



# *Cancer Survivorship - Enhancing the Length and Quality of Survival*

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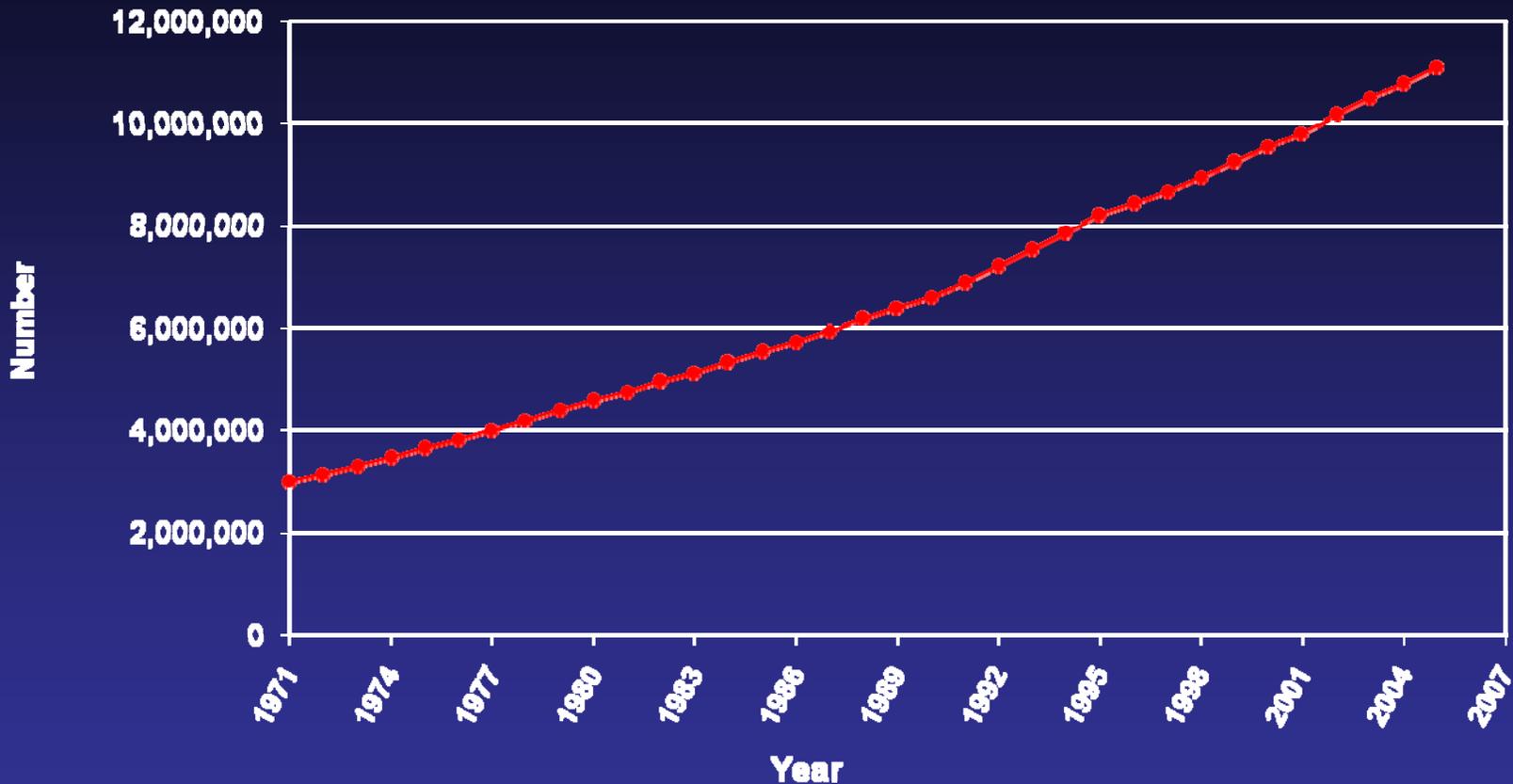
Office of Cancer Survivorship

National Cancer Institute • National Institutes of Health • DHHS



*UICC Congress, Geneva, August 2008*

# Estimated Number of Cancer Survivors in the United States From 1971 to 2005



Data source: Surveillance, Epidemiology, and End Results (SEER) Program ([www.seer.cancer.gov](http://www.seer.cancer.gov)). Prevalence database: "US Estimated 30-Year L-D Prevalence Counts on 1/1/2005 by Duration." National Cancer Institute, DCCPS, Surveillance Research Program, Statistical Research and Applications Branch, released April 2008, based on the November 2007 SEER data submission.

## *What Has Contributed to this Remarkable Progress?*

- Earlier detection
- New and more effective therapies, often including multimodal and multi-agent combinations
- More effective adjuvant and/or maintenance therapies
- Better supportive care
- Growing attention to long-term surveillance

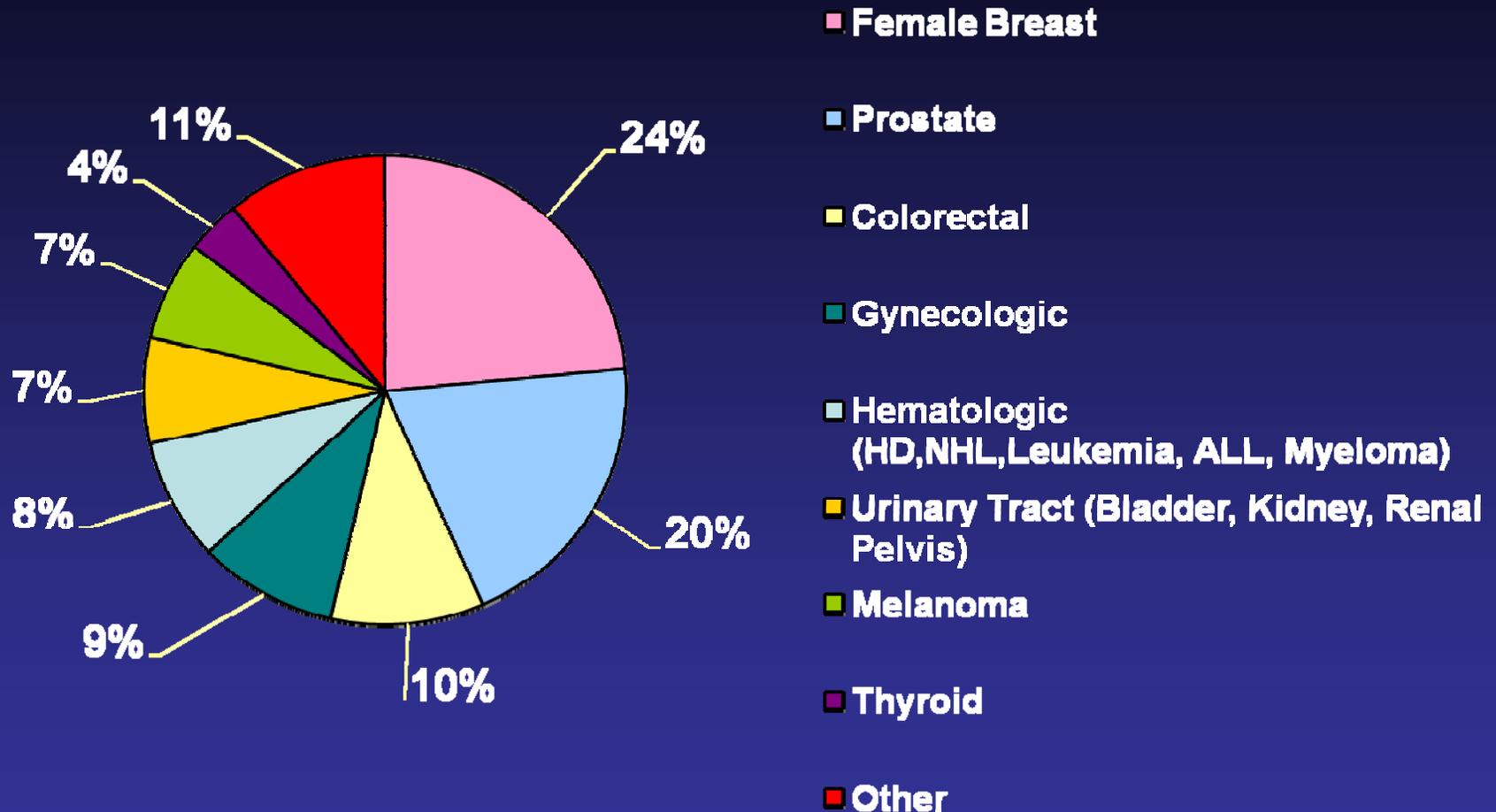
## Who Are Our Survivors?



## *Number of Cancer Survivors*

- It is currently estimated that there are 11.1 million cancer survivors in the United States
- Cancer survivors represent approximately 3.5 % of the US population
- IARC estimate for worldwide *5-Year Prevalence is 10.9 Million*

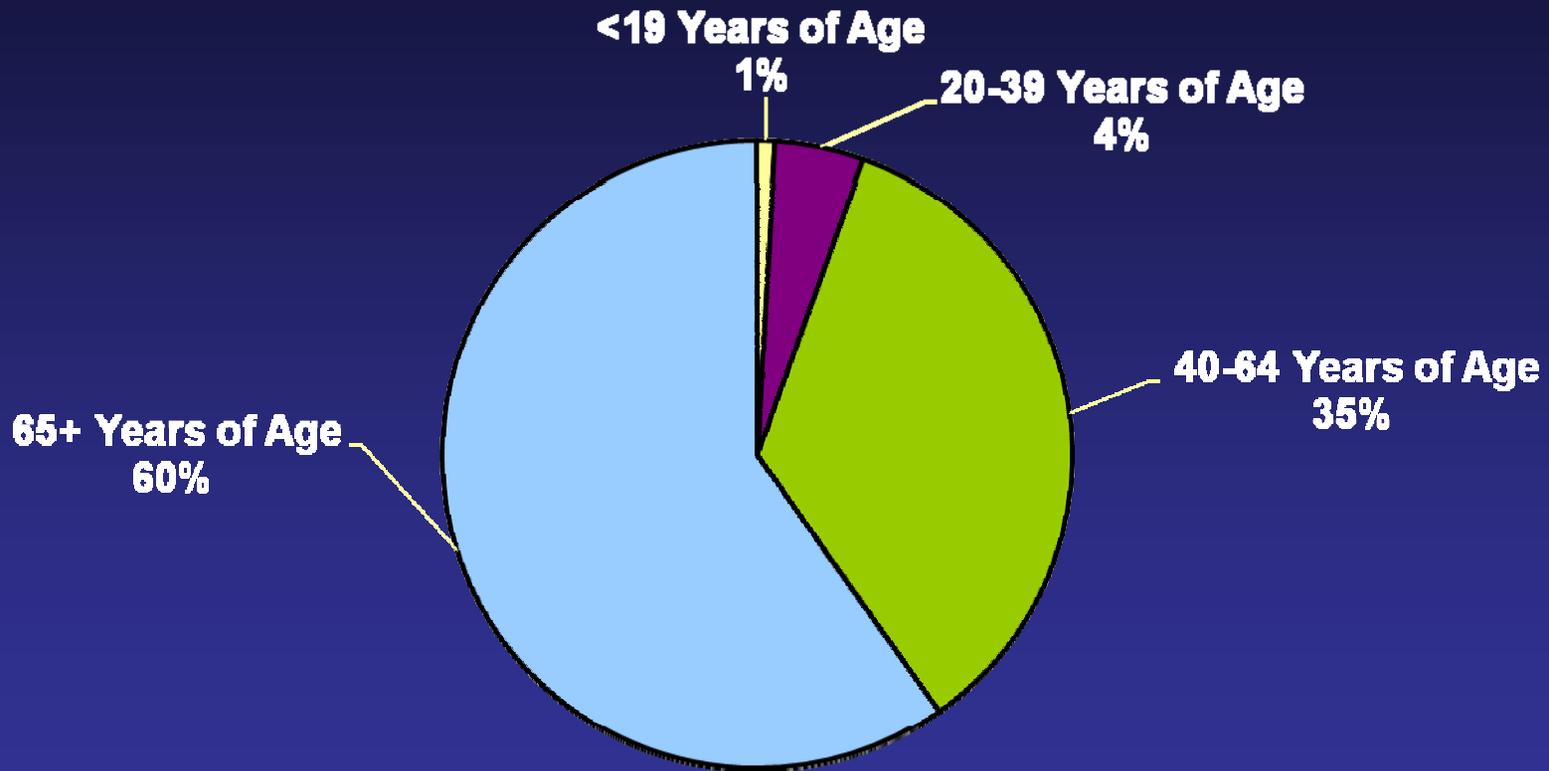
# Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2005 by Site (N = 11.1 M)



Data source: Surveillance, Epidemiology, and End Results (SEER) Program ([www.seer.cancer.gov](http://www.seer.cancer.gov)). Prevalence database: "US Estimated Complete Prevalence Counts on 1/1/2005." National Cancer Institute, DCCPS, Surveillance Research Program, Statistical Research and Applications Branch, released April 2008, based on the November 2007 SEER data submission.

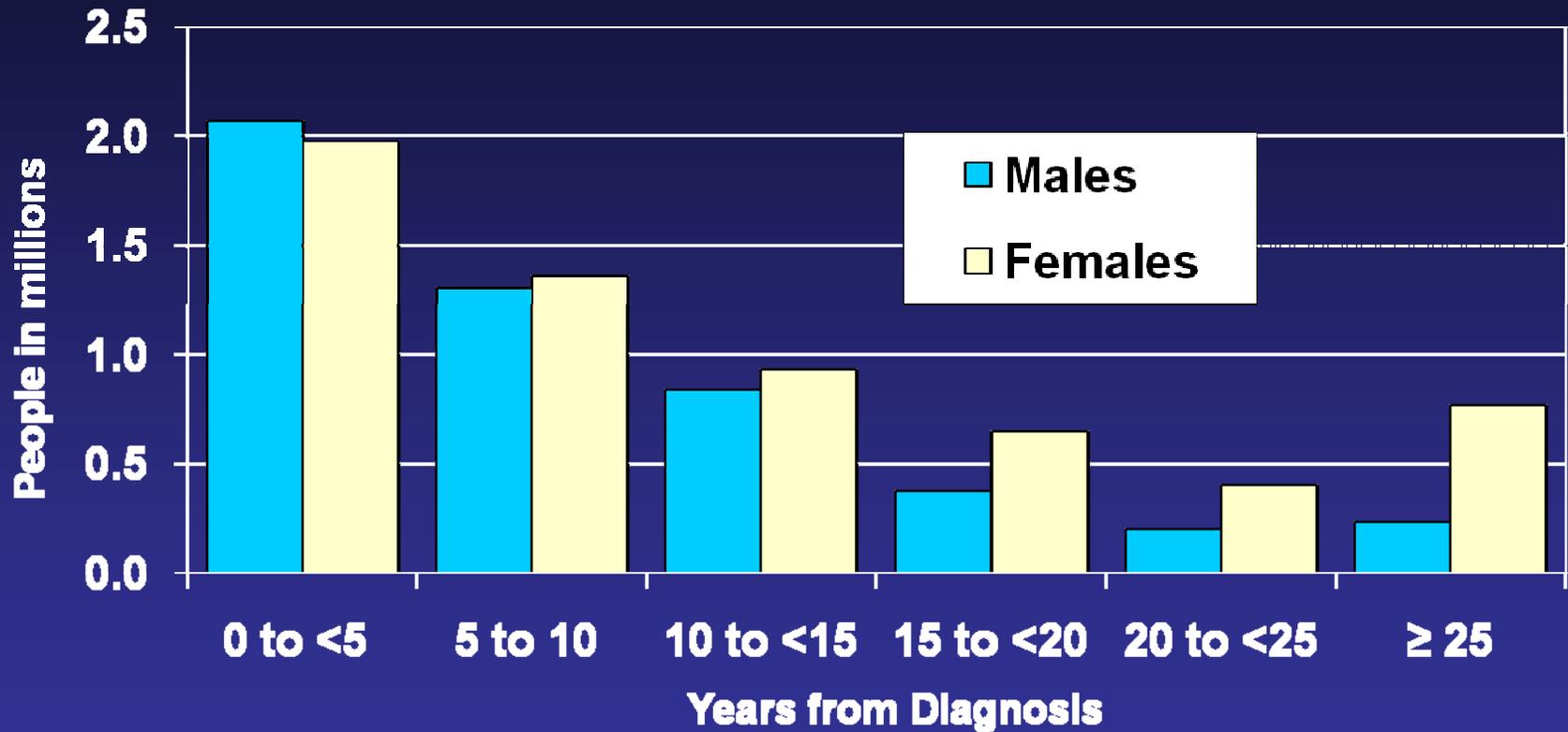
# Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2005 by Current Age

(Invasive/1<sup>st</sup> Primary Cases Only, N = 11.1 M survivors)



Data source: Surveillance, Epidemiology, and End Results (SEER) Program ([www.seer.cancer.gov](http://www.seer.cancer.gov)). Prevalence database: "US Estimated Complete Prevalence Counts on 1/1/2005." National Cancer Institute, DCCPS, Surveillance Research Program, Statistical Research and Applications Branch, released April 2008, based on the November 2007 SEER data submission.

# Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2005 by Time From Diagnosis and Gender (Invasive/1st Primary Cases Only, N = 11.1 M survivors)



Data source: Surveillance, Epidemiology, and End Results (SEER) Program ([www.seer.cancer.gov](http://www.seer.cancer.gov)). Prevalence database: "US Estimated 30-Year L-D Prevalence Counts on 1/1/2005 by Duration." National Cancer Institute, DCCPS, Surveillance Research Program, Statistical Research and Applications Branch, released April 2008, based on the November 2007 SEER data submission.

# Survivorship – Understanding the Issues, Defining the Research!



## *The Changing Demography of Cancer Survivorship*

- Cancer for many may be viewed as a “chronic” illness
- Cancer for most, affects the entire family, and often a community

## *Definitions*

- Who is a cancer survivor?
  - Philosophically, anyone diagnosed with cancer or their family members, is a survivor
- What is cancer survivorship research?
  - Cancer survivorship research seeks to examine, prevent, manage, or reduce the adverse physiological, psychologic, social, and economic sequelae associated with cancer and its treatment

## *What is the Purpose of Cancer Survivorship Research?*

*The Office of Cancer Survivorship, NCI, USA, established in 1996, has the following goals:*

- Enhance the length and quality of survival for all cancer patients
- Understand, prevent, or reduce the adverse physiological, psychosocial, and economic sequelae associated with cancer and its treatment
- Educate health professionals about issues and practices critical to the optimal well-being of their patients who have survived cancer, as well as survivors themselves and their families

## Phenomenal Treatment Successes, But... Long-Term and Late Adverse Sequelae!



## *Long Term and Late Effects of Cancer Treatment*

- Physical/Medical (e.g., second cancers, cardiac dysfunction, pain, lymphedema, sexual impairment)
- Psychological (e.g., depression, anxiety, uncertainty, isolation, altered body image)

## *Long Term and Late Effects of Cancer Treatment*

- Social (e.g., changes in interpersonal relationships, concerns regarding health or life insurance, job lock/loss, return to school, financial burden)
- Existential and Spiritual Issues (e.g., sense of purpose or meaning, appreciation of life)

## *Impact of Adverse Disease and Treatment Outcomes*

- Cancer Survivorship, especially long-term, may act as a chronic stressor
- Variables affecting this chronic stress are multifaceted, integrated, and cross various survivorship outcome domains

## *Impact of Adverse Disease and Treatment Outcomes*

*Why Do We Need to be Cognizant of this Issue?*

- Address the lack of familiarity of primary care physicians or other specialists with health risks of the heterogeneous population of survivors
- Promote evaluation of late effects that may be modifiable or amenable to early diagnosis and treatment prevent early detection and appropriate management

*What is the Research Telling Us?*



## *Lessons Learned From Ongoing Research*

- Adverse outcomes are chronic or late occurring, and more prevalent and serious than expected among survivors of both adult and paediatric cancer
- The majority of individuals successfully treated for cancer report adequate to good health-related quality of life following treatment — *Resilience!*
  - *But...*

## *Lessons Learned From Ongoing Research*

- Being disease free, does NOT mean you are free of your disease
- Cancer can affect all aspects of a person's life

*Achieving Quality Survivorship – What are the Challenges and the Facilitators?*



## *Challenges to Recovery*

- **Physical**
  - Symptoms (pain, fatigue, lymphedema)
  - Medical Sequelae ( long term or late effects; e.g., 2<sup>nd</sup> cancers or organ toxicities such as cardio or gonadal toxicity)
  - Co-Morbidities (diabetes, arthritis, heart disease)

## *Challenges to Recovery*

- **Emotional**
  - Fear of Recurrence, Depression, Uncertainty, Distress, Altered Body Image
- **Socio-Economic**
  - Isolation, Stigma, Altered Roles (School, Work, Family, Peers)
- **Existential**
  - Sense of Meaning and Purpose, New Priorities

## *Positive Response to Challenges*

- Resilience
- Active Coping
- Health and Help Seeking Behavior
- Benefit Finding (Post-Traumatic Growth)

## *Factors Associated with Good Outcomes*

- **Communication**
  - Physician – Patient
  - Physician - Physician
  
- **Follow Up care**
  - Provision of state of the art comprehensive care
  - Education regarding follow up care
  - Receipt and Use of Treatment Summaries
  - Receipt and use of Follow Up Care Plans
  
- **Developing and Testing Models of Care**

## What Does the Future Hold?



## *Unanswered Questions and Future Research*

### *Examining*

- Emerging Late and Long-Term Effects of cancer and its treatment
- Examining the Barriers and Facilitators for positive survivorship

## *Unanswered Questions and Future Research*

### *Examining*

- Strategies to build an evidence base for survivors' follow-up care
  - Developing innovative models of care
  - Testing them
  - Collaborating
  - Understanding and implementing quality care
  
- Developing, testing, and disseminating interventions

## *Continuing Scientific Needs*

*Why is this information important?*

- Prevent, detect early, or intervene (medical, behavioral) to decrease morbidity and mortality
- Guide follow-up care and practice
- Consonant with our overall missions as scientists and care providers – This is what we are here to do!
  - Reduce the burden of cancer-related illness