respond to the question, will be presented with the question again when they return to select a plan.

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



The screenshot shows the nystateofhealth website interface. At the top, there is a navigation bar with "New York State" and "State Agencies" links, and a search bar for "Search NY.GOV site". Below this is a secondary navigation bar with "ABOUT", "RESOURCES", "FORMS", "GET HELP", a phone number "1-855-356-5777", "ESPAÑOL", and "LANGUAGES". The main content area is titled "Plan Selection Introduction" and features a sidebar menu on the left with categories like "ACCOUNT INFORMATION", "BUILD HOUSEHOLD", "COVERAGE PREFERENCE", "INCOME INFORMATION", "OTHER INFORMATION", and "APPLICATION SUMMARY". The main content area displays a "Donate Life Registry" section with a thank-you message and a question: "Would you like to be added to the NYS Department of Health's Donate Life Registry?". Below this, there are sections for "Coming Up in this Section" and "What You Need to Know".

## Organ Donation Registration Question Acknowledgement Placement on Plan Selection Pop-Up Screen



The screenshot shows the NYS State of Health website interface. A dark sidebar on the left contains a navigation menu with categories like ACCOUNT INFORMATION, BUILD YOUR PROFILE, COVERAGE PREFERENCE, INCOME INFORMATION, OTHER INFORMATION, APPLICATION SUMMARY, and FIND A PLAN. The main content area is partially obscured by a light pink pop-up window titled "Donate Life Registry".

**Donate Life Registry**

By checking yes, you are certifying that you are 16 years of age or older; consenting to donate all of your organs and tissues for transplantation and research; authorizing NY State of Health to transfer your name and identifying information to the NYS DOH for enrollment in the Registry; and authorizing NYS DOH to allow access to this information to federally regulated organ donor organizations and the NYS-licensed tissue and eye banks and hospitals, upon your death. You will receive a confirmation from NYS DOH, which will also provide you an opportunity to limit your donation.

Please note that your response will not affect your eligibility or the assistance you will be provided by NY State of Health.

**Agree** **Disagree**

Below the pop-up, the background page shows a confirmation message: "Thank you for completing your application. You may select your plan next." It includes a user name "Charles Pac" and a question: "Would you like to be added to the NYS Department of Health's Donate Life Registry?" with "Yes" and "Skip this question" buttons. Further down, there are sections for "Coming Up in this Section" and "What You Need to Know" with descriptive text and bullet points.

# Paper Applications

- Paper application 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/donatelife](http://www.health.ny.gov/donatelife)
- 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?

