



Cancer Survivorship - Achieving The "New Normal"

Noreen M. Aziz, M.D., Ph.D., M.P.H

Senior Program Director

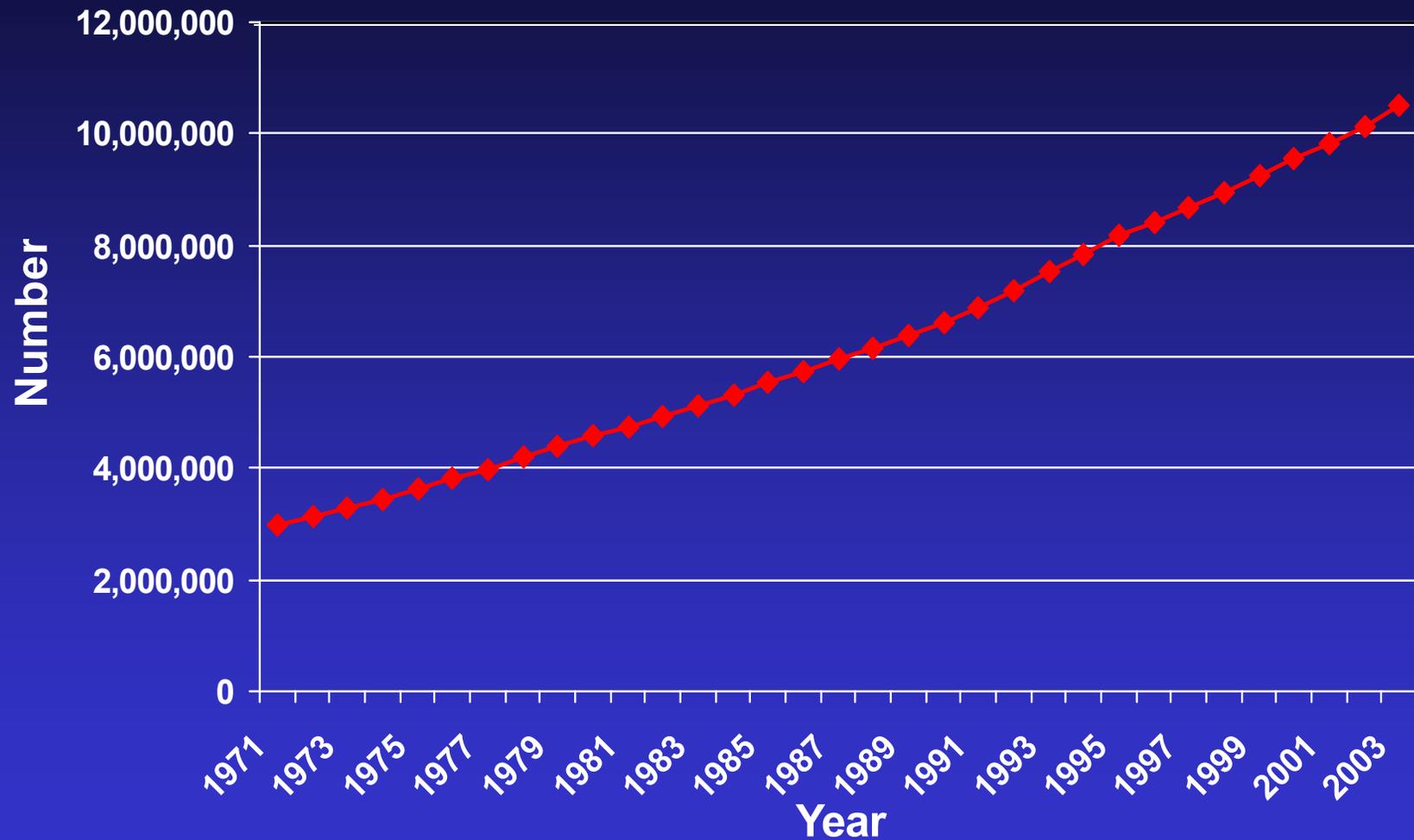
Office of Extramural Programs, NINR

National Institutes of Health • DHHS



Maryland State Cancer Control Conference, December 2010

Estimated Number Cancer Survivors in the United States from 1971 to 2003



Data source: 2004 Submission. U.S. Estimated Prevalence counts were estimated by applying U.S. populations to SEER 9 and historical Connecticut Limited Duration Prevalence proportions and adjusted to represent complete prevalence. Populations from January 2002 were based on the average of the July 2001 and July 2002 population estimates from the U.S. Bureau of Census.

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
- Key importance of Palliative Care and End of Life Issues

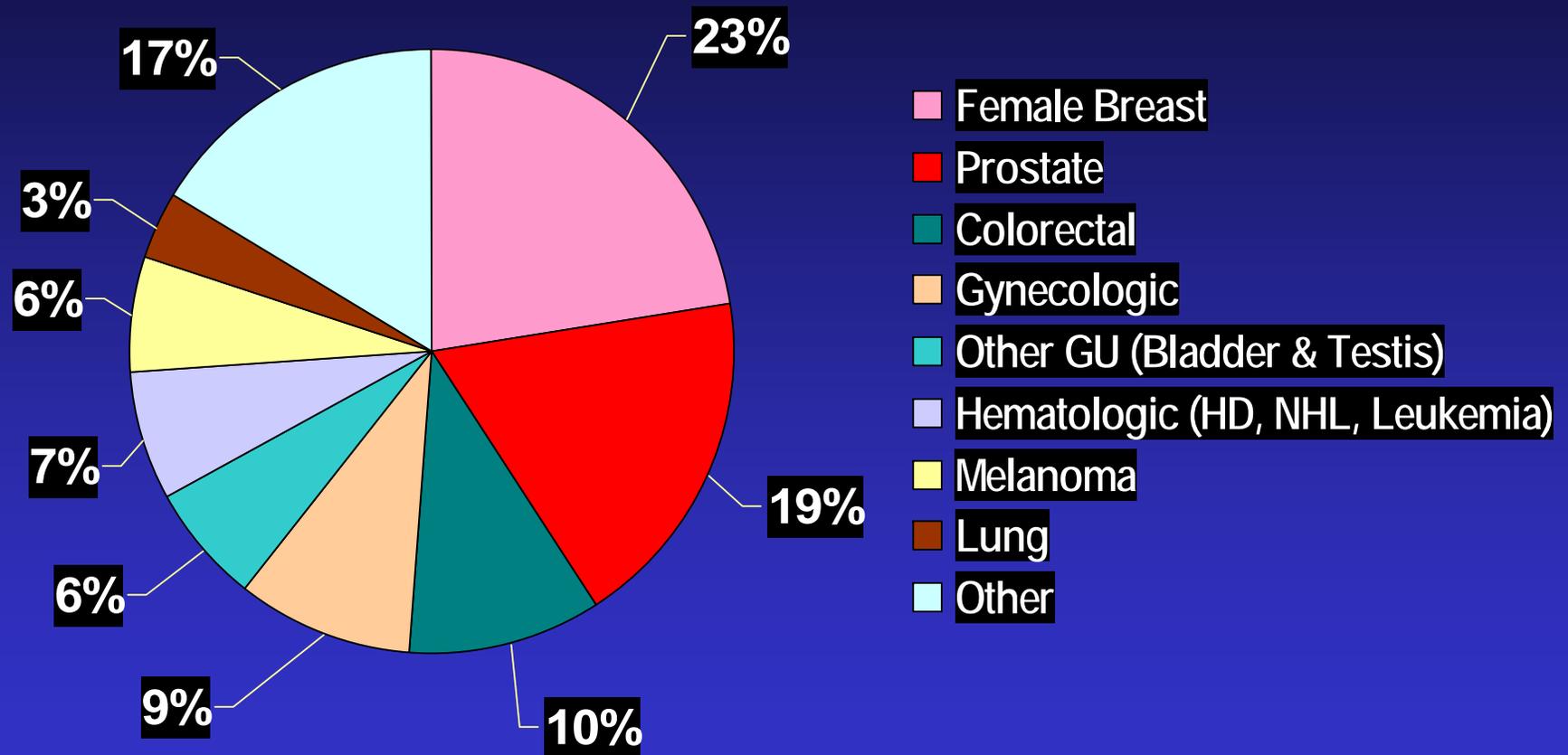
Who Are Our Survivors?



Number of Cancer Survivors

- It is currently estimated that there are 10.8 million cancer survivors in the United States
- Worldwide estimates are around 22.4 Million
- Cancer survivors represent approximately 3.5 % of the US population – The numbers of those facing Palliative Care for incurable disease are among this number

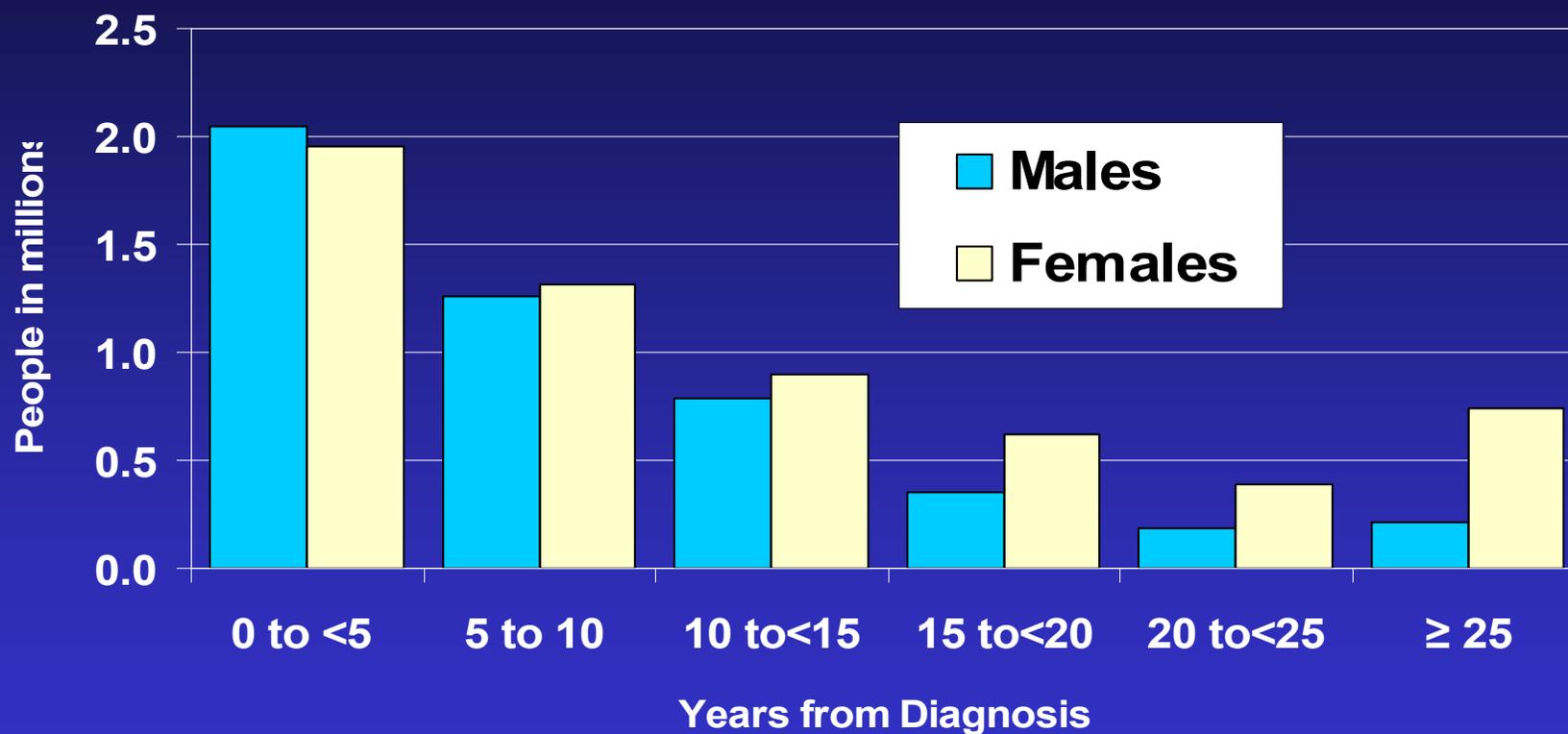
Estimated Number of Persons Alive in the U.S. Diagnosed With Cancer by Site (N = 10.5 M)



Data source: 2005 Submission. U.S. Estimated Prevalence counts were estimated by applying U.S. populations to SEER 9 and historical Connecticut Limited Duration Prevalence proportions and adjusted to represent complete prevalence. Populations from January 2003 were based on the average of the July 2002 and July 2003 population estimates from the U.S. Bureau of Census.

Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2004 by Time From Diagnosis and Gender

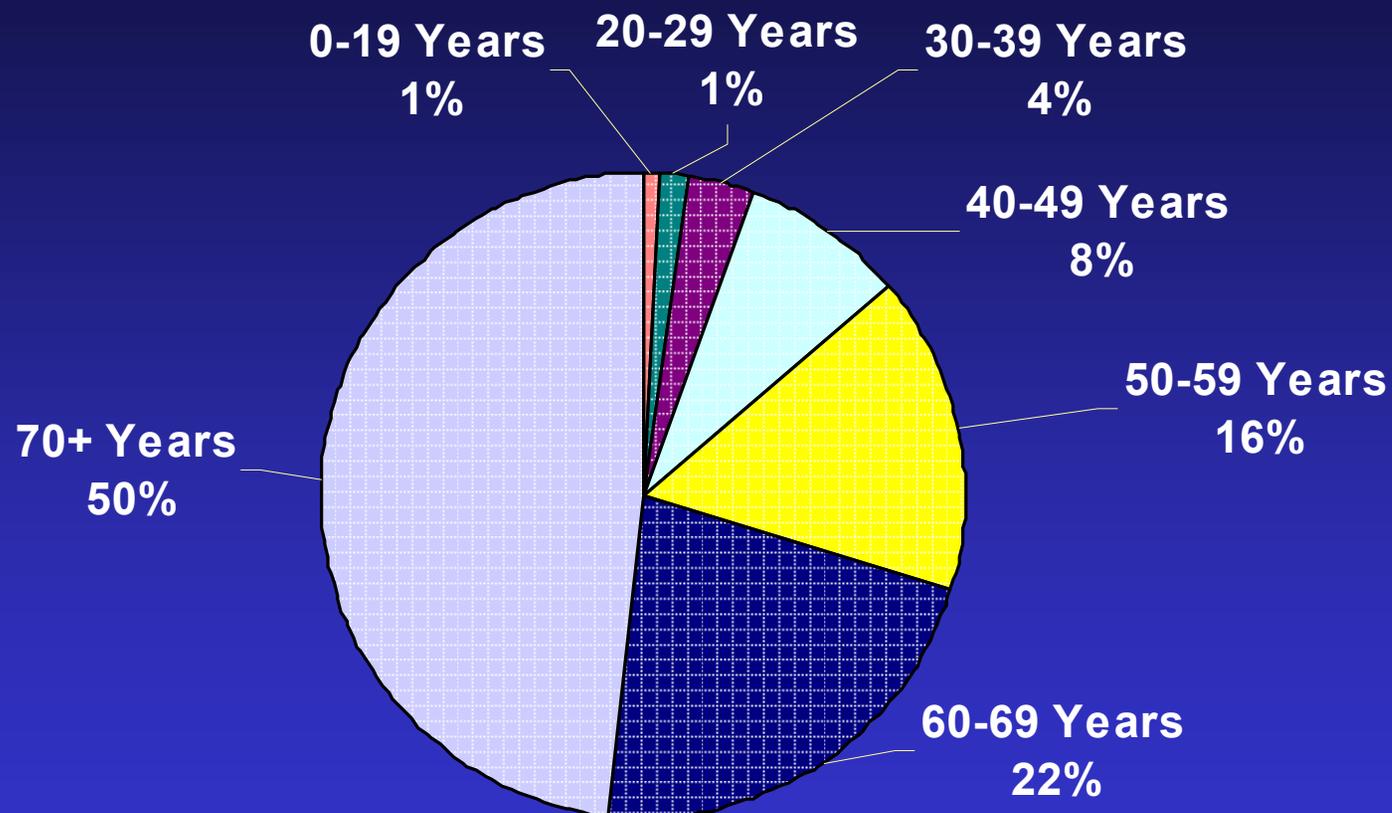
(Invasive/1st Primary Cases Only, N = 10.8M survivors)



Data source: Ries LAG, Melbert D, Krapcho M, Mariotto A, Miller BA, Feuer EJ, Clegg L, Horner MJ, Howlader N, Eisner MP, Reichman M, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2004, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2004/, based on November 2006 SEER data submission, posted to the SEER web site, 2007.

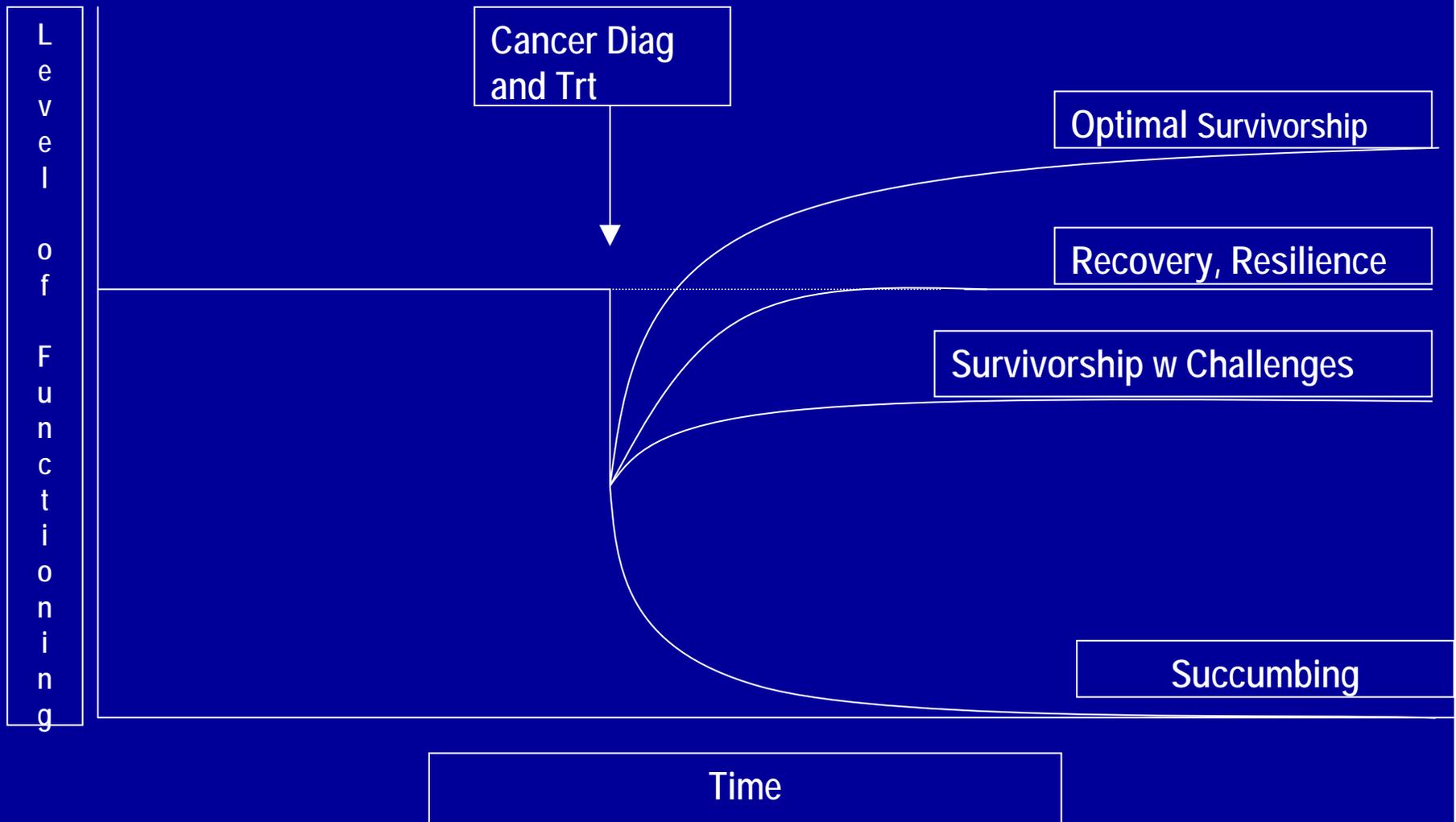
Estimated Number of Persons Alive in the U.S. Diagnosed With Cancer by Current Age*

*(Invasive/1st Primary Cases Only, N=10.8M survivors)



Data source: Ries LAG, Melbert D, Krapcho M, Mariotto A, Miller BA, Feuer EJ, Clegg L, Horner MJ, Howlader N, Eisner MP, Reichman M, Edwards BK (eds). SEER Cancer Statistics Review, 1975-2004, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2004/, based on November 2006 SEER data submission, posted to the SEER web site, 2007.

Range of Responses to Cancer (Adverse Event)



Original source: O'Leary & Ickovics, 1994

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

- "Cure" has a cost – damage to organ systems, long-term and late effects
- Therapies used against cancer can cause organ toxicity – which might *manifest as a wide array of chronic diseases that* become clinically evident at different periods of a survivor's life

Impact of Adverse Disease and Treatment Outcomes

Why Do We Need to be Cognizant of this Issue?

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

Impact of Adverse Disease and Treatment Outcomes

Why Do We Need to be Cognizant of this Issue?

- We need risk-based health care for survivors
 - Longitudinal, proactive, and anticipatory
 - A systematic plan of prevention and surveillance predicated on risks associated with the previous cancer, therapy, genetic predispositions, lifestyle behaviors, and comorbid health conditions

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

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 the New Normal – What
are the Challenges and the Facilitators?*



Challenges to Recovery

- Physical

- Long Term and Late Effects of Cancer and its Treatment

- Symptoms

- Medical Sequelae

- Co-Morbidities

Challenges to Recovery

- Emotional

- Fear of Recurrence, Depression, Uncertainty, Distress

- Socio-Economic

- Isolation, Stigma, Altered Roles (work, Family)

Positive Response to Challenges

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

Factors Associated with Good HRQOL Outcomes

- Access to (State of the art?) Care
- Having (and using) a social support network
- Coping and Adjustment
- Being an active participant in one's care (and one's health behaviors!)
- Finding or having a sense of purpose or meaning in one's life

What Does the Future Hold?



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