



# CANCER SUPPORT COMMUNITY

*A Global Network of Education and Hope*

# The Challenge of Cancer Care Today

- Increasing Numbers
- More Complexity
- Rising Costs
- Growing Social and Emotional Needs



# Striving for Complete Cancer Care

“Health is a state of **complete physical, mental and social well-being** and not merely the absence of disease or infirmity.”



“All cancer care should include appropriate psychosocial support.” (*Cancer Care for the Whole Patient*, 2008)

“Care plans should address a patient’s psychosocial health needs.” (*Delivering High Quality Cancer Care*, 2013)



# Today's Reality - Distress

## Social and emotional needs go unrecognized or untreated

- “Significant” problem for one-third to one-half of all patients



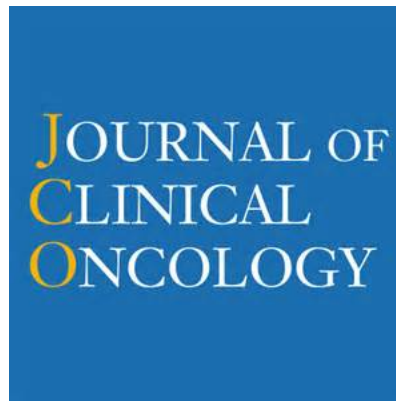
- 87% report at least one issue of “significant” distress



# Today's Reality – Physical Effects

**Psychosocial distress can be correlated with poorer physical function**

“...41% of patients score above the threshold for psychological distress and poorer physical function is associated with increased distress levels.” (Hurria, et al. 2009. JCO)



# Today's Reality - Cost

## The cost of care increases alongside distress

- \$8,400 more per individual, per year with depression  
(Jeffrey, et al. 2010. APA)

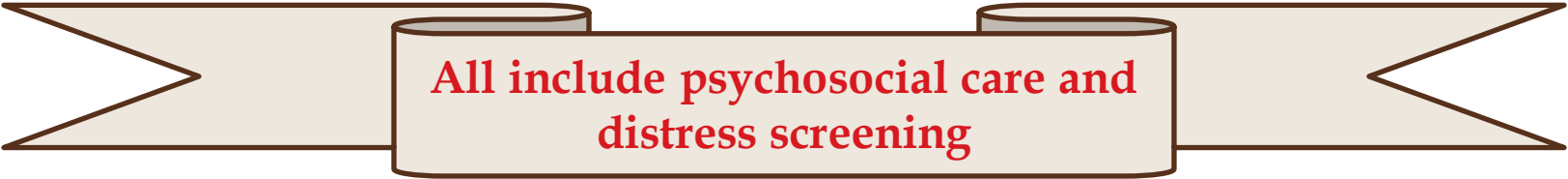


- Early diagnosis and intervention = 25% savings  
(Carlson, et al. 2004. Psycho-Oncology)



# Striving for Patient-Centered Care

- Institute of Medicine (IOM)
  - *“Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs”*
  - *“Delivering High Quality Cancer Care: Charting a New Course for a System in Crisis”*
- Patient-Centered Outcomes Research Institute (PCORI)
- American College of Surgeons Commission on Cancer  
*2012 Patient-Centered Standards*
- American Society of Clinical Oncology  
*Quality Oncology Practice Initiative (QOPI)*
- Community Oncology Alliance  
*Medical Home*



**All include psychosocial care and  
distress screening**



# Cancer Support Community

OUR MISSION:

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.





# Cancer Support Community



# Program and Service Delivery

- Affiliate Network
- Cancer Support Helpline<sup>SM</sup>
- Online Support: The Living Room<sup>®</sup>
- Frankly Speaking About Cancer<sup>®</sup>
- Cancer Transitions<sup>®</sup>
- Teens and Children

# Affiliate Network

- 50+ centers
- 100+ satellite locations
- Hospital partnerships
- Deliver support groups, educational, health and wellness programs



## News Archive

Tuesday, June 26, 2012 - First-in-nation partnership paves the way for major leap forward in total cancer care  
GREENVILLE, S.C. - Recognizing that social and emotional support are critical components of complete cancer care, Greenville Hospital System announced today the Center for Integrative Oncology and Survivorship and a pioneer partnership with Cancer Support Community (CSC) - one of the largest worldwide providers of social and emotional support for cancer patients and their caregivers.

According to a 2008 report from the Institute of Medicine (IOM), between one-third and one-half of all cancer patients experience some level of distress, which can range from expected levels of sadness and anxiety to very high levels that can interfere with a patient's treatment and ability to cope. Studies conducted by the IOM and others show that integrating psychosocial services into the medical standard of cancer care can reduce distress, improve patient outcomes and optimize quality.

"Research shows that social and emotional support is as important as medical care in the face of a cancer diagnosis," said Dr. Larry Gluck, medical director of GHS' Cancer Center. "Cancer Support Community is a leader in psychosocial oncology, and we are pleased to integrate their evidence-based programs and services into our cancer care delivery model so our patients get the best medical and psychosocial care available."

*"It is just the greatest place; I have found support, friends and new ways to meet the challenge of having cancer."*

# Cancer Support Helpline<sup>SM</sup>

- Toll-free 1-888-793-9355
- Staffed by licensed mental health professionals
- Home to Open to Options<sup>SM</sup> – Treatment Decision Counseling Program



# Online Support: The Living Room<sup>®</sup>

- Online support groups led by licensed mental health professionals
- 24/7 discussion boards on topics like cancer type, living after treatment and caregiving



*"The CSC taught me the importance of taking a proactive role in my decision making."*

Sharista, Breast cancer survivor

# Frankly Speaking About Cancer®

- CSC's landmark cancer education series
- Educational material developed in partnership with oncology professionals, survivors and advocates
- Professionally led patient education workshops integrating psychosocial support and stress reduction
- Weekly internet radio show





# Cancer Transitions®

- Six-week face-to-face program for cancer survivors who have completed active treatment
- Developed in partnership with the LIVESTRONG Foundation
- Online delivery now available
- Professionally facilitated



**cancer**  
**transitions**  
Moving Beyond Treatment

# Children and Teens

- 2.85 million children in the U.S. are living with a parent who has been diagnosed with cancer
- CSC offers professionally facilitated evidence-based help for children touched by cancer directly or indirectly
- Online and face-to-face groups



# Research and Training Institute

Experts in the Cancer Patient Experience



# Research and Training Institute

- The first and only *Institute* in the U.S. dedicated to psychosocial, behavioral and survivorship research and training
- Led by a PhD behavioral psychologist and staffed by a multidisciplinary team of clinical and research professionals
- Delivers one-on-one interviews, focus groups, patient surveys, registries and other peer-reviewed research

# Original Research

- Cost effectiveness research
  - Cost study ION/Priority Health
- Distress screening
  - Development and validation of CancerSupportSource<sup>SM</sup>
  - Identification of four predictors of depression
- Treatment decision-making
  - Development and validation of Open to Options<sup>SM</sup>

# Cancer Experience Registry®

- First cancer registry in the world focused on understanding and addressing the psychosocial and survivorship needs of **anyone** ever faced with a cancer diagnosis
- Currently 6,000+ participants
- Goal >10,000 (all cancers) in 2014
- [www.cancerexperienceregistry.org](http://www.cancerexperienceregistry.org)



**CANCER EXPERIENCE  
REGISTRY.**



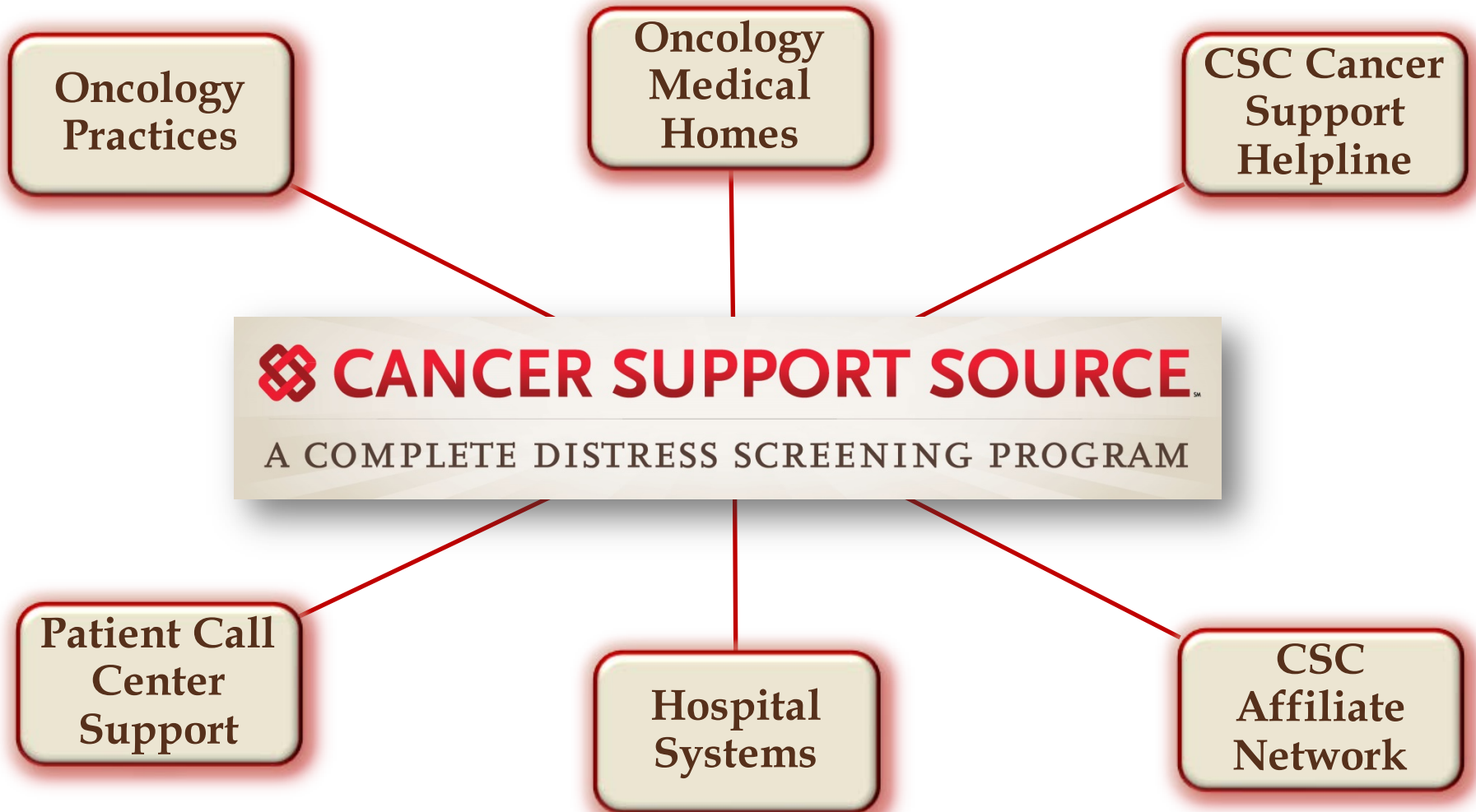
# CancerSupportSource<sup>SM</sup>

- Web-based program that integrates distress screening, referral and follow-up care
- Developed and validated by CSC's research team in partnership with hospitals and cancer centers
- Designed to help institutions meet the new American College of Surgeons Commission on Cancer accreditation standards

 **CANCER SUPPORT SOURCE<sup>SM</sup>**

A COMPLETE DISTRESS SCREENING PROGRAM

# CancerSupportSource<sup>SM</sup>



# Open to Options<sup>SM</sup>

- 40 minute treatment decision counseling session
- Resulting in:
  - Greater satisfaction with interaction with the doctor
  - Less decisional regret
  - 47% asking about clinical trials
  - 9% enrolling into clinical trials



# Cancer Policy Institute

- Formally launched on June 19, 2013
- Experienced CSC policy team
- Uniting direct patient and family engagement with research to shape the future of quality cancer care



# Cancer Policy Institute

The Cancer Policy Institute *at the*



**CANCER SUPPORT COMMUNITY**

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## *Core Principles*

*Access* to care for all patients

*Quality* as a central theme

*Research* as a critical priority

# Cancer Policy Institute Priorities

- Comprehensive Quality Cancer Care
  - Biology
  - Psychology
- Parity across boundaries
- Primacy of evidence
- Protection of patient as True North



# Advisors to the Institute

**Jeff Allen, PhD**

Friends of Cancer Research

**Lauren Barnes, MHS**

Avalere Health

**Jeff Belkora, PhD**

Institute for Health Policy Studies, UCSF

**Amanda Bennett**

Author, *The Cost of Hope*

**Linda Blumberg, PhD**

The Urban Institute

**Caroline Brown**

Covington & Burling LLP

**Michele R. Dietz, RN, MSN**

Oncology Nursing Society

**Mary Beth Donahue**

America's Health Insurance Plans

**Stephen Edge, MD, FACS**

Former Chair, American College of Surgeons

Commission on Cancer

Baptist Cancer Center

**Pamela Greenberg, MPP**

Association for Behavioral Health and Wellness

# Advisors to the Institute

**Jessie Gruman, PhD**

Center for Advancing Health

**Diana Jeffery, PhD**

Government Health Psychologist

**Lovell A. Jones, PhD**

Professor Emeritus

U.T. Distinguished Teaching Professor

U.T. M.D. Anderson Cancer Center

Co-Founder, Intercultural Cancer Council

**Deborah Kamin, RN, PhD**

American Society of Clinical Oncology

**C. Daniel Mullins, PhD**

University of Maryland School of Pharmacy

**Sharyl J. Nass, PhD**

Institute of Medicine

**Dylan H. Roby, PhD**

UCLA Fielding School of Public Health

UCLA Center for Health Policy Research

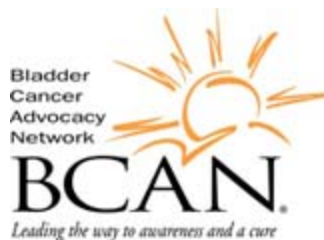
**Lisa Simpson, MB, BCh, MPH, FAAP**

AcademyHealth

**Daniel E. Smith, JD**

AdvocacySmiths

# Friends of the Cancer Policy Institute



# Friends of the Cancer Policy Institute



University of California  
San Francisco



Philip R. Lee Institute  
for Health Policy Studies



free to breathe  
a partnership for lung cancer survival



Research Advocacy Network

*Advancing Patient-Focused Research*



# Cancer Policy Institute: Unique Activities

- ✓ Cancer Insurance Checklist
- ✓ CSC statement on evidence-based, patient informed care
- Access Documentary: Patient experience with access to health care
- Advocacy toolkit – internal and external use
- Virtual grassroots network



**Your guide to shopping for insurance on the Marketplace/Exchange if you have cancer, have a history of cancer, or are at risk for cancer.**

**CancerInsuranceChecklist.org**



# Cancer Policy Institute: Next Steps

- Goals and action
  - IOM
    - Drive update to *Cancer Care for the Whole Patient*
  - HHS
    - Monitor and advise on ACA implementation
    - Advocate for coverage of distress screening
  - FDA
    - Ensure a more patient-centered approach to review
    - Advocate to keep pace with science and innovation
  - NCI
    - Partner to incorporate distress screening in clinical trials
    - Secure more dollars for psychosocial research
  - Capitol Hill
    - Ensure patient-centered approach to cancer legislation

# Cancer Support Community

So that no one faces cancer alone<sup>®</sup>





# Back-up slides

# 2013

## Posters / Presentations / Publications

# 2013 RTI/Programs/Education Posters/Presentations/Publications

- Academy of Oncology Nurse Navigators (1)
- American College of Surgeons Commission on Cancer (1)
- American Public Health Association (1)
- American Society of Clinical Oncology (3)
- Association for Value Based Cancer Care (1)
- Association of Oncology Social Work (1)
- International Cancer Education Conference (5)

# 2013 RTI/Programs/Education Posters/Presentations/Publications

- Florida Society of Oncology Social Workers (1)
- Journal of Cancer Survivorship (manuscript)
- MPN Education Foundation (1)
- National Comprehensive Cancer Network (2)
- Ohio Partners for Cancer Control (2)
- Society of Behavioral Medicine (2)
- Translational Behavioral Medicine (manuscript)

# Cancer Policy Institute: 2013 Presentations

- Association of Community Cancer Centers, 39<sup>th</sup> Annual National Meeting, Panel Discussion: Who Defines Quality Cancer Care
- American Society of Clinical Oncology, ASCO/AAHPM Palliative Care in Oncology Practice Statement Panel
- Vital Options International, Panel Discussion: Advocacy in Action: Palliative Care Video
- DC Cancer Consortium, Panel Discussion: Advancing Health Equity for Patients Living With Cancer: Fostering Collaboration to Implement the ACA
- American Journal of Managed Care: Multiple Myeloma Roundtable
- Biotechnology Industry Organization Patient and Health Advocacy Summit, Panel Discussion: “One Week In: A Look at Enrollment, Coverage and Access in the New Health Insurance Exchanges”

# Cancer Policy Institute: 2013 Presentations (cont'd)

- Colon Cancer Alliance: "Let Your Voice be Heard" re: Grassroots Advocacy
- Patient Access Network Foundation, Panel Discussion: "Access and Cost Sharing of Specialty Medications for Underinsured Patients: The Patient and Chronic Care"
- Patient Access Network Foundation, Panel Discussion: "Access and Cost Sharing of Specialty Medications for Underinsured Patients: Patient Assistance Trends"
- NCCN Patient Advocacy Summit, Panel Discussion: "Defining Essential Health Benefits"
- NCCN Patient Advocacy Summit, Panel Discussion: "Patient Advocate Perspectives on Health"

# Cancer Policy Institute Coalition Engagement

- Leading
  - Alliance for Quality Psychosocial Care
  - C-Change Value of Cancer Sub-Committee
- Participating
  - Alliance for a Stronger FDA
  - Cancer Leadership Council
  - C-Change Workforce Committee
  - Coverage Counts
  - Global Access Project
  - One Voice Against Cancer
  - Patients Equal Access Coalition
  - Quality of Life Coalition
  - Regulatory Education and Action for Patients
  - State Patients Equal Access Coalition