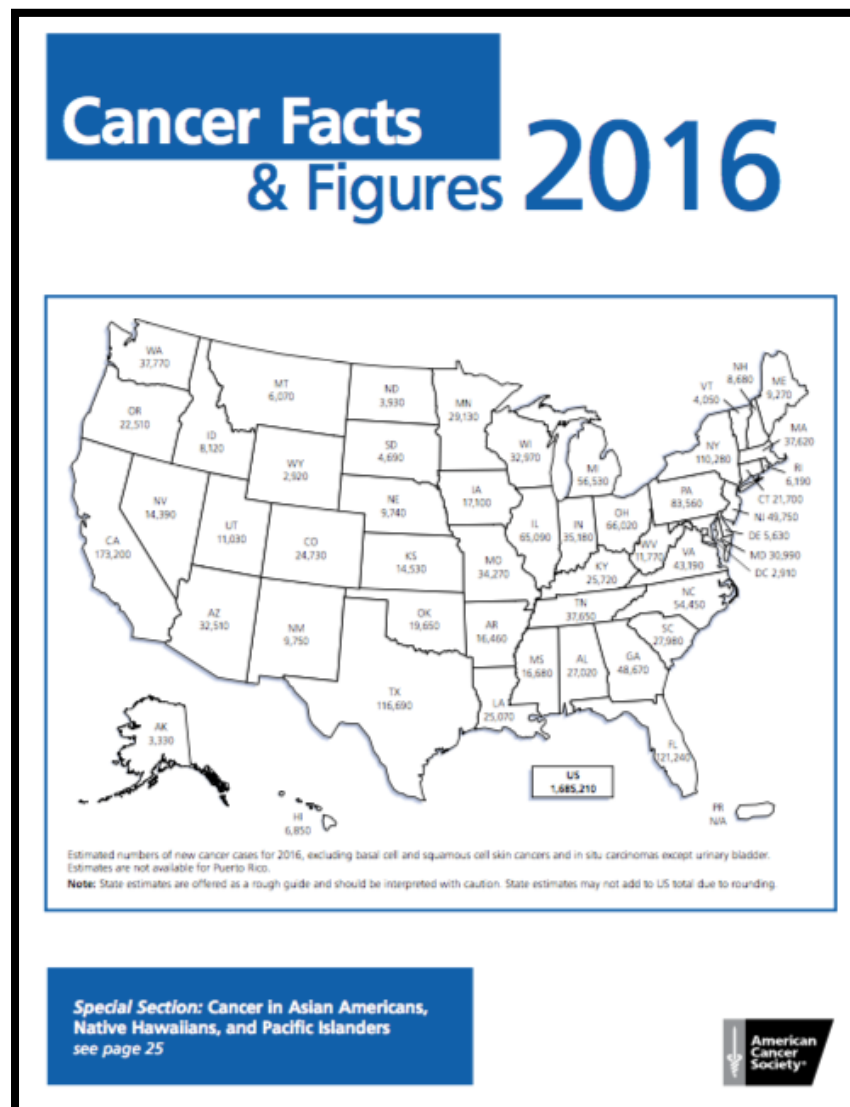


Survivorship in the USA— Making Change Happen

Catherine M. Alfano, PhD
Vice President, Survivorship



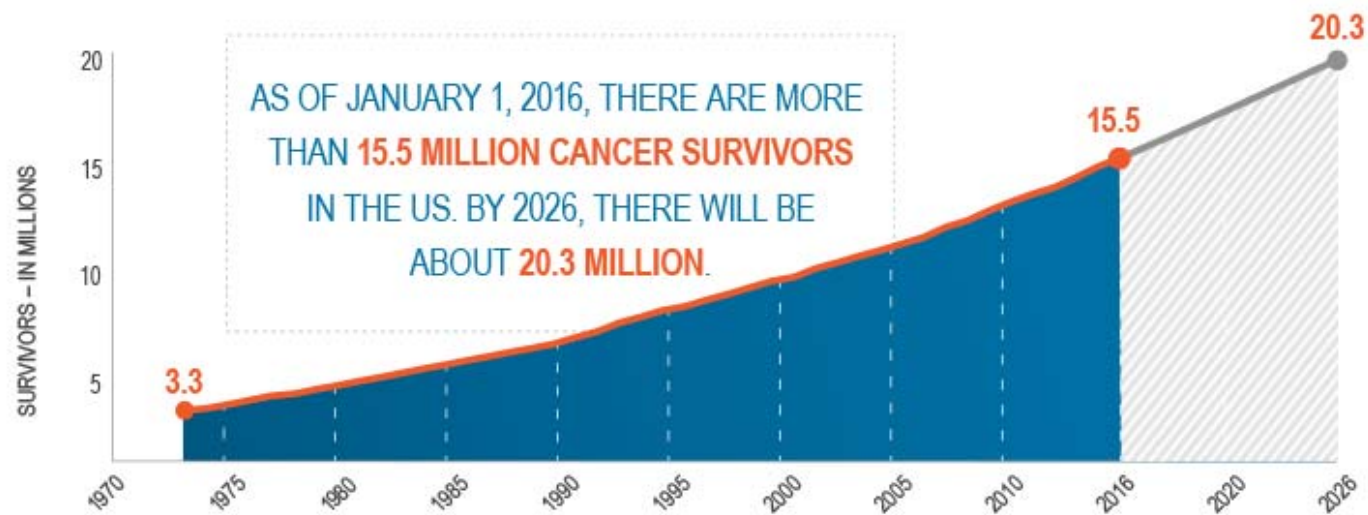
1,685,210 New US Cancer Cases Diagnosed in 2016



LIFE AFTER CANCER: SURVIVORSHIP BY THE NUMBERS

American Cancer Society // Infographics // 2016

The number of cancer survivors in the United States is increasing, and is expected to grow to about 20.3 million by 2026 according to *Cancer Treatment & Survivorship Facts & Figures 2016-2017*. Even though cancer incidence rates are declining in men and stable in women, the number of cancer survivors is rising due to a growing and aging population, as well as earlier detection and better treatments. As this population continues to increase, it will be more important than ever to address this group's unique needs.



Source: Surveillance, Epidemiology, and End Results Program, National Cancer Institute.



The Perfect Storm

Skyrocketing
Cancer Care
Costs

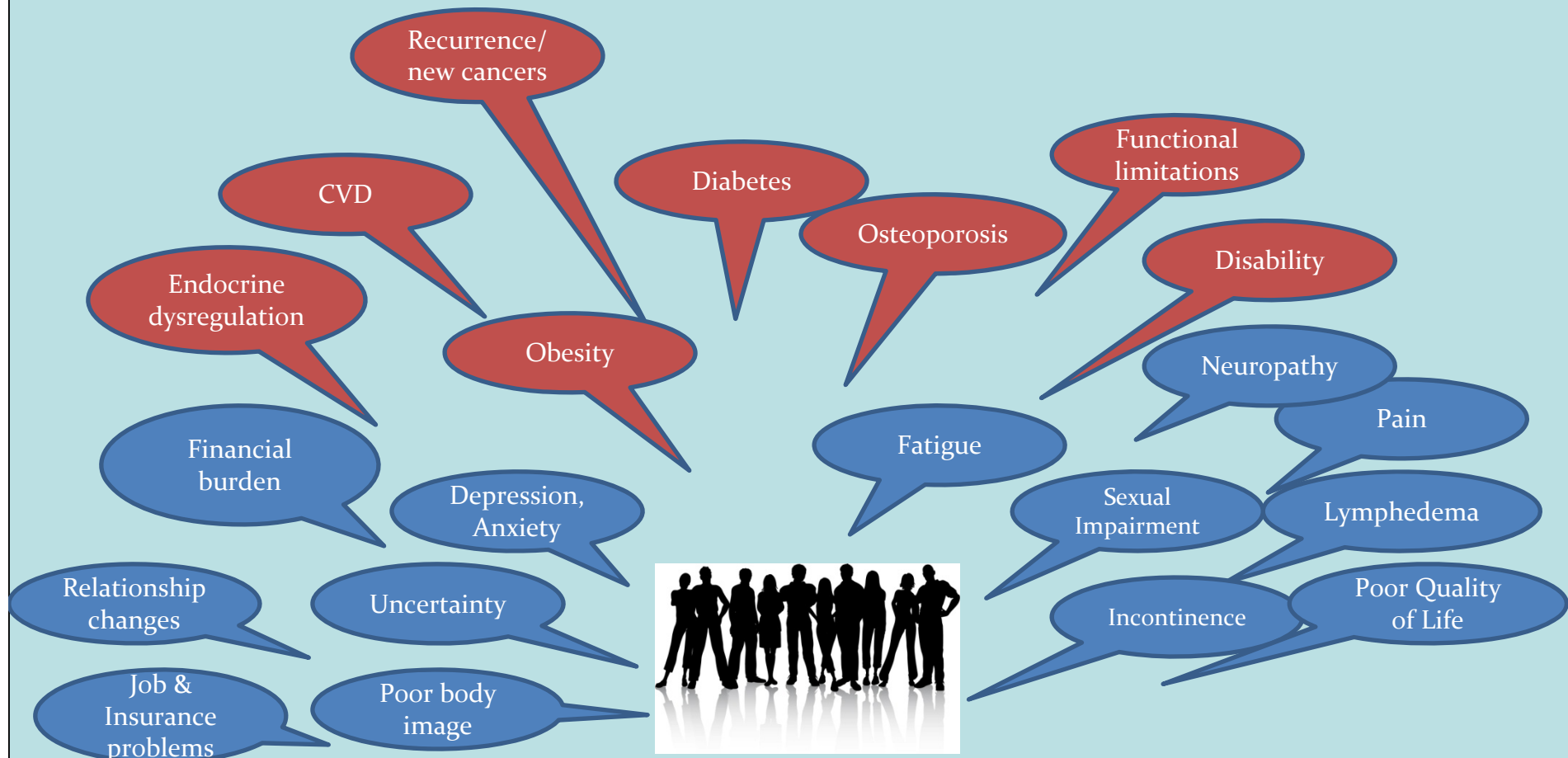
15.5 Million
Survivors

Provider Knowledge
Deficits

Chronic & Late
Effects of Cancer
(Physical,
Psychosocial,
Economic)

Provider
Shortages (ONC,
PCP, Nursing)

Cancer Survivors are at risk: Chronic & Late Effects of Cancer



Toxicity from Cancer Immunotherapy

“...hyperactivated T-cell response with reactivity directed against normal tissue”

Checkpoint inhibitors induce
autoinflammatory response

IFN-alpha, IL-2 induce
**fatigue, fever, autoimmunity,
neurotoxicity, and
myocarditis**



Adoptive cell therapy
(T cells) induces
**Cytokine Release
Syndrome resembling
sepsis**

Long-term toxicities???

The Perfect Storm

Skyrocketing
Cancer Care
Costs

15.5 Million
Survivors

Provider Knowledge
Deficits

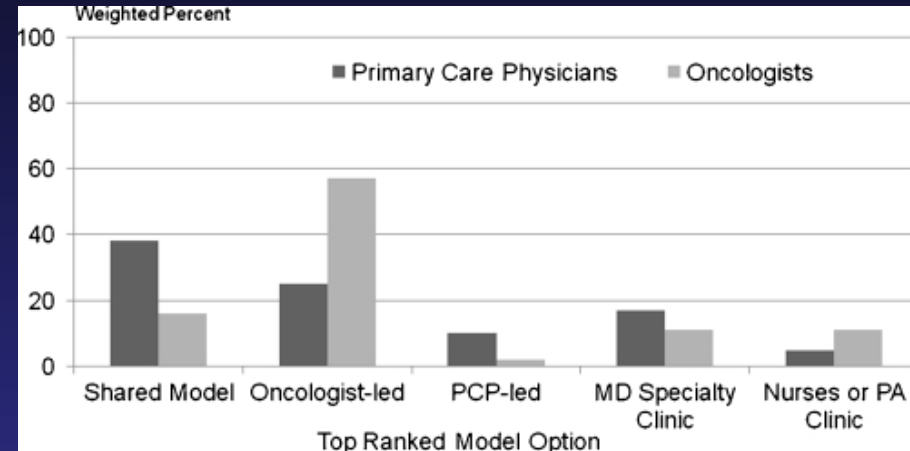
Chronic & Late
Effects of Cancer
(Physical,
Psychosocial,
Economic)

Provider
Shortages (ONC,
PCP, Nursing)

Delivering Survivorship Care

- Divergent perceptions about who should provide care for survivors

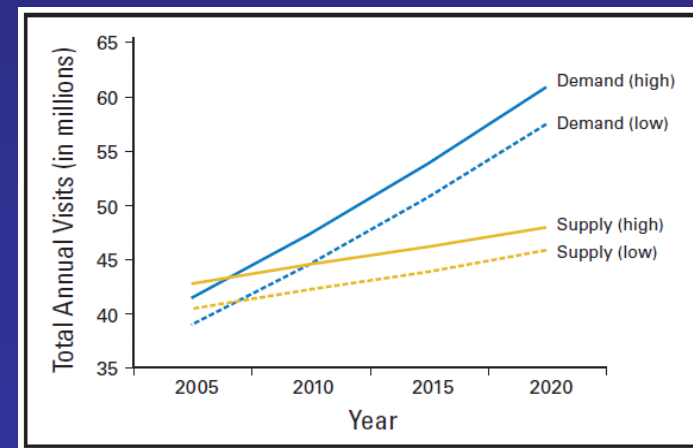
Potosky et al, JGIM 2011



- Who should be responsible for survivorship care?

Erikson et al., 2007, JOP

Projected Shortage of Oncologists



The Perfect Storm

Skyrocketing
Cancer Care
Costs

15.5 Million
Survivors

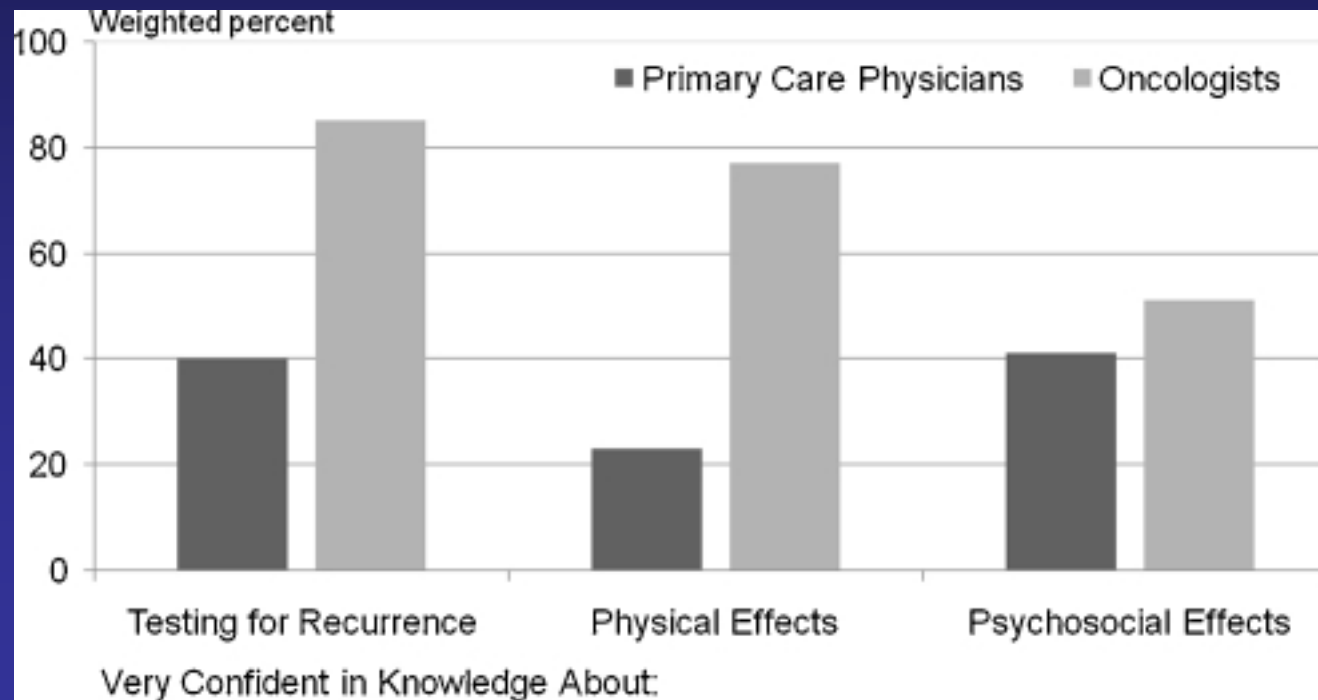
Provider Knowledge
Deficits

Chronic & Late
Effects of Cancer
(Physical,
Psychosocial,
Economic)

Provider
Shortages (ONC,
PCP, Nursing)

Problem Delivering Survivorship Care

- Knowledge gaps among PCPs (& oncologists)



Potosky et al, JGIM 2011

The Perfect Storm

Skyrocketing
Cancer Care
Costs

15.5 Million
Survivors

Provider Knowledge
Deficits

Chronic & Late
Effects of Cancer
(Physical,
Psychosocial,
Economic)

Provider
Shortages (ONC,
PCP, Nursing)

Costs of Cancer Care (US)

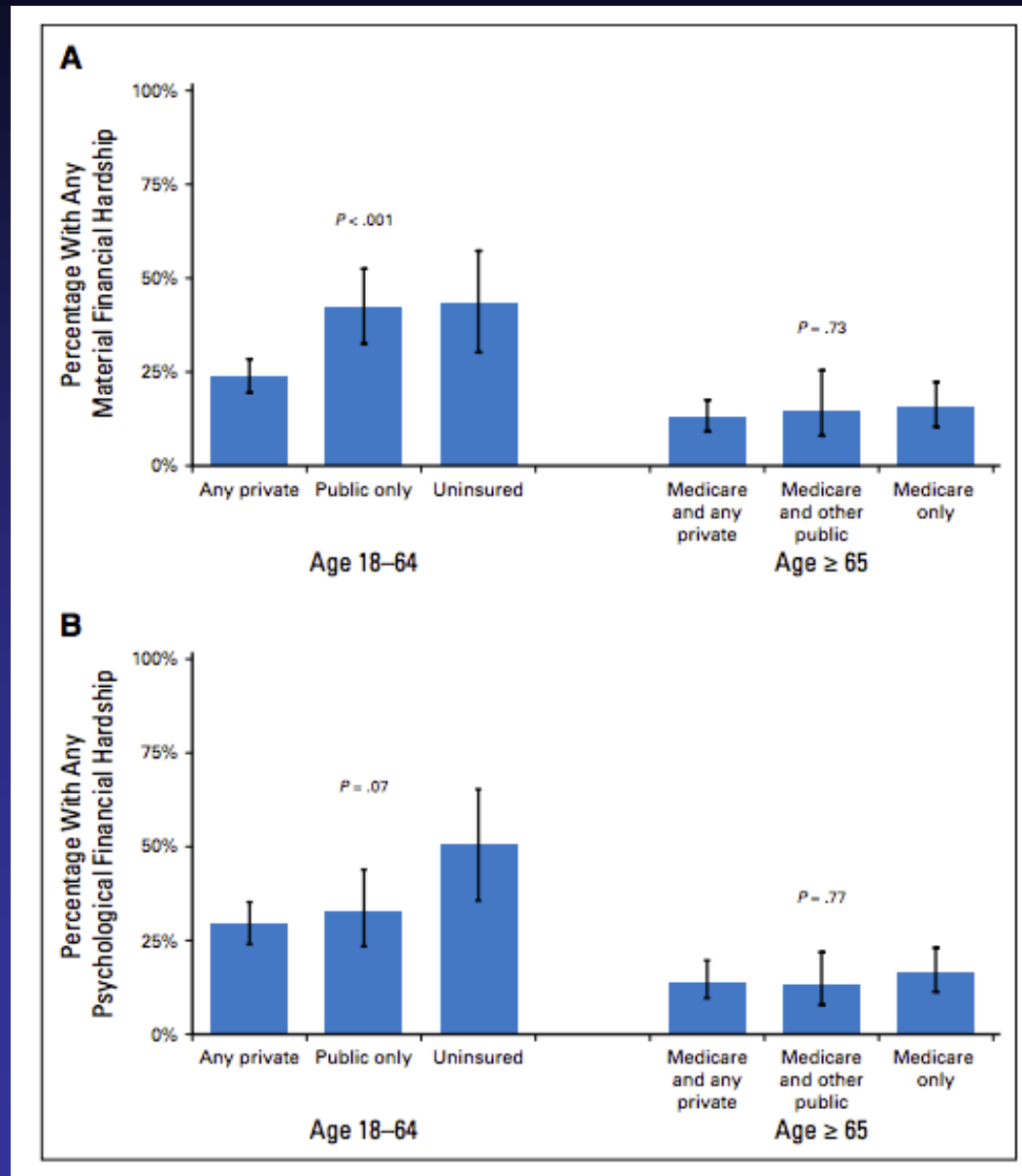
- \$157.77 billion by 2020
- Survivorship excess medical costs: \$25-48 billion
- Lost productivity among survivors: \$8-16 billion

Costs of Cancer Care (Survivors)

Survivors **2.65 X** more likely to file **bankruptcy**
Ramsey, *Medical Affairs*, 2013

Bankruptcy among survivors: **1.79 X** higher risk of mortality
Ramsey, *JCO*, 2016

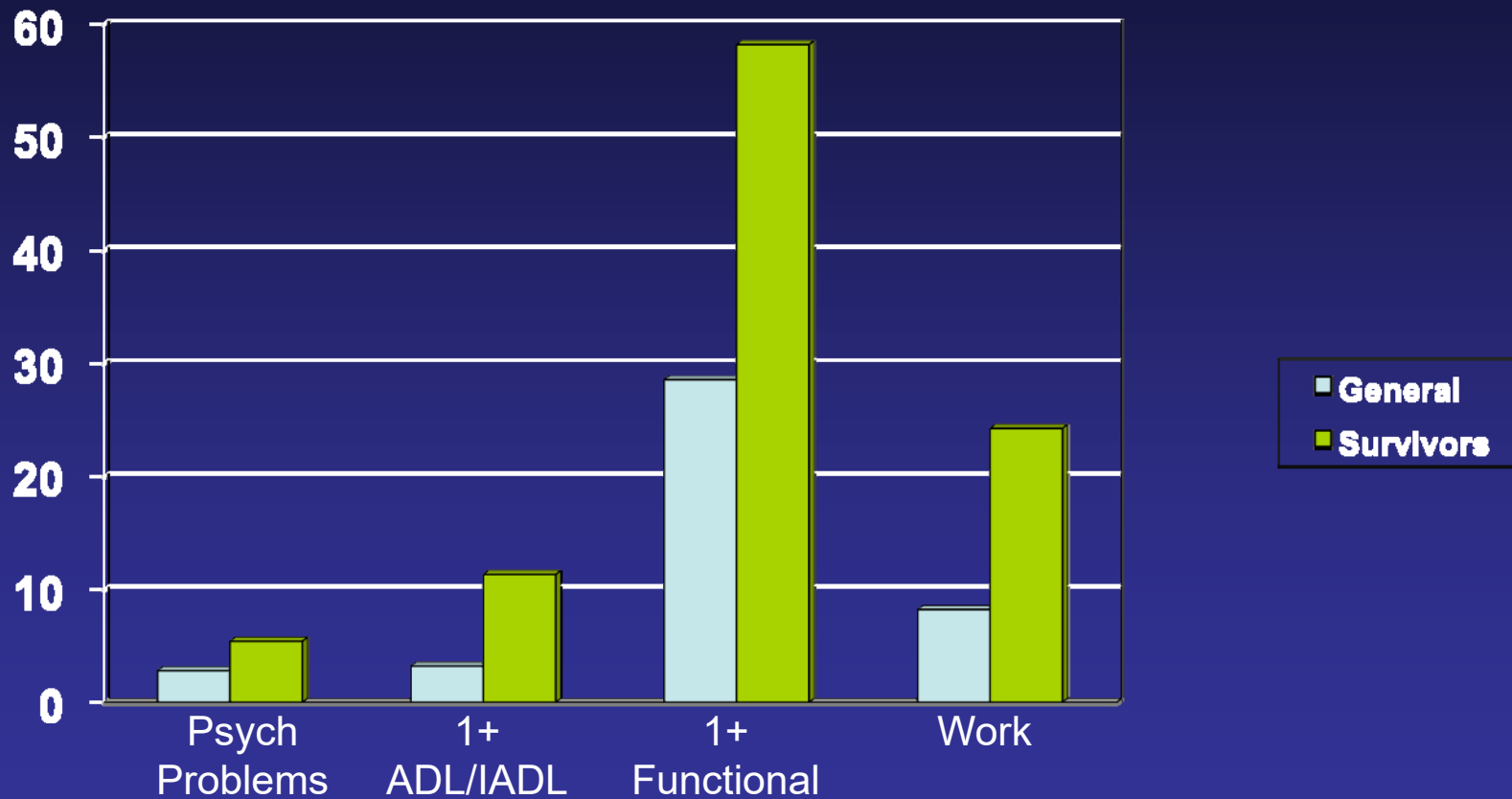
Yabroff, *JCO*, 2016



Results of Fragmented System

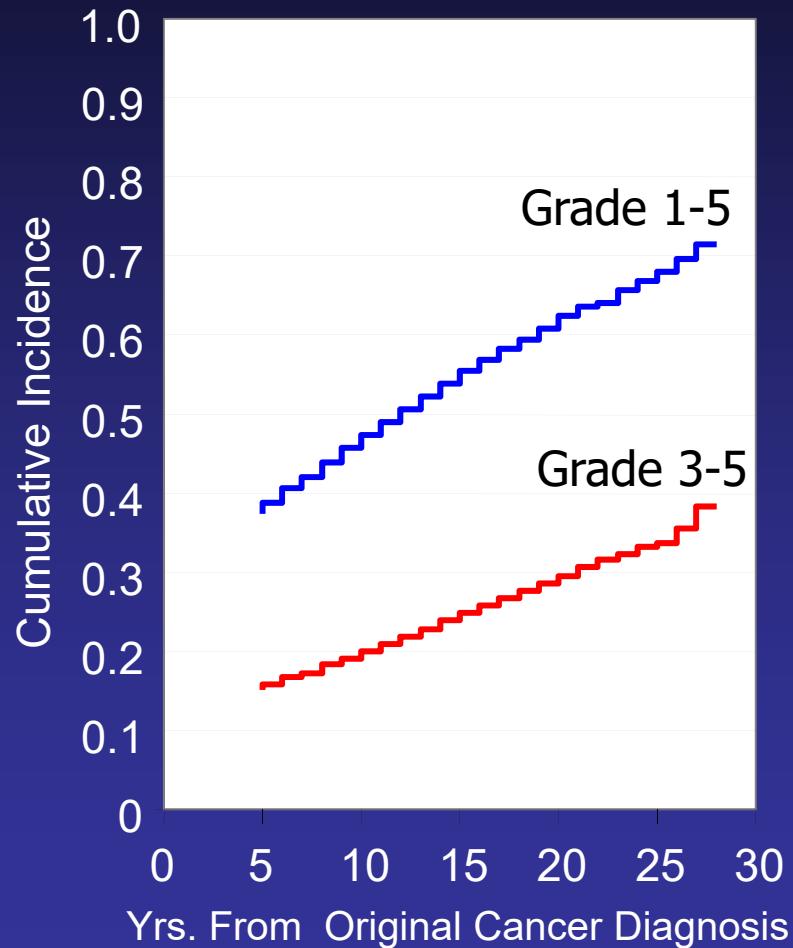
- Unrecognized Impairments & symptoms:
 - ↳ ↓QOL, functioning, work; ↑healthcare utilization
- Most oncologists don't assess symptoms and functional problems; patients don't report them either
- 60%+ of cancer survivors need rehabilitation
(Thorsen et al, 2011)
 - Treatment rates as low as 1-2% (Cheville et al., 2009)

% with Limitations: Survivors vs. General Population



Hewitt, Rowland, Yancik. J Gerontol. 58:82, 2003

Incidence of Chronic Health Conditions in 10,397 Adult Survivors of Childhood Cancer



Mean age of 26.6 years (18-48 years)

By 30 years post cancer:

- 73% survivors with at least one chronic health condition
- 42% with a Grade 3-5 (severe, life-threatening, death)
- 39% had ≥ 2 chronic health conditions

Survivors – 8.2 times more likely to have a severe or life threatening condition compared to siblings

Childhood Cancer Survivor Study

Clinical Care Follow-up Guidelines



What Are American Cancer Society Survivorship Guidelines?

Survivorship guidelines are advice from the American Cancer Society to help patients who have finished their cancer treatment. The survivorship guidelines provide help with care after treatment. They are not meant to replace the care you receive from your doctor. They are meant to help you understand the care you receive and to help you make decisions about your care.

Why Are Prostate Cancer Survivorship Guidelines Needed?

Each year about 300,000 men in the United States are diagnosed with prostate cancer. Most of these men will be treated for their cancer and survive for many years. In fact, most men diagnosed with prostate cancer will still be alive 10 years after their diagnosis. This means that many men will live with prostate cancer for the rest of their lives. It is important to have survivorship guidelines to help you understand the care you receive and to help you make decisions about your care.

How Should the Guidelines Be Used?

The guidelines are meant to be used by patients and their doctors. They are not meant to be used by patients alone. They are meant to be used by patients and their doctors together. They are meant to be used by patients and their doctors to help them understand the care they receive and to help them make decisions about their care.



American Cancer Society Prostate Cancer Survivorship Care Guidelines

Authors: Ted A. Skonecny, MD, MPH; Andrew M.D. Wolf, MD; Nicole L. Erb, BA; Orlando D. Block, MD, MPH; Brian M. Ryan, PhD, MPH; Willie Underwood, II, MD, MPH; Andrew C. Sauer, MD; Michael J. Zelefsky, MD; Jonny B. Aspenberg, MD; Susan F. Shure, MD; David A. Wittmann, PhD; Mark C. Miller, PhD; David A. Hays, PhD; Victoria L. Srinivas, CRNP; Gerard Chuang, MD; Maril J. Pritchard, MD; Rebecca L. Coover, PhD; Alvaro, MD.

Reference: Skonecny, T.A., Wolf, A.M.D., Erb, N.L., Block, O.D., Ryan, B.M., Underwood, W., Sauer, A.C., Zelefsky, M.J., Aspenberg, J.B., Shure, S.F., Wittmann, D.A., Hays, M.A., Srinivas, V.L., Chuang, G., Pritchard, M.J., and Coover, Alvaro, S. L. (2014). American Cancer Society prostate cancer survivorship care guidelines. *CA: A Cancer Journal for Clinicians*, 64, 275-295. doi: 10.3323/caj.2014.0113.3323caj.21234567

Program Support: The American Cancer Society thanks the National Cancer Institute for their support of this project. The American Cancer Society is a national, voluntary health care organization. It is a 501(c)(3) nonprofit organization. It is a member of the American Cancer Society.

- **Prostate Cancer** – Published online in *CA Cancer J Clin* on June 10, 2014. (www.bit.ly/ACSPPrCa)

- **Colorectal Cancer** – Published online in *CA Cancer J Clin* on September 8, 2015. (bit.ly/acscolorc)

- **Breast Cancer** – Collaboratively developed and released with ASCO. Published online in *CA Cancer J Clin* and *JCO* on December 7, 2015. (bit.ly/BrCaCare)

- **Head and Neck Cancer** – Published online in *CA Cancer J Clin* March 22, 2016. (bit.ly/acshadneck)



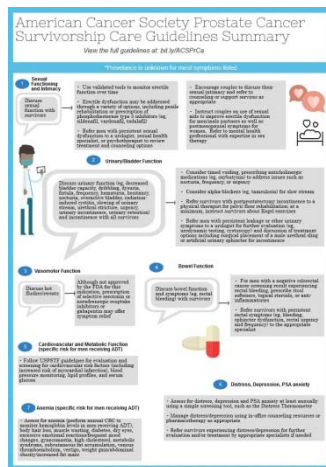
The National Cancer Survivorship Resource Center offers a free, innovative, online continuing education program to educate primary care providers about cancer survivorship. The Survivorship Center, a collaboration between the American Cancer Society and The George Washington University Cancer Institute, is funded by a five-year cooperative agreement through the Centers for Disease Control and Prevention.

The Cancer Survivorship E-Learning Series for Primary Care Providers features the following content:

- The role of clinical generalists and specialists in providing follow-up care to survivors of adult-onset cancers
- Managing long-term and late physical and psychological effects of cancer and its treatment
- Survivorship care planning and care coordination

The series is available at no cost and offers continuing education credits for physicians, physician assistants, nurse practitioners, and nurses. New content will be added on an ongoing basis. Each webinar is led by national experts and features a cancer survivor.

Visit cancersurvivorshipcentereducation.org for more information, and help spread the word about this program to your network of colleagues, especially those in primary care.




- Smartphone app; E-learning series CME
- Implementation toolkit & materials

Expecting Primary Care to Solve this Alone



We're Looking at Cancer Care with 1 Lens



Treat the
Tumor

To optimize the long-term health of cancer survivors, we need to change the way we deliver cancer care from the moment of diagnosis forward.



Effective, Efficient Cancer Care to Create **Healthy Survivors**

- ✓ Treat the tumor
- Monitoring biological systems perturbed by cancer treatment; Assess risk of toxicities, late effects
 - Prevent problems to increase function, lighten load in primary care
- Assess symptoms and impairments & facilitate referrals from diagnosis forward
 - Treat impairments and symptoms early

To Better Manage Toxicity

- Baseline Pre-surgical Comprehensive Assessment of needs & risk
 - Facilitates patient-provider conversation about needs
- Refer for interventions
 - Prevent future toxicities, late effects
 - Treat current impairments, symptoms
- Repeat assessments through/beyond treatment in primary care

Evidence For This Approach

[BMC Health Serv Res.](#) 2013; 13: 211.

PMCID: PMC3700832

Published online 2013 Jun 11. doi: [10.1186/1472-6963-13-211](https://doi.org/10.1186/1472-6963-13-211)

A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting

N=27 RCTs

[Jack Chen](#),^{1,2} [Lixin Ou](#),^{1,2} and [Stephanie J Hollis](#)^{1,2}

Strong Evidence	Modest Evidence
Improved pt-provider communication	Better patient outcomes
Improved patient satisfaction	
Identifying unrecognized problems	

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N=27 RCTs

Strong Evidence	Modest Evidence
Improved pt-provider communication	Better patient outcomes
Improved patient satisfaction	
Identifying unrecognized problems	



What are the Interventions?

- Physical, occupational, or speech therapy
- Psychosocial and cognitive interventions
- Symptom management
- Specialist referrals, e.g. Endocrinology, cardiology, orthopedic interventions
- Tailored exercise and nutrition prescription and lifestyle recommendations

Need Multi-modal, “Team Sport” Partnership Approach



New US National Initiative



The Survivorship Roundtable:

- Bring together organizations with a stake in the care of cancer survivors
- Mission: To meet the physical, functional, and psychosocial needs of people living through and beyond cancer and optimize functioning and well-being through enhancing the delivery of services from diagnosis through post-treatment survivorship in clinical, community, and worksite settings in the US
- Tackle agendas that no single organization can do alone

Coordinated Strategies

Offense, Defense, Plant & Shoot, Rebound, Pass



Coordinated Strategies



1. Assessment, Triage, & Surveillance

- NCI GEM project: Crowd-source comprehensive assessment of symptoms, impairments
 - Given in oncology
 - Tech-based administration
- Improve guidelines for tailored treatment
 - Help oncology make timely appropriate referrals
- Ongoing surveillance of survivors' needs

2. Patient Activation & Empowerment

- Use the assessment to facilitate patient-provider conversation about needs
 - Enable patient-centered care
- Workplace solutions
- Tools to help survivors self-manage health, become active participants in care
 - NCI/ACS: Springboard Beyond Cancer
<https://Smokefree.gov/springboard/>

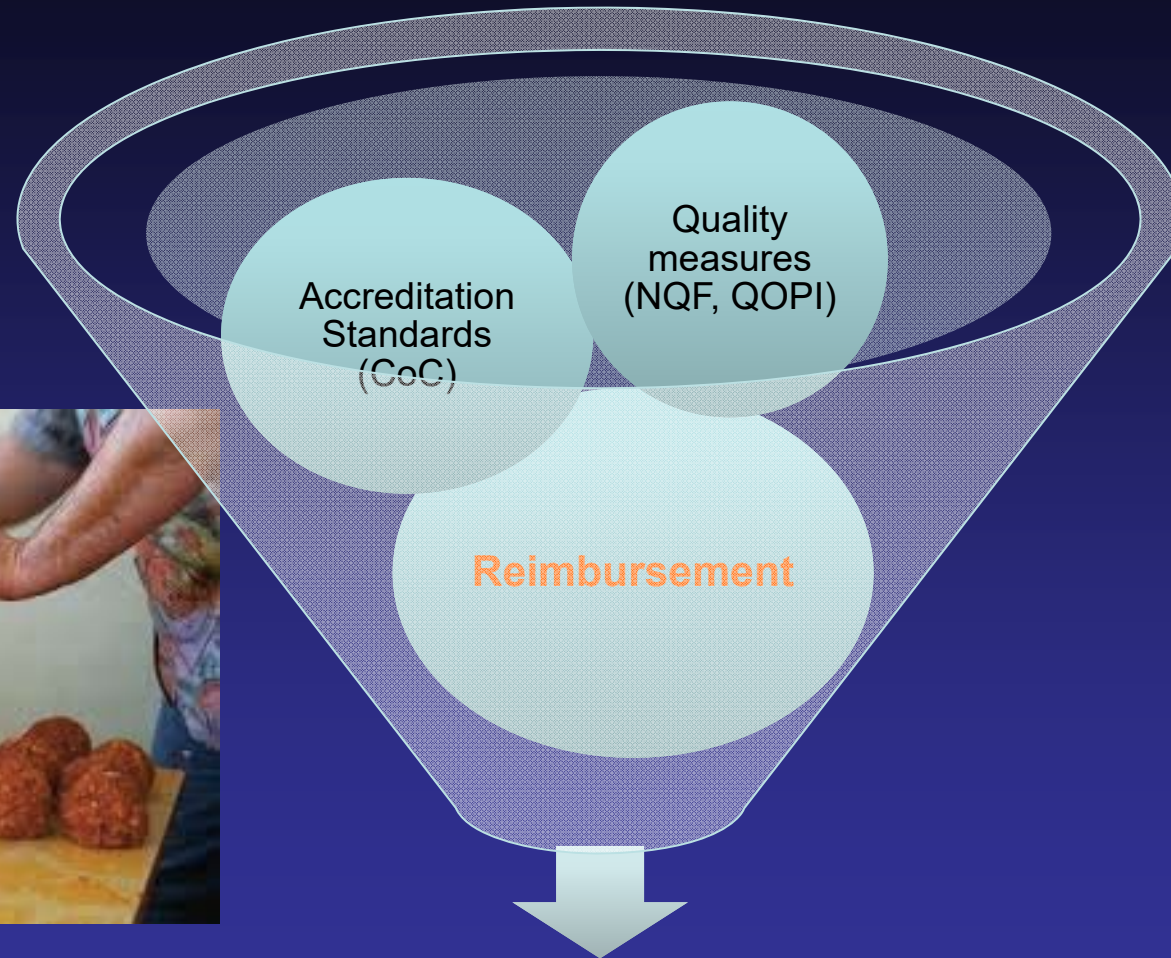
3. Provider Training

- Educate trainees in survivorship, rehabilitation
 - Oncology, primary care, nursing, pharmacy, rehabilitation, specialists)
- Continuing education for existing workforce
 - CME, cancer rehabilitation, certification programs, ASCO-primary care conference

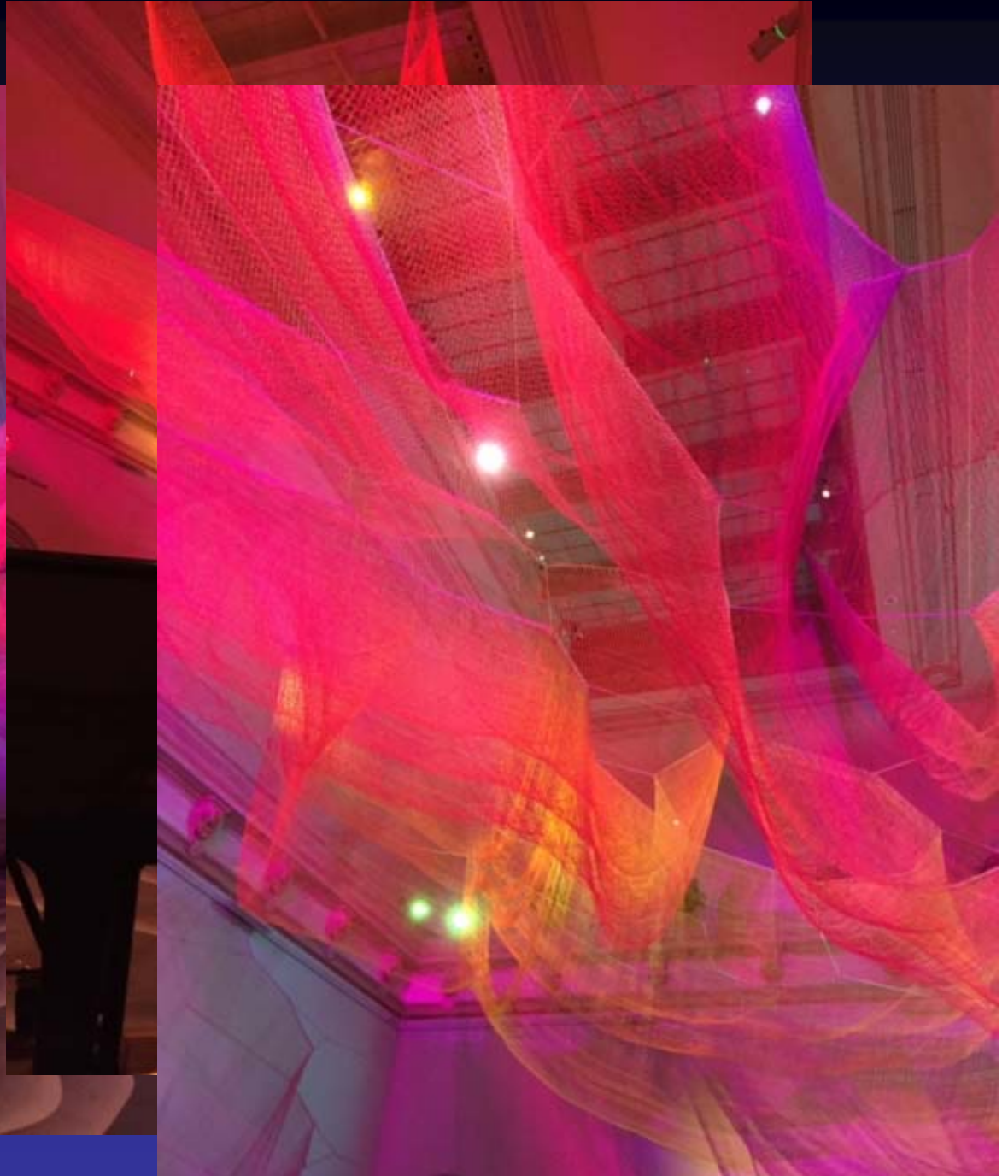
4. Healthcare Delivery Innovation

- Test implementation of assessment
 - ROI: referrals, morbidity, mortality, costs
- Test integrated care delivery models, alternative payment models
 - Decrease patient burden
 - Tele-medicine

5. Legislative, Regulatory, Policy Reform



Policy Supporting Practice Change
that Improves Patient Outcomes





“As individuals we may feel fragile, like a length of thread, but when knotted together we have the capacity for incredible strength and resiliency”



TOGETHER



**WE CAN DO
THIS!**



THANK YOU !

CATHERINE.ALFANO@CANCER.ORG

CANCER.ORG 800-227-2345