

Living with 9/11 Cancer

- **A Support Group Aimed at Helping WTC Health Program General Responders and Survivors Diagnosed with 9/11 Related Cancers**
- **Introduction of Patient Centered Goals**
- **Exploring how palliative care improves quality of life for both the patient and their family**

Sharon Daneshgar, LCSW-R, OSW-C

Georgianne Kraft, LCSW-R, OSW-C



Living with 9/11 Cancer

Abstract Summary:

There is an indisputable link between 9/11 and chronic health problems for General Responders and Survivors of the attacks on the World Trade Center. The WTC Health Program has identified several types of cancers that research has definitively linked to 9/11 exposures. The diagnosis of cancer brings emotional distress to patients and that stress is amplified for those who have been certified with 9/11 related-cancer attributable to their presence in the New York City Disaster Area. Oncology social workers identified the gap in support and patient education to meet the unique needs of those living with 9/11 related-cancer.

A monthly virtual support group was established to educate and empower General Responders and Survivors diagnosed with 9/11 related-cancer to connect with others who are going through the same experience. To achieve patient-centered goals when living with cancer, advance directives and goals of care need to be discussed. Oncology social workers developed a standard way to introduce family meetings in a positive way for individual group members. Group members are informed that palliative care focuses on symptoms management for the person. Palliative care is introduced positively with the goal of assuring the patient that they will not be abandoned, and a plan can be developed to address their everyday quality of life.

September 11, 2001



- The September 11 attacks, known as 9/11, were four coordinated suicide terrorist attacks carried out by the militant Islamist extremist network al-Qaeda against the United States on September 11, 2001.
- That morning, nineteen terrorists hijacked four commercial airliners scheduled to travel from the East Coast to California. The hijackers crashed the first two planes into the Twin Towers of the World Trade Center in New York City, and the third into the Pentagon in Arlington County, Virginia near Washington, D.C.
- The fourth plane was similarly intended to hit a federal government building in Washington, D.C., but crashed in a field following a passenger revolt.
- The attacks killed nearly 3,000 people and initiated the global war on terror.



**Where were
you on 9/11?**

Who were you with?
What were you feeling?
What is your story?
What do you remember?

REMEMBERING

9/11

NEVER FORGET

9-11-01



Exposure and Impact



The 9/11 terrorist attack on the World Trade Center in New York resulted in the loss of 2,753 people in the WTC Tower and the surrounding area. At least 100,000 responders and recovery workers from every U.S. state with 400,000 residents and other workers around Ground Zero – were exposed to a toxic cloud of dust filled with a thick layer of ash that remained for 3 months.



The WTC consisted of a dangerous mixture of cement dust and particles, asbestos and a class of chemicals called persistent organic pollutants. These include cancer-causing dioxins and polycyclic aromatic hydrocarbons, which are byproducts of fuel combustion. The dust contained heavy metals that are known to be poisonous to the human body.



Many first responders and others who were directly exposed to the dust developed a severe cough that lasted for a month, on average. After the initial health problems that 9/11 responders faced, they soon began experiencing a wave of chronic diseases that continue more than 20 years later.

Program Overview



WTC Health Program provides WTC-related medical and mental health services to Responders and Survivors.

Responders - worked or volunteered to provide rescue, recovery, debris clean-up on or in the aftermath of September 11.

Survivors – worked, resided, or attended school in the NYC Disaster Area on or in the aftermath of September 11.

WTC Health Program – Provides Cancer Diagnostic and Screening Services.

WTC Health Program MD requests certification of WTC-related health conditions approved by the WTC Health Program.



WTC Health Program Statistics (09/24/2025)



WTC Health Program Enrollment

Member Type	#	%
General Responders	69,558	49.95%
FDNY Responders	15,751	11.31%
Survivors	52,475	37.68%
Pentagon / Shanksville Responders	1,456	1.05%
Total Members	139,240	100%



WTC Health Program Statistics (09/24/2025)



Diagnosed with 9/11-related Cancer

Responder	Survivor
23,100	23,900

Top 15 Certified Cancers

Certified Cancer	Responder	Survivor
Non-melanoma Skin	10,800	5,500
Prostate	6,100	5,400
Breast – Female	600	3,700
Lymphoma	900	1,300
Thyroid	900	1,400
Lung/Bronchus	600	1,100
Kidney	900	900
Melanoma of Skin	2,100	1,400
Leukemia	700	700



Note: Individual members may have certifications in more than one category. September 2024.

Learning Objectives:

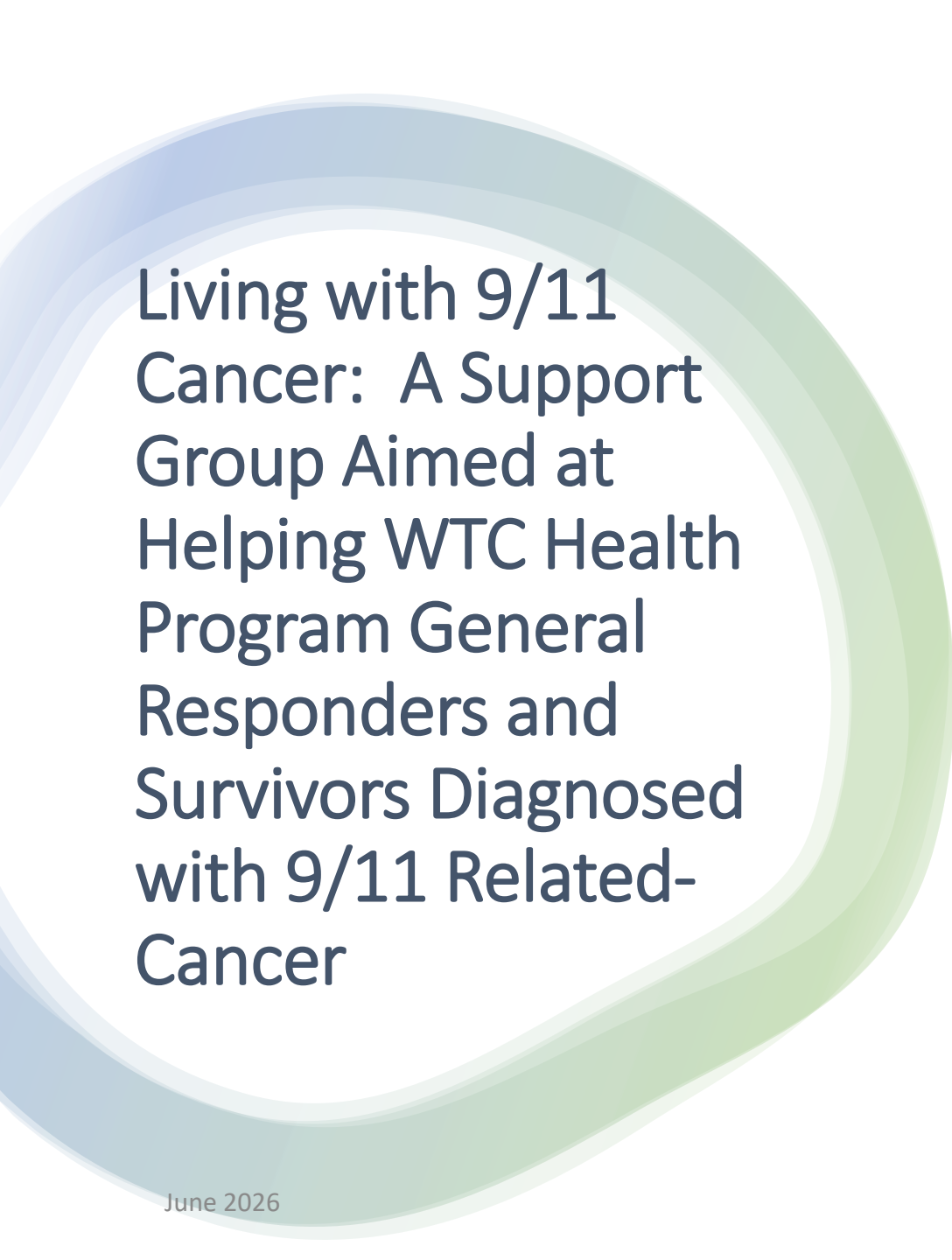
Discuss the benefits of providing a support group to General Responders and Survivors diagnosed with 9/11 related-cancer with a focus on peer support to share feelings and to reduce isolation. Goals-of-care conversations can help clarify patients' priorities and values and can be discussed early on and throughout treatment and care.

Explain the family meeting process, introduce the palliative care team, and define shared decision making. Assist individual group members as advocates of self-determination and for care that meets their culture needs.

Palliative care team introduction to the group to discuss improving quality of life for members facing problems with cancer causing life-limiting illness. Presenter, an expert in palliative care, to address the prevention and relief of pain and suffering through a comprehensive assessment by the palliative care team.

Provide a support system to group members to help cope with their cancer, enhance their quality of life by integrating their psychological and spiritual care, and a team approach to help to cope and live as actively as possible.





Living with 9/11 Cancer: A Support Group Aimed at Helping WTC Health Program General Responders and Survivors Diagnosed with 9/11 Related- Cancer

June 2026

Identifying the need and assessment for the support group.

Collaboration between Oncology Social Worker and WTC Health Program Social Worker

Planning Model

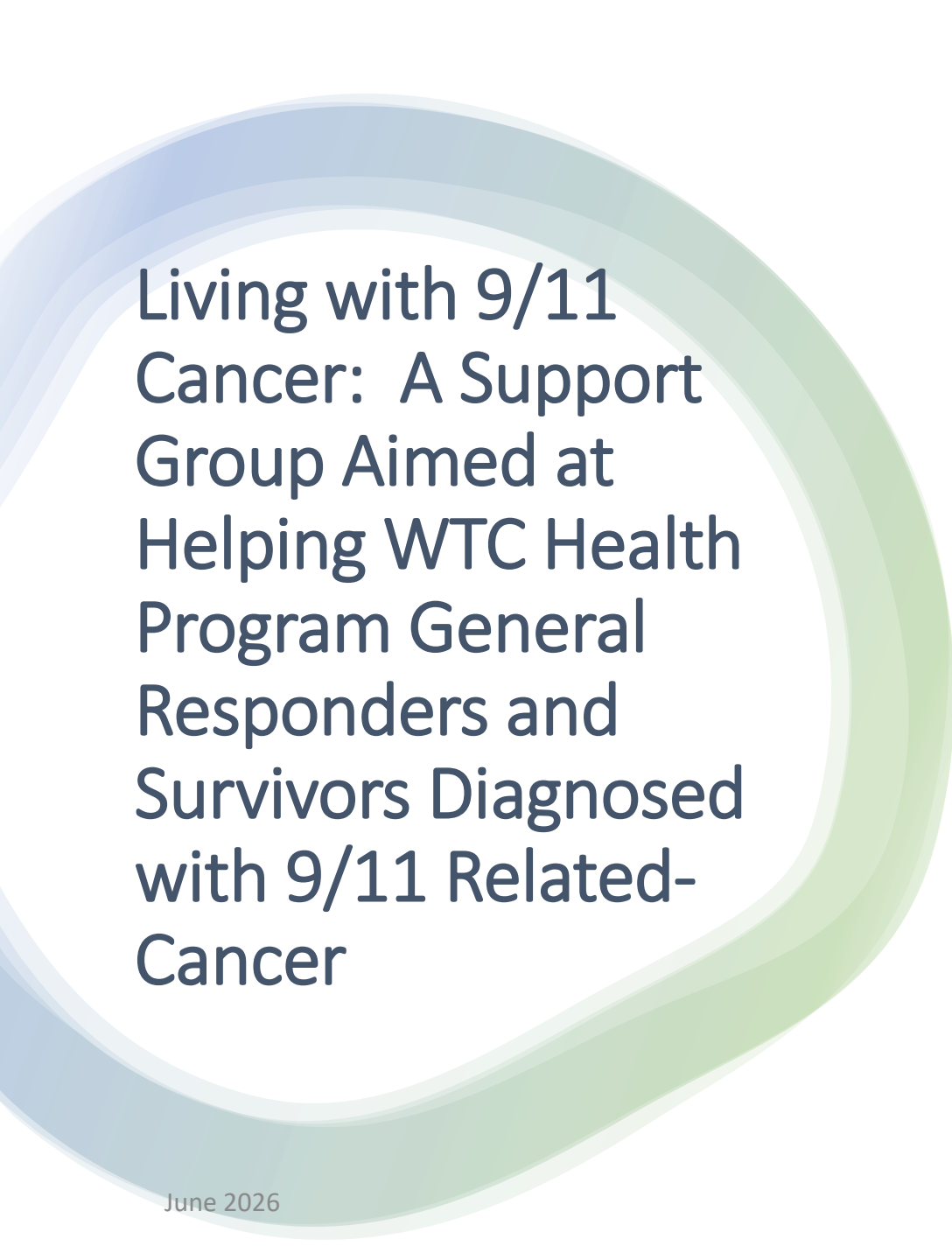
Need

Why not a regular cancer support group?

Oncology patients with 9/11 related cancer relate their cancer to their efforts during 9/11. Their needs are different from patients with non-9/11 cancer. Their decision to help others during 9/11 or the fate of where they were when 9/11 happened contributed to the development of their 9/11 related cancer.

Purpose

Group work to provide support and mutual aid between members. We created a needs-based assessment. Goals to decrease isolation and to bring the group together in a monthly support/educational group. Support and education specific to the 9/11 General Responders and Survivors population included discussing WTC Health Program benefits, research, treatments and future needs.



Living with 9/11 Cancer: A Support Group Aimed at Helping WTC Health Program General Responders and Survivors Diagnosed with 9/11 Related- Cancer

June 2026

Composition

Group will consist of 9/11 General Responders and Survivors diagnosed with WTC certified cancer. Family and non-9/11 cancer patients are not included.

Structure

Virtual, monthly meeting, open, with no set duration. Patients are screened for criteria eligibility. Patients that would benefit from individual counseling are referred to a therapist for a diagnostic evaluation for mental health services through the WTC Health Program.

Content

Provide support and educational presenters on topics related to patient's concerns. Social workers to facilitate exploration of the concerns of the group and presentations that the group would benefit from. If needed, concrete services provided.

Contacting the group

Email to WTC Health Program patients diagnosed with 9/11 cancer. Referrals from group members. Referrals from the Cancer Institute.

Group Work

Understanding the Social Content/Characteristics of the Group

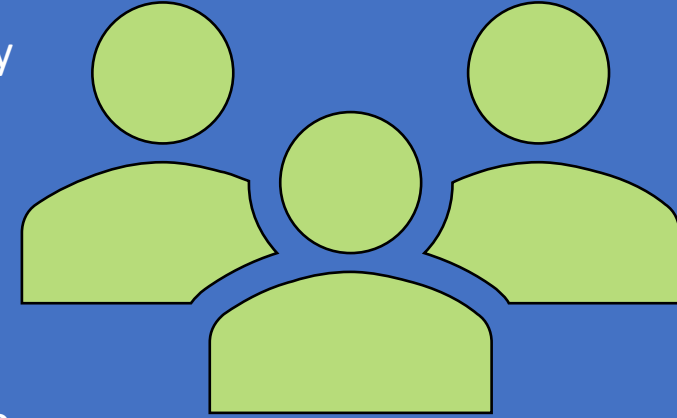
Group consisted of General Responders and Survivors who either volunteered, worked, lived or attended school in lower Manhattan. Group at different stages of cancer diagnosis, treatment and remission. Group addressing different stages of grief with facing where they were on 9/11 and how it has impacted their health. Group supportive to checking in and listening to other's stories. Trust developed between members and facilitating social workers.

Group work guidelines

Group provided with verbal contract to respect each other when speaking and sharing and to keep the confidentiality of the group. Social workers helped those new to group work to assimilate to the group. Group to focus on mutual support and goal achievement.

Assessment of the Group

There was uncertainty with attendance, cohesion and stabilizing membership. Group support was achieved with members providing encouragement and positivity to other members. Group was screened for their thoughts on how the group was working for them and suggestions for change, if any.



Group Assessment

Feelings and thoughts addressed by the participants in the group:

1. I feel isolated.
2. The world has forgotten about us and that day. There is a new WTC building, and the world has moved on. However, we are still living with the effects of that day.
3. No one understands.
4. Will my 9/11 coverage continue?
5. How do I access counseling?
6. PTSD reliving that day. How do I cope with this?
7. I have pain, problems managing my symptoms?
8. How do I share my wishes and preferences regarding my end of life wishes?



Psychosocial Factors Effecting this Population

Concrete/Emotional

- PTSD
- Loneliness
- Isolation
- Guilt
- Anxiety and Depression
- Interpersonal Relationship
- Divorce
- Housing
- Financial
- Occupational concerns and issues
- End of Life Decision Making
- Pain



How can we improve the quality of life for our group members?

Introduction to the Palliative Team – Supportive Oncology

Guest Speaker – Dr. Pavel Groysman – Supportive Oncology and Palliative Medicine

Guest Speaker – Dr. Diana C. Martins-Welch – Hospice and Palliative Medicine

- Defining palliative care and cancer – treating the whole person by helping to relieve symptoms, pain and stress.
- Palliative care can be provided at any phase of the cancer journey – chemo, radiation and immunotherapy.
- Palliative team is separate from the oncology care team.
- Palliative team manages mental, physical, emotional, social and spiritual issues.

Next visit with the Palliative Team – Supportive Oncology to be scheduled

- Discussed pain issues with emphasis on creating and maintaining quality of life
- Low attendance for the meeting and concerns that palliative care is not well understood by the group.
- Group members may be fearful by the word “palliative,” and we will explore options on how to introduce at a future meeting.



Defining Palliative Care

Palliative care is different from one person to the next.

Goals of care plan includes:

- alleviating symptoms, including side effects of treatment.
- improving understanding of illness and its progression.
- identifying and addressing practical and spiritual needs.
- helping to cope with feelings and changes related to illness.
- assisting in understanding treatment options, making treatment decisions, and coordinating care.
- identifying and accessing additional resources to provide support.

Introducing Advance Care Planning

Introduction to Advance Care Planning

- Discussing and preparing for future decisions about your medical care if you are unable to communicate your wishes.
- Meaningful conversations with loved ones.
- Choose to put preferences in writing – health care proxy and living will.

Challenges for the group with understanding palliative care.

- Hospice care vs. Palliative care
- Palliative care focusing on comfort and quality of life at any stage of cancer. Cancer treatments are designed to cure or control the disease.
- Palliative care helps to relieve the symptoms or problems caused by cancer.
- Palliative care focuses on the patient's goals of care, values and what is important to them.

Debunking Myths about Palliative Care

- It hastens death.
- It is only for people dying.
- It is only provided in a hospital.
- Pain is part of dying.
- Taking pain medication leads to addiction.
- It means my doctor has given up.
- There is no hope for me.



9/11 CANCER SUPPORT GROUP

If you are a General Responder/Survivor diagnosed with 9/11 cancer you may feel a tremendous loss of control as you cope with the challenges of managing your illness. To assist you with finding the tools to regain a sense of control over your life, the Northwell WTC Clinical Center of Excellence and R.J. Zuckerberg Cancer Center at Northwell Cancer Institute will be offering a free virtual *“9/11 Cancer Support Group.”*

This free monthly meeting will give General Responder/Survivor with 9/11 cancer a chance to meet others and share experience, comfort, and support. It will be an opportunity to share information, coping skills and to network. The support group will be devoted to patients with 9/11 cancer.

“9/11 Cancer Support Group” will meet virtually via Microsoft Teams monthly.

For more information and to pre-register please contact Sharon Daneshgar, LCSW-R, OSW-C at R.J. Zuckerberg Cancer Center, sdaneshg@northwell.edu or Georgianne Kraft, LCSW-R, OSW-C at Northwell Cancer Institute at Rego Park, gkraft@northwell.edu





CANCER INSTITUTE OVERVIEW

CANCER TREATMENT AND PROCEDURE VOLUME BY REGION*

Northwell Health Cancer Institute treats more New Yorkers than any other health system



Western Region

57,000+ Medical Oncology Treatments
28,000+ Radiation Medicine Treatments
8,000+ Surgical Cases

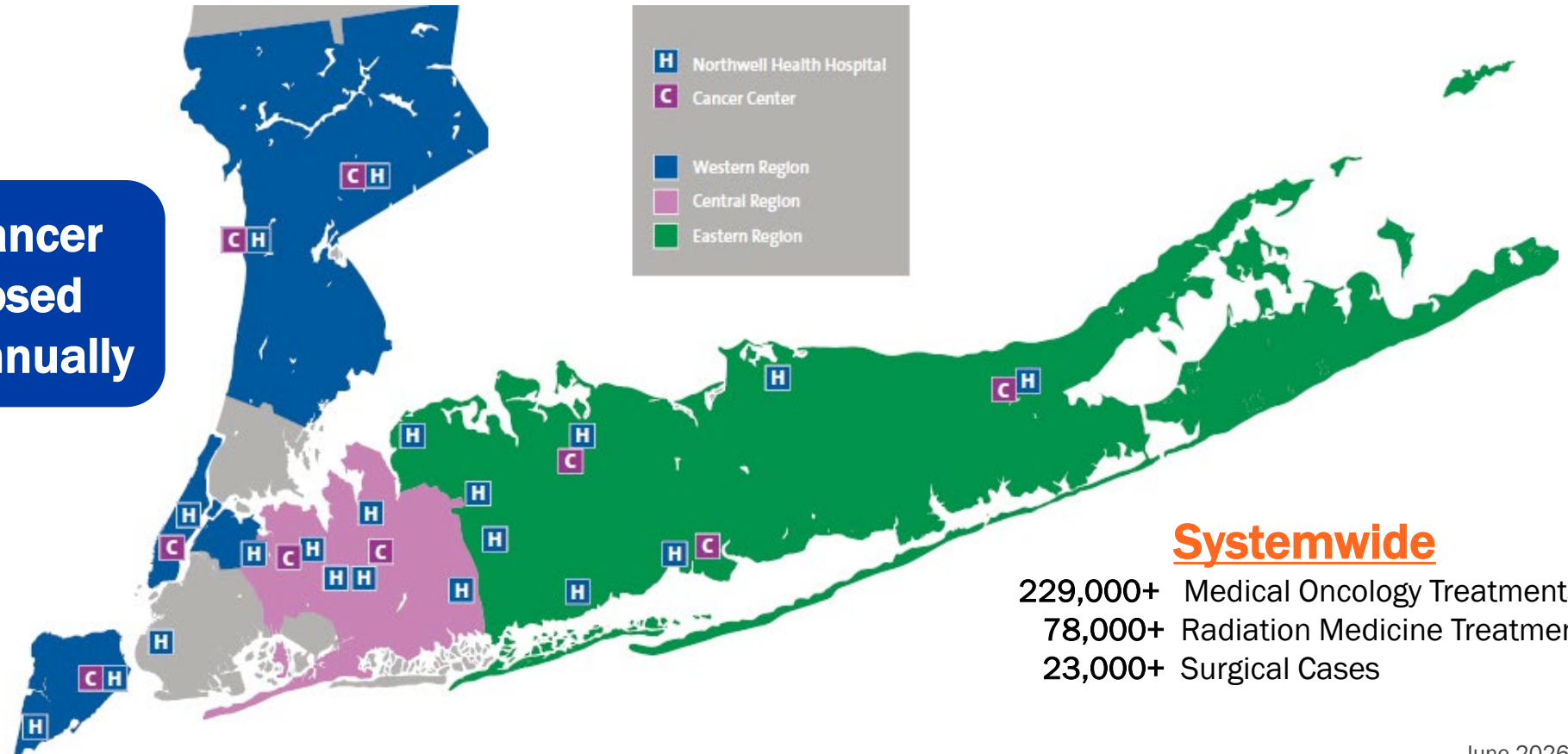
Central Region

126,000+ Medical Oncology Treatments
32,000+ Radiation Medicine Treatments
9,000+ Surgical Cases

Eastern Region

45,000+ Medical Oncology Treatments
17,000+ Radiation Medicine Treatments
5,000+ Surgical Cases

19,500+ New Cancer Patients Diagnosed and/or Treated Annually



Systemwide

229,000+ Medical Oncology Treatments
78,000+ Radiation Medicine Treatments
23,000+ Surgical Cases

ECONOMIC IMPACT



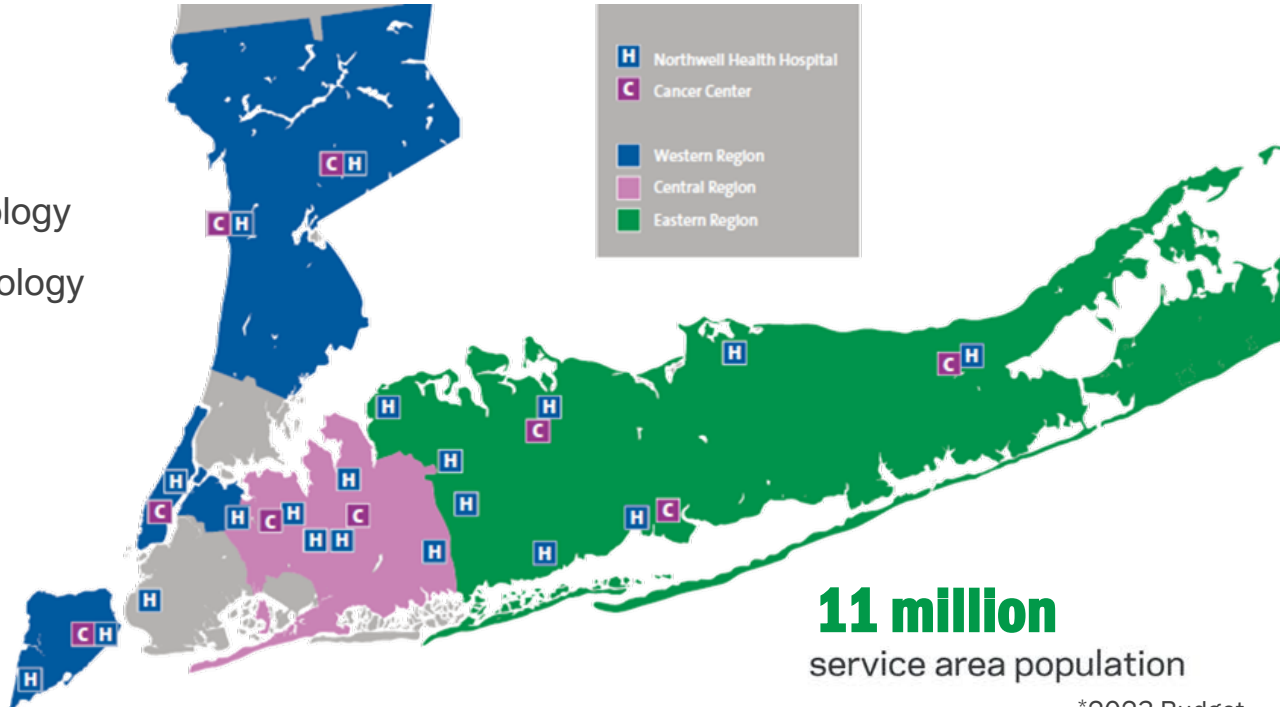
\$37.5 million* medical oncology
\$30.4 million* radiation oncology
annual operating budget



1
cancer hospital



9
cancer centers



CAREGIVERS



300+
employed physicians

200+
nurses

70+
advanced care providers

50+
oncology residents & fellows across four cancer-specific programs

OPERATING STATISTICS

19,500+^a
new cancer patients diagnosed and/or treated annually

229,000+ medical oncology treatments^b

78,000+ radiation oncology treatments^b

23,000+ surgical cases^b



330+
active cancer clinical trials

70+
principal investigators

^a 2022 Actual
^b 2023 Actual

COMMUNITY IMPACT



\$25.7^c million in education & research

\$1.3^c million in health improvement service

\$3.4^c million in charity care

^c 2023 Data

CANCER INSTITUTE FACILITIES BY REGION

World-class cancer care in a comfortable, state-of-the-art setting



Western Region

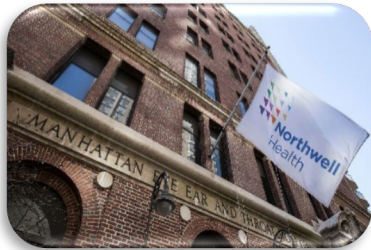
(Manhattan, Westchester, & Staten Island)



Cancer Institute at Northern Westchester Hospital



Cancer Institute at Phelps Hospital



Manhattan Eye, Ear & Throat Hospital



Florina Cancer Center

Central Region

(Queens, Nassau County)



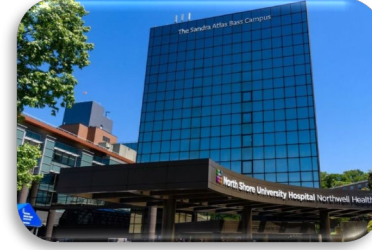
R.J. Zuckerberg Cancer Center



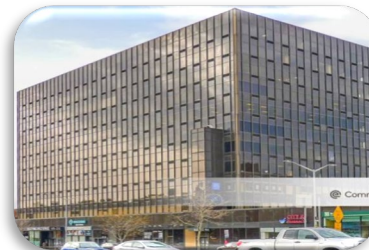
The Center for Genomic Medicine



R.J. Zuckerberg Cancer Hospital



North Shore University Hospital



Cancer Institute at Rego Park

Eastern Region

(Suffolk County)



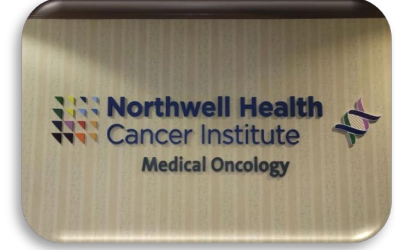
Northwell Health Cancer Institute at Huntington



Northwell Health Imbert Cancer Center



Northwell Health Cancer Institute at Riverhead

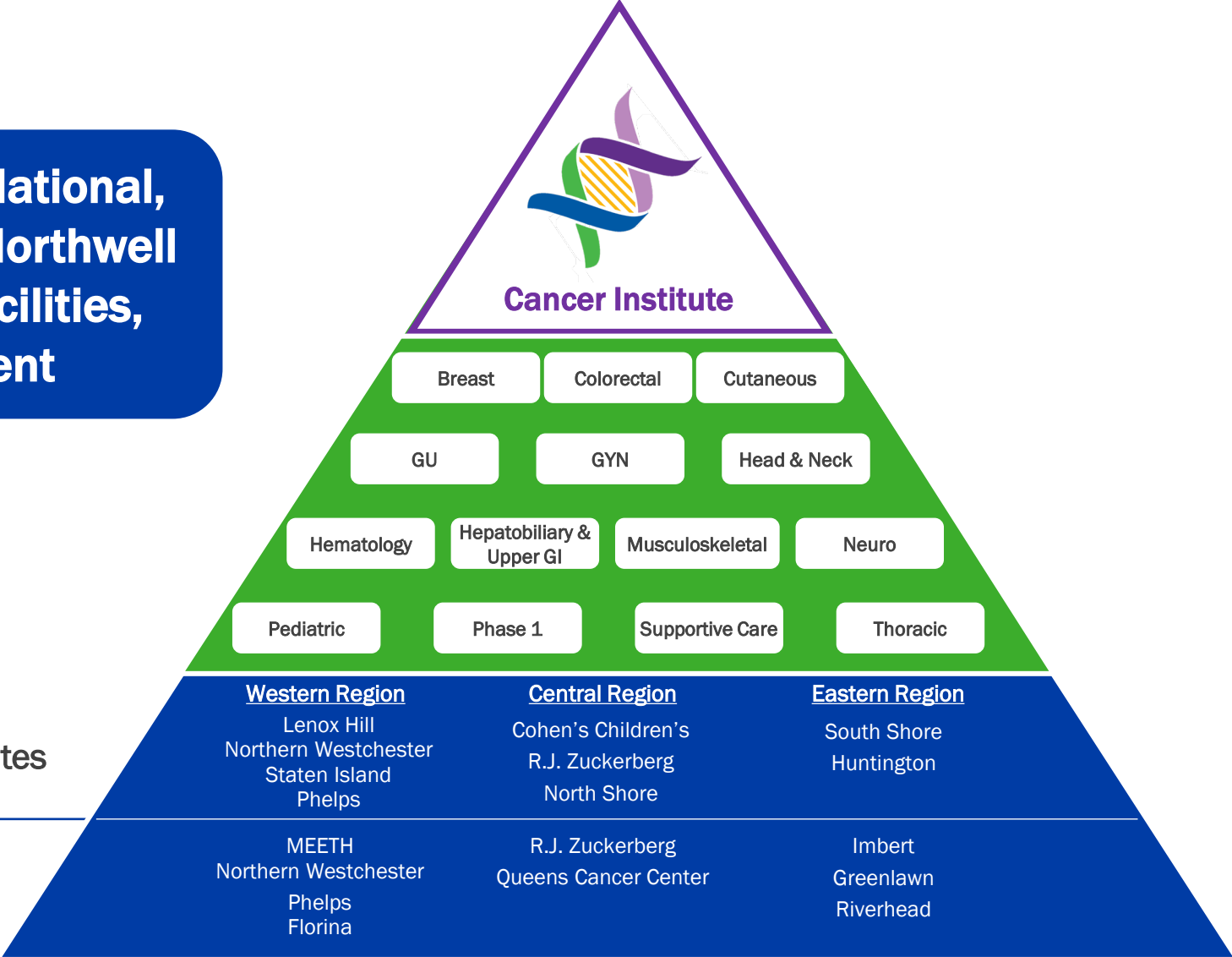


NHPP Medical Oncology at Woodbury

DISEASE MANAGEMENT TEAM (DMT) DRIVEN CARE, SUPPORT, & RESOURCES



Our 14 DMTs provide foundational, systemwide support to all Northwell Health Cancer Institute facilities, inpatient and outpatient



Hospitals and Inpatient Sites

Outpatient Cancer Centers

NATIONALLY RECOGNIZED FOR EXCELLENCE IN CANCER CARE



Top 50 Hospitals
NS and Lenox Hill



Accreditation obtained at multiple sites
Including Lenox Hill Hospital in December 2020



Top 50 Hospitals
Cohen Children's



NATIONAL ACCREDITATION PROGRAM FOR BREAST CENTERS
ACCREDITED BREAST CENTER

Accredited at multiple sites including Lenox Hill Hospital, Phelps Hospital, and Northern Westchester



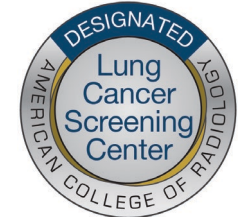
National Accreditation Program
for Rectal Cancer
American College of Surgeons

Accredited at multiple sites including
Lenox Hill Hospital

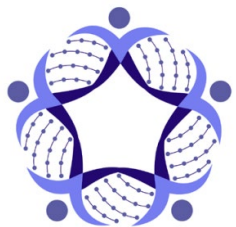


Quality Oncology Practice Initiative

Accreditation expected
in Q1 2024



Designated Center



NATIONAL PANCREAS FOUNDATION
CENTERS OF EXCELLENCE

Pancreas COE



Stem Cell Transplantation



Robotic Surgery



The Society
of Thoracic
Surgeons



Thoracic Surgery



Radiation Oncology



GYN Oncology



THANK YOU.

Questions.

June 2026