The Patient Voice:

Living With and Beyond Cancer in Rural Communities ECHO

Thursday June 18, 2026

This project was funded in part by the Centers for Disease Control and Prevention NU58DP007218.

Housekeeping Items

Please type your full name - *First Name, Last Name- organization and email into the Chat Box.* If you're in a room with others, please add all names in the Chat for accurate attendance.

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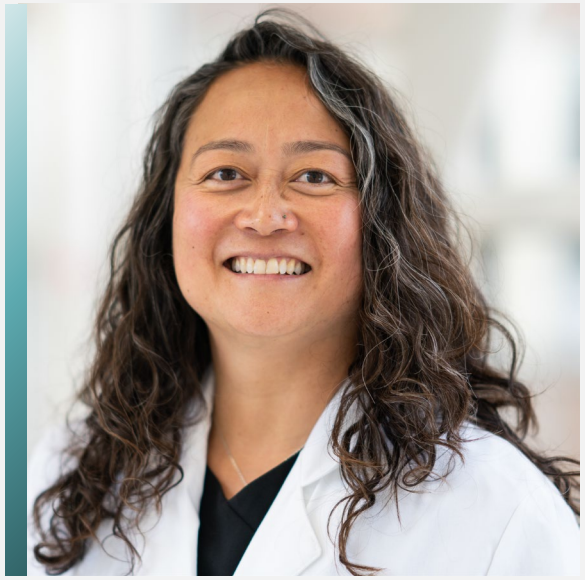
Do NOT share any personal health information (PHI) about any patient.

If you have a question, please type it in the Chat Box any time during this presentation.

Today's Agenda

Topic	Facilitator/Presenters	Time
Welcome & Introductions	Tessa Flores, MD	10 mins
Background Information	Tessa Flores, MD	10 mins
Case Presentation(s)	Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP	15 mins
Discussion/Questions, Answers & Solutions?	Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP	20 mins
Feedback Survey & Wrap Up	Tessa Flores, MD	5 mins

Introductions



Tessa Flores, MD

Medical Director of Cancer Survivorship and Screening

Roswell Park Comprehensive Cancer Center

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Director, Ph.D. Program in Nursing

Stony Brook University School of Nursing, Clinical Nurse Researcher, Stony Brook Cancer Center

New York State Cancer Consortium

Project ECHO®

Speakers have no disclosures or conflicts to report.

Introductions

Christina Crabtree-Ide, PhD, MPH

Director of Population Health Outreach

Roswell Park Comprehensive Cancer Center

Maureen Killackey, MD, FACS, FACOG

Chair, NYS Cancer Advisory Council and **American College of Surgeons Commission on Cancer Site Reviewer,** Bassett HealthCare

Killackey has no disclosures or conflicts to report. Crabtree-Ide reports funding support from Genentech, and stock ownership of Danaher, Fortive, Vontier, and Veralto Corps.

The New York State Cancer Consortium

Working Together,
Reducing Cancer,
Saving Lives

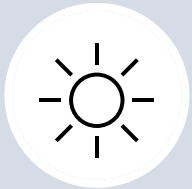
Visit us at
nyscancerconsortium.org

We work together to implement the **NYS Comprehensive Cancer Control Plan** and reduce the burden of cancer through the following activities:

- Increase public knowledge of the Consortium and Plan
- Collaborate to achieve Plan goals and objectives
- Share progress, insight and expertise
- Track progress on cancer indicators tied to the Plan

Consortium Action Teams

- Learn about the latest updates in state-wide cancer prevention efforts
- Promote Plan priorities through webinars, trainings, or workshops
- Collaborate with team members to achieve Plan goals



Skin Cancer

Lung Cancer

Colorectal Cancer

HEAL (Healthy Eating Active Living)

Environmental Carcinogens

Survivorship

Survivorship ECHO Program

HPV Coalition

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Survivorship Community Engagement Forums

2024: Rural Cancer Survivorship Across the Continuum

- Rural setting catchment area >> NCI designated Cancer Center

2026: Enhancing Rural Survivorship Care: Patient Perspectives on Navigating Healthcare Needs in Rural Communities, the Patient Voice

- Rural setting catchment area>> Multidisciplinary community hospital

Topics explored:

- Care Coordination & Communications
- Barriers/Access to survivorship care
- Quality and Availability of care
- Impact of rural living on survivorship care & biggest challenges
- What healthcare providers should understand about their experience as a cancer survivor living in a rural community

Survivorship Community Engagement Forum

Focus Group Findings on Access and Availability in Rural Survivorship Care

Access to Care is Uneven and Often Delayed

- Long wait times for specialty and supportive care services is a major barrier
- Appointment scarcity and overbooking; Perceived urgency mismatch
- Access problems not related to provider incompetence but as SYSTEM STRAIN
- Continuity itself functions as a **therapeutic intervention**, buffering fear of recurrence and reinforcing trust.

High Quality of Care Exists with Fragile Continuity

- Strong trust in the quality of oncologic care, but that trust is destabilized by provider turnover and discontinuity
- Preference for known providers-anxiety and distress seeing locums unfamiliar with patients complicated history
- Survivorship is experienced as a **second vulnerable phase**, distinct from treatment but less structurally supported

Survivorship Community Engagement Forum

Focus Group Findings on Access and Availability in Rural Survivorship Care

Rurality Shapes the Survivorship Experience

- Geography is not just logistical—it shapes emotional risk, fatigue, and anxiety.
- Travel burden; long drives, winter weather, transportation dependence affect adherence and well-being

Financial strain

- Repeated copays, transportation costs, and lack of coverage for non-cancer appointments post-treatment.

Mixed impact of small-community care

- Benefits: being known, personal relationships, providers living locally.
- Costs: fewer specialists, limited choice, vulnerability when providers leave.
- Rural survivorship involves a **constant negotiation between closeness and scarcity**

Session 2: Access and Availability in Rural Survivorship Care

June 18, 2026 | 12:00 - 1:00pm

Moderator: Tessa Flores, MD

Presenter:
Sylvia K. Wood PhD, DNP, ANP-BC, AOCNP

Learning Objectives

1. Identify common access issues for cancer survivors in rural communities.
2. Describe resources to improve access to care for cancer survivors
3. Describe best practices to improve access and availability to survivorship care in rural communities.

Cancer Survivor Profile & Hx

Name: Mr. R. (pseudonym)

Age: Approximately 62 years

Cancer History: Esophageal cancer, s/p curative-intent treatment Chemo/RT

Current Status: Remission x 4 yrs in follow-up care

Care Setting: Rural & Regional health systems

Occupation: Retired farmer

Residence: lives on farm with wife of 35 yrs:1 child deceased

Background

- During diagnosis & active Rx care was timely, coordinated & highly focused
- Once Rx ended, profound shift in healthcare experience
- Marked by access barriers, fragmentation, loss of person-centered care

"After Treatment, Everything Got Harder"

Case Study #1

Experience of Access & Availability in Rural Survivorship Care

Following Rx Mr. R. required frequent surveillance including endoscopies and CT scans accessing appointments became a major burden

> *"Accessing care to schedule endoscopies was difficult. Many times, the doctors were overbooked. It took a long time to get appointments, and I was always worried about delays in care…*Just making and coordinating all the appointments was difficult."

Mr. R. emphasized that while chemotherapy and active treatment were intense, survivorship care felt less supported and less coordinated

> *"It's tougher to go through follow-up with no coordination."*

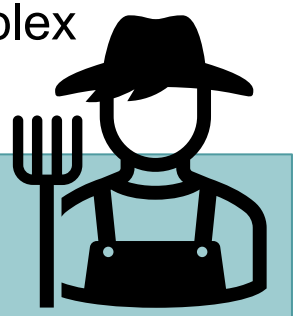
Mr. R. had challenges accessing primary care. His PCP was often overbooked, leading to referrals to urgent care instead.

> *"My own doctor doesn't have time for me sometimes—he is too busy."*

When sent to urgent care, continuity was disrupted.

> *"I'm told to go to urgent care because my PCP is overbooked, then I have to go through my whole story with someone else. The continuity of care is gone."*

He found this repetitive storytelling exhausting and emotionally draining, particularly given his complex cancer history.



Case Study #1

Experience of Access & Availability in Rural Survivorship Care

Mr. R. identified broader system-level challenges as significant obstacles. Navigating care across multiple health systems, for specialty care, particularly outside his primary cancer center, was especially difficult.

> *"The type of health system is an obstacle. The other health system I had to go to was a nightmare to navigate in."*

Travel to appointments added another layer of burden, and financial cost particularly in areas without robust public transportation.

> *"Travel to appointments can be difficult—we don't have a subway. It's just a given that you have to travel to get care."*

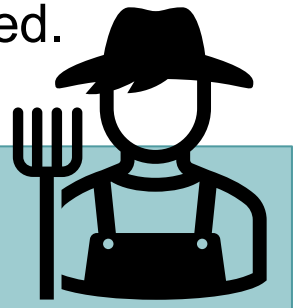
He also noted workforce shortages as a growing problem.

> *"It can be hard to find new PCPs if someone leaves. There are not enough doctors or nurse practitioners."*

While telemedicine was offered as a solution to access issues, Mr. R. found it unsatisfying.

> *"Telemedicine is a headache. Face-to-face communication is best. I want to see the person."*

For him, face-to-face communication was essential for feeling heard, understood, and reassured.



Case Study #1

Experience of Access & Availability in Rural Survivorship Care

Key Challenges Identified as a Rural Cancer Survivor for Mr. R

- *Limited access to primary care providers and specialty providers between scheduled visits for problems, new symptoms or issues, heavy use of urgent care.*
- *Travel burden and multi-system fragmentation*
- *Long wait times and overbooked clinics*
- *Insufficient visit time to address concerns*
- *Difficulty coordinating and scheduling survivorship surveillance*
- *Loss of continuity in primary care*
- *Depersonalization and focus on documentation over the patient*
- *Dissatisfaction with telemedicine*
- *Workforce shortages affecting access and quality*

Mr. R. summarized the contrast between active treatment and survivorship succinctly:

"Once you got your cancer diagnosis, that initial care was good. After active treatment, things were a lot harder."

Case Study #1

Session Two Case Study #1 Discussion:

This case illustrates the need for:

- Timely access to care
- Reduce healthcare workforce and geographic shortages
- Adress financial toxicity with mounting travel costs, copays
- Improved care coordination during survivorship
- Enhanced communication pathways between visits
- Continuity with primary and oncology care teams
- Reduction of overreliance on telemedicine and urgent care when not preferred
- Re-centering care on the survivor as a whole person

Session Two Case Study #1 Discussion:

- **Health System Barriers:** What barriers can we mitigate to promote timely access to care within strained healthcare systems?
- **Care Coordination**: What makes coordination especially difficult when survivors receive care from more than one health system?
- **Patient Advocacy:** Who should be responsible for tracking and coordinating Mr. R.'s follow-up endoscopies and CT scans?
- **Timeliness:** What processes could help ensure that surveillance procedures are scheduled on time, especially when care occurs across multiple health systems?
- **Communication:** What information should urgent care clinicians have access to when caring for cancer survivors?
- **Provider Shortages:** What alternatives could be developed when rural primary care appointments are not available in a timely way?
- **Patient Education:** What can we do as health care providers to improve meaningful education for effective patient self-care and self advocacy
- **Care Navigation:** How could a nurse navigator or survivorship coordinator reduce the burden of self-advocacy for Mr. R.?

Cancer Survivor Profile & Hx

Name: Ms. L. (pseudonym)

Age: Approximately 59 years

Cancer History: Breast Cancer

Current Status: Post-lumpectomy, adjuvant chemotherapy & RT

Care Setting: Rural Multidisciplinary community hospital

Occupation: Retired

Residence: Rural farming community

Background

- Current need: Physical therapy for lymphedema, cording, and fibrosis
- Key access issue: Two-month delay before initial lymphedema therapy appointment

"If I had gotten treatment sooner, this might not be a lifelong problem"

Case Study #2

Experience of Access & Availability in Rural Survivorship Care

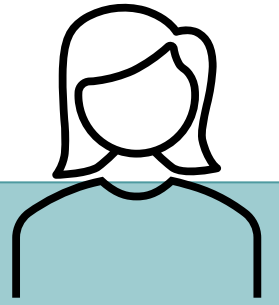
Ms. L. is a breast cancer survivor living in a rural area with a local multidisciplinary community hospital nearby, within a two-hour catchment area of a comprehensive oncology center. She completed surgery and radiation.

During active treatment, she felt that her oncology team was committed and supportive, helping access needed services, including calling other facilities when local appointments were unavailable. She describes the providers as:

> “….superb, my oncology providers were strong advocates for me during my treatment journey."

After treatment, however, Ms. L. developed symptoms of lymphedema, cording, and fibrosis. She was referred for physical therapy, but the first available appointment was two months away. She believed this delay had lifelong consequences.

> "Wait times to get into specialty follow-ups are a concern….Physical therapy for lymphedema...I had to wait 2 months for initial appointment. I have a lifetime of consequences for lymphedema because they couldn’t see me sooner…these problems should be addressed immediately,”



Case Study #2

Experience of Access & Availability in Rural Survivorship Care

For Ms. L., this delay raised a larger concern: cancer survivors' post-treatment complications need to be treated as high-priority issues, not routine referrals.

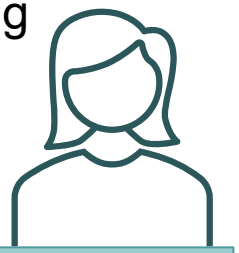
Her access challenges were not limited to physical therapy. She described long waits for specialty follow-up visits, including, neurology, and endocrine care. Some waits were as long as four to six months, and endocrine follow-up was described as nearly unavailable.

Ms. L. also faced transportation barriers each time she comes for care. Traveling to appointments can take an hour or more, and the appointments may last only a few minutes.

> "If you know, you know, but you gotta find out" about reserved radiation parking. Parking can take over "15 to 20 minutes,"

Surveillance procedures, such as colonoscopy, require preparation plus a long drive, coordination for caregiver support, making follow-up physically and emotionally burdensome, and especially difficult when she is timing medications, managing diarrhea, or trying to arrive on time for treatment.

> "…you time everything then have to find the "darn parking" describing constant stress accessing care



Case Study #2

Session Two Case Study #2 Discussion:

This case illustrates the need for:

- Delayed cancer rehabilitation
- Long-term consequences of delay
- Specialty care shortages
- Coordination across systems
- Travel burden
- Weather-related barriers
- Caregiver reliance
- Supportive service gaps
- Emotional burden due to complexities and challenges navigating access to care

Session Two Case Study #2 Discussion:

Referral urgency: Not all follow-up needs can wait months; some require rapid assessment and intervention, and some do not. What do patients need to know? What symptoms should trigger expedited referrals & cancer rehabilitation?

Patient Self-Advocacy: What patient education is needed and what steps could the patient take in assuming agency over healthy survivorship behaviors, and self-care management of lymphedema?

Interprofessional role clarity: What can oncologists, nursing, physical therapy, primary care, navigators and social work each do when any specialty therapy is delayed?

Care coordination: How can we be more effective in coordinating rural care across different systems and available resources?

Specialty care shortages: What resources can bridge care while the patient waits for needed therapies and specialty appointments?

Systems improvement: How can rural systems prioritize time-sensitive survivorship complications before they become chronic?

Open Discussion: Questions, Answers and SOLUTIONS?

The Rural Gap:
Unique Challenges in Cancer Survivorship for Older Adults

The Rural Reality:
Unique Barriers to Care

The Burden of Geographic Isolation

1.5x

Rural survivors are 1.5 times more likely to present with advanced-stage cancer diagnoses.

The "Farming Factor" in Treatment

Providers often overlook rural-specific stressors, such as the care and cost of farm animals.

Late-Stage Presentation:
Rural Survivors (1.5 times more likely) vs. Urban (Baseline)

Financial Toxicity and Economic Strain

42%

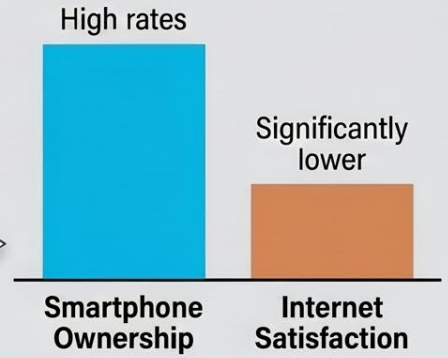
42% of survivors exhaust their life savings within two years of a cancer diagnosis.

The Digital Bridge:
Technology Trends and Gaps

High Tech Ownership, Low Connectivity Satisfaction

Internet Use for Health:
Rural (78.1%) vs. Urban (80.1%)

High-Speed Satisfaction:
Rural (4.6% Extremely) vs. Urban (18.8% Extremely)



Social Media as a Support System

2.6x

Rural survivors are 2.6x more likely to share personal health information on social media.

Recommendations for Better Survivorship

Survivors request in-person walkthroughs of care plans and referrals to exercise and nutrition programs.

Experience of Access & Availability in Rural Survivorship Care-Takeaways

Access to care issues for rural cancer survivors is multifaceted and inter-related

- Geographic & Transportation Barriers
- Workforce & Healthcare infrastructure
- Financial & Socioeconomic Challenges
- Care Coordination and Supportive Services
- Digital Health and Telehealth Barriers

Challenges often intersect, leading to later-stage diagnoses and poorer survival outcomes compared to urban populations.

Persistent disparities highlight the need for **comprehensive, context-sensitive interventions** that address both systemic and individual-level factors.

New York State Cancer Consortium

Project ECHO®

National Academy of Medicine Recommendation

National Comprehensive Cancer Network (NCCN)

Dr. Tessa Flores!

By Topic:

- Anthracycline-induced cardiac toxicity
- Anxiety and depression
- Cognitive function
- Exercise
- Fatigue
- Healthy lifestyles
- Immunizations and infections
- Menopause-related symptoms
- Pain
- Sexual function (female/male)
- Sleep disorders

The Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, & Young Adult Cancers

By Topic:

- Any Cancer Experience
  - Psychosocial, Fatigue, Sleep, limitations in healthcare access, subsequent malignancy, malignancy risk offspring
- Blood/Serum Products
- Chemotherapy
- Radiation
- Hematopoietic Cell Transplant
- Surgery
- Other Therapeutic Models
- General Health Screening

American Society of Clinical Oncology (ASCO)

By Topic:

- Anxiety and depression
- Cardiac dysfunction
- Chronic pain
- Fatigue
- Fertility preservation
- Neuropathy
- Palliative care

By Cancer Site:

- Breast (ASCO/ACS)

American Cancer Society (ACS) Survivorship Care Guidelines for Primary Care Providers

By Topic:

Holistic:

- Care coordination
- Health promotion
- Long-term and late effects
- Nutrition and physical activity
- Screening
- Surveillance

By Cancer Site:

- Breast (ACS/ASCO)
- Colorectal
- Prostate
- Head and neck

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WASHINGTON, DC

Advancing Patient-Centered Cancer Survivorship Care

Adapted from the National Cancer Survivorship Resource Center

www.cancer.org/survivorshipcenter

Dr. Maureen Killackey, GWU External Advisory Board, CoC Project

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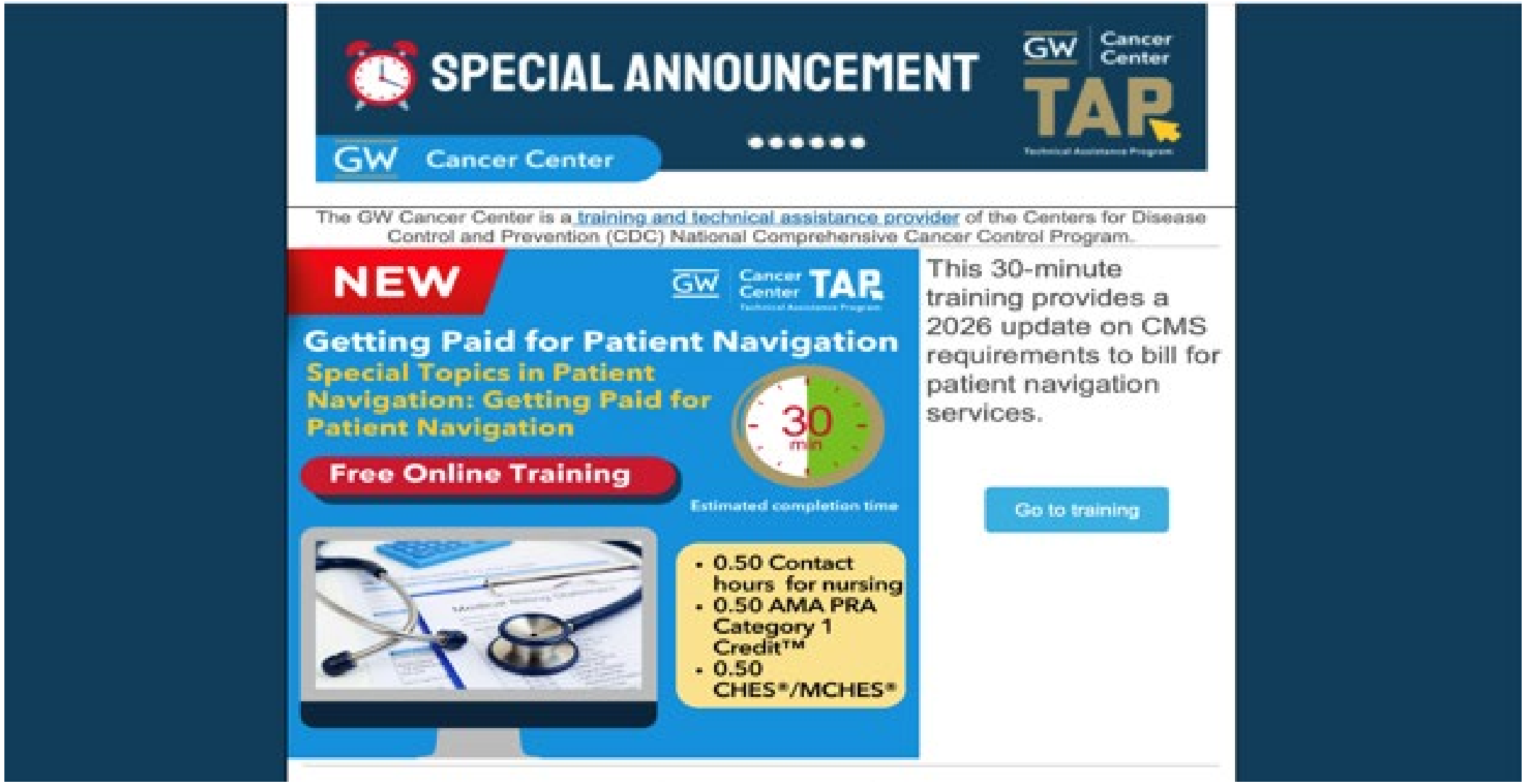

https://cancercontroltap.org/gw-cancer-center-patient-navigation-resources/

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Upcoming Session Date

New Date

July 2nd
12 – 1:00pm

Session 3: Navigating Health Information in the Digital Age

Thank you for attending

Please complete the session evaluation