## State of

# Tennessee



## Cancer Plan 2013-2017



HTTP://TNCANCERCOALITION.ORG

This cover represents residents of Tennessee whose lives has been touched by cancer. The map of Tennessee features survivors, co-survivors, caretakers and those whose lives were lost in the fight against cancer.

## **Executive Summary**

The Tennessee Comprehensive Cancer Control Plan provides a roadmap for the activities of the Tennessee Cancer Coalition (TC2) during the years of 2013 – 2017. Ultimately, the goals and objectives of the plan will be seamlessly integrated and implemented by the TC2 regional coalitions of the state. The annual work plan is prepared using the framework of the Plan to prioritize and establish annual measurable outcomes for evaluation. The incidence and mortality data used in this plan are for the diagnosis years of 2005-2009 from the State Cancer Profiles web site, http://statecancerprofiles.cancer.gov/index.html

Each cancer specific chapter has goals that have been identified for the continuum of cancer care, including primary prevention, early detection, treatment and care, survivorship, and palliative care. The overarching issues of cancer disparities, cancer advocacy, health literacy, surveillance and lifestyle and environment that appeared in the 2009-2012 plan remain in the 2013-2017 plan. New chapters in lung cancer, independent of tobacco related cancers, navigation, hematological cancers, and genetics were added to this version of the plan to remain cutting edge and current in representing the status of cancer in Tennessee. Goals, objectives and strategies are present in each chapter to address the individual topics.

Readers are invited to visit the web site at http://tncancercoalition.org to review the plan, complete a membership form and access additional resources.

This plan is provided to the citizens of Tennessee as a comprehensive strategy to reduce the burden of cancer in Tennessee.

### Dedication of State Cancer Plan to John J. Chiaramonte, Jr.



*It is with great pride and admiration that The Tennessee Cancer Coalition dedicates the 2013-2017 State Cancer Plan to our friend and colleague, John J. Chiaramonte, Jr.* 

John was a consummate cancer advocate. After surviving cancer (and retirement), John was seeking an opportunity to become engaged in cancer policy. In February 2006 he moved to Nashville to serve as Tennessee Government Relations Director for the American Cancer Society. John served passionately in this capacity until his retirement in December 2011. In his public policy role with American Cancer Society, and also as Advocacy Committee Chair for the Tennessee Cancer Coalition, John was known by legislators, administration officials, and

other stakeholders as an uncompromising advocate for policies that supported cancer prevention and control.

In 2007 John helped lead the fight for passage of the Tennessee Non-Smokers Protection Act, the statewide smoke-free workplace law which supports Tennesseans in breathing smoke-free air at numerous restaurants, hotels, and many other public establishments. John Chiaramonte was respected by members of the Tennessee General Assembly as a non-partisan professional committed to increasing awareness of the burden of cancer in our State.

In addition to his work with Smokefree Tennessee, John was a major asset to the Tennessee Cancer Coalition as he guided our volunteer-driven coalition in best practices of advocacy techniques and approaches in support of such legislative issues as increasing funding for the Tennessee Breast and Cervical Cancer Screening Program, awareness of colon cancer's impact on Tennesseans and the necessity of early diagnosis and access to screening.

After 14 years as a kidney cancer survivor, John was diagnosed with cancer recurrence with bone metastases in July 2011 leaving him unable to continue his cancer advocacy work. During the treatment of his disease John and his wife Marty bore their struggles with grace and determination, openly sharing the good days and the bad days with us all. Sadly, John succumbed to his disease on December 16, 2012 leaving a legacy of volunteerism, passion, and excellence characteristic of a true Tennessean. John was committed until the very end to eradicating the burden of cancer on the citizens of Tennessee. His legacy will continue through the efforts of the many Tennessee Cancer Coalition volunteers who knew John and continue to be inspired by him.

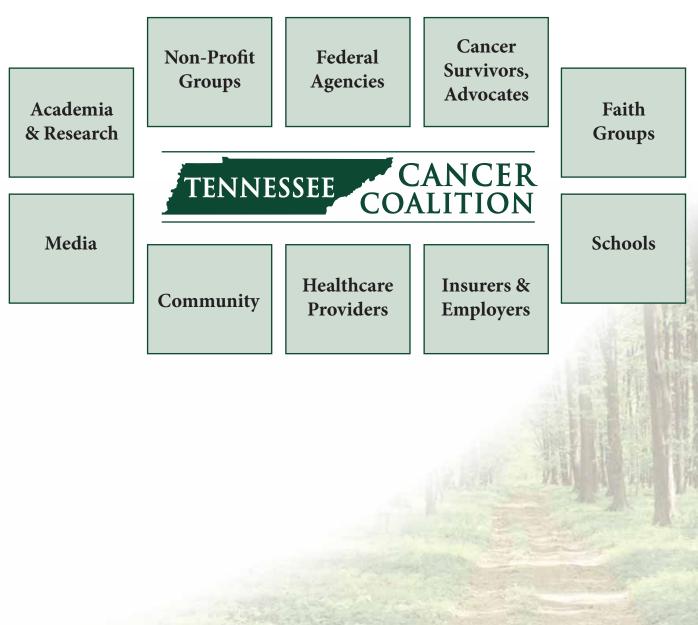
## TABLE of CONTENTS

Conceptual Framework	.Page 3
Chapter 1 - Advocacy and Awareness	.Page 4
Chapter 2 - Cancer Research, Clinical Trials and other Human Studies	.Page 5
Chapter 3 - Childhood/Adolescence Cancer	.Page 6
Chapter 4 - Colorectal Cancer	Page 11
Chapter 5 - Disparities	Page 14
Chapter 6 - Genetic Testing and Hereditary Cancer	Page 16
Chapter 7 - Health Literacy	Page 18
Chapter 8 - Hematological Cancers	Page 20
Chapter 9 - Lung Cancer	Page 22
Chapter 10 - Melanoma and Non-Melanoma Skin Cancers	Page 26
Chapter 11 - Palliative Cancer Care	Page 28
Chapter 12 - Patient Navigation	Page 30
Chapter 13 - Primary Prevention	Page 31
Chapter 14 - Prostate Cancer	Page 35
Chapter 15 - Screening and Early Detection	Page 38
Chapter 16 - Surveillance and Evaluation	Page 40
Chapter 17 - Survivorship	Page 43
Chapter 18 - Tobacco	Page 45
Chapter 19 - Women's Cancers	Page 48
Glossary	Page 50
Selected References/Resources	Page 51
The Burden of Cancer in Tennessee	Page 52
U.S./TN Comparison	Page 53
Counties with Higher Mortality Rates	Page 54
What Can You Do To Fight Cancer in Tennessee?	Page 55
Acknowledgements	Page 64
TC2 Leadership	Page 66

## FRAMEWORK

This framework illustrates the concept that creating and implementing a comprehensive strategic plan to control cancer requires diverse perspectives and resources. Health care providers, researchers, cancer survivors, advocates, public health planners and educators, as well as insurers and employers all need to be involved. Multiple perspectives should be reflected in the makeup of each resource group, as well as the statewide coalition.

The Tennessee Cancer Coalition (TC2) was formed in 2003 to create and implement the 2005-2008 Tennessee Comprehensive Cancer Control Plan. In 2013, TC2 includes more than 500 individuals, organizations and health care professionals.



## Chapter 1

## **ADVOCACY and AWARENESS**

#### **Definition:**

Advocacy is the act of supporting, recommending or requesting the cause of another. Through public policy advocacy and awareness, the Tennessee Cancer Coalition (TC2) seeks to reduce the burden of cancer in Tennessee by supporting public laws or policies that positively impact cancer awareness, treatment and prevention in Tennessee.

#### Goal 1:

Ensure that elected officials are aware of cancer issues throughout the state and that they hear that curing cancer is a priority to the citizens of Tennessee. No Centers for Disease Control funds will be used by the Tennessee Cancer Coalition (TC2) to conduct advocacy activities which otherwise may be restricted by law and regulation.

#### **Objective 1.1:**

Identify issues/bills each year about which the TC2 can have meaningful impact on the legislative process.

#### Strategies:

- The Advocacy and Awareness Committee will review bills filed at the start of the General Assembly in January of each year and communicate to TC2 members summaries of those bills affecting cancer care, treatment, or funding in Tennessee.
- Serve as a resource to elected officials and government agencies regarding cancer prevention and control policies in Tennessee.

#### **Objective 1.2:**

Recommend to the TC2 Executive Committee 1-3 core issues per year about which TC2 will request grassroots participation to contact elected officials.

#### **Strategies:**

• The Advocacy and Awareness Committee will work with representatives from the American Cancer Society, National Cancer Institute, and other national resource partners to identify cancer advocacy activities in other states that have been successful and make recommendations for action in the upcoming legislative session to the TC2 Executive Committee in the fall of each year.

#### **Objective 1.3:**

Educate members on how they can influence legislators.

#### **Strategies:**

- At the annual Summit on the Burden of Cancer, train regional leaders in how to work with their constituencies in grassroots advocacy.
- Develop and organize an e-mail alert system to alert coalition members for legislative action.
- Invite elected officials to the Annual Summit on the Burden of Cancer so that coalition members can develop personal relationships with them.

4

## Chapter 2

## CANCER RESEARCH, CLINICAL TRIALS and other HUMAN STUDIES

#### **Definition:**

Cancer research has been defined as the scientific effort to understand cancer processes and discover possible therapies. Cancer research includes the exploration of underlying biological processes (basic research), populationbased studies to determine disease patterns and causes (epidemiology), and how to apply basic knowledge to patient care and treatment (translational research). Clinical trials are epidemiologic studies that involve people and are often the final step in a long process that begins with research in a laboratory and animal testing. Clinical trials and "observational" epidemiological studies (those that involve observing what people are exposed to rather than controlling the exposure, as in clinical trials) are human studies designed to answer questions about ways to prevent cancer, locate and diagnose cancer, treat cancer, and manage symptoms of cancer or its treatment.

#### Goal 1:

Promote education and awareness of human studies on cancer conducted in our state.

#### **Objective 1.1:**

To develop and maintain a website of information on current cancer research and human studies conducted in Tennessee.

#### Strategies:

- Identify and partner with relevant local, regional, and national organizations such as the American Cancer Society (ACS), the National Cancer Institute (NCI), and the Leukemia and Lymphoma Society (LLS) to identify Tennessee resources for human studies.
- Include relevant information regarding human studies in every TC2-sponsored activity.

#### Goal 2:

Increase professional and public access to human study participation.

#### **Objective 2.1:**

Create access to a dynamic, searchable website to identify human studies available in Tennessee that is current, reliable, readable, and user-friendly, on or before December 31, 2017.

- Provide simple instructions to find relevant human studies using NCI.gov and Cancer.gov.
- Develop and maintain a website listing of current human studies in Tennessee.
- Identify point persons in each region who will regularly provide information to update the website and to identify resources related to regional human studies.

## Chapter 3

## **CHILDHOOD/ADOLESCENT CANCER**

#### **Definition:**

Childhood/Adolescent cancer is the number one cause of death due to disease in children younger than 20 years of age.<sup>1</sup> Deaths from cancer exceed those related to cystic fibrosis, muscular dystrophy, asthma, and AIDS combined<sup>2</sup>. Tennessee is a leader in treating these young cancer patients whose average age at diagnosis is six years old, subsequently resulting in the most years of life lost per person, compared to all adult cancers.<sup>3</sup> Childhood/Adolescent cancers differ from adult cancers in many ways.<sup>4</sup>

Differences	Childhood/Adolescent	Adult	
Prevention & Early Detection	There are currently no known behavioral interventions or screening tests available that would result in early detection. Symptoms often mimic other childhood diseases, which delays diagnosis. Therefore, childhood cancers are often diagnosed at an advanced stage.	Lifestyle risk factors such as tobacco, diet, and exercise have been identified. In addition, screening tests such as mammograms and colonoscopies are available. Thus, some adult cancers can be diagnosed and treated at earlier stages.	
Frequent Types	Blood (Leukemia, Lymphoma), Brain, Bone, Soft Tissue	Lung, Breast, Colon, Prostate, Skin, and other organs	
Incidence Per Year	18,000	1,500,000	
Approximate 5 year Survival Rate	75% However certain cancer types remain at <50%	50%	
Percent of Patients Enrolled in Clinical Trials	70%	3%	
Length of Treatment (depending upon diagnosis)	6 months to 3 years	6 months to 1 year	
Long Term Effects of Treatment	Due to young age at diagnosis and highly toxic treatments, approximately 70% of survivors suffer serious long term effects impacting organ function, growth and de- velopment, reproductive outcomes, and risk of subsequent cancers.	Varies based on treatment	
Research/ Drug Development	Termed an "orphan" disease and only 2 new drugs have been approved in the last 20 years. Receives 4% of National Cancer Institute budget and virtually no pharmaceutical research funds are allo- cated to childhood cancers.	Receives 96% of National Cancer Institute budget and multiple billions of dollars of pharmaceutical research funds are allocated to adult cancers.	

#### Goal 1:

To reduce/eliminate suffering and death due to childhood/adolescent cancers and to provide survivors and families the services needed to live meaningful and productive lives.

#### **Objective 1.1:**

All children/adolescents in Tennessee will receive the highest quality, state-of-the-art, comprehensive cancer care to meet their medical, psychosocial, and educational needs.

#### Strategies:

• Recognize and support the need for increased capacity at pediatric cancer centers, as a result of the increase both in incidence and in the number of patient visits per year.

Keys to the Cure: Tennessee Hospitals				
	Annual Hematological/Oncology Pediatric Visits 2010	Reach		
*St. Jude Children's Research Hospital	76,135	Global		
*Vanderbilt-Ingram Cancer Center/ Monroe Carell Jr. Children's Hospital	23,308	TN, KY, AL, IN, GA, NC, FL		
East Tennessee Children's Hospital	6,696	TN, NC, GA, KY, VA		
Children's Hospital at Erlanger	4,660	TN, GA, AL, NC		
Niswonger Children's Hospital/ St. Jude Affiliate	3,590	TN, VA, WV, KY, NC		
TOTAL	114,389	- AL		

\*National Cancer Institute (NCI) designated Comprehensive Cancer Center - recognized for excellence in research, treatment, education and outreach.

- Educate local medical providers and school nurses about the: a) symptoms of childhood cancer b) location of the nearest pediatric cancer center, and c) needs of survivors, including the need for continuity of care and the effective transition of care between pediatric oncologists and subsequent healthcare providers.
- Establish and make easily accessible a statewide inventory identifying existing local/state/national resources written in layman's terms (low reading level) that offer psychosocial, educational, complementary (i.e. yoga, art therapy, diversionary therapy), fertility, financial, spiritual, and community support/services both during treatment and throughout the child's life. If necessary resources are not available to families in Tennessee, the Children's Committee seeks to create programs to fulfill the identified needs.

- Help families address the major financial burdens resulting from childhood/adolescence cancers including direct medical expenses, ongoing insurance coverage, missed work, transportation costs (as treatment centers are often far from home), childcare for siblings, and funeral expenses.
- Collaborate with health insurers and legislators to provide full coverage of all required services for: a) patients (including pain/palliative care), b) survivors (Children's Oncology Group (COG) including neuropsychological testing), and c) families (including psychosocial diagnoses such as Post-traumatic Stress Disorder).

#### **Objective 1.2:**

All children/adolescents in Tennessee will receive a Treatment Summary and Survivorship Plan (based on COG Guidelines<sup>5</sup>) which will include details about the modalities (surgery, chemotherapy, radiation therapy) used to treat childhood cancer, a description of the health risks associated with their individualized treatment, methods of risk reduction, and a schedule of necessary health screenings and annual exams.

#### Strategies:

- Healthcare providers schedule each survivor for an appointment at a specialized Survivorship Program at the culmination of active treatment/follow-up visits.
- Promote the creation of an online Survivorship Plan that is easily accessed and updated as the survivor moves or changes medical providers (http://txch.org/for-professionals/passport-for-care/).
- Ensure that survivors, as a high-risk population, have access to continuing resources and programs that promote the practice of positive health behaviors and that optimize physical, intellectual, social, and emotional (targeting feelings of loss/isolation, fear of recurrence, issues of independence) development.
- At hospitals that serve childhood cancer patients but do not yet offer specialized, ongoing survivorship care, post and distribute information about specialized, off-site survivorship programs.

#### **Objective 1.3:**

Increase knowledge among primary health care providers, patients/families, educators and the public as well as increase cooperative efforts between agencies, and institutions regarding the unique aspects of childhood/adolescent cancer, the long-term effects of treatment, and the need for specialized support systems by conducting 10 regional childhood cancer action team meetings in the state each year beginning in 2013 through 2017.

- Conduct one statewide workshop for education professionals per year during the period 2013 through 2017 addressing school reentry/adjustment to: a) foster communication between health care providers, school staff, patients/families, and the community, b) increase awareness of the symptoms of childhood/adolescent cancer, and c) raise awareness of the long-term effects (physical, neurocognitive, and psychosocial) of childhood/adolescent cancer.
- Conduct statewide training for preschool/daycare staff to implement the A-B-C-1-2-3 Healthy Kids Tennessee curriculum.
- Conduct workshops, offer retreats and provide resources for childhood/adolescent and young adult cancer survivors addressing specialized follow-up care, psychosocial needs, employment (discrimination, disability rights), health insurance, fertility, relationships, advocacy, and moving forward positively as healthy survivors.
- Conduct statewide workshops for primary care providers to: a) foster communication between oncology and community health care providers and b) raise awareness of the symptoms of childhood/adolescent cancer and assist with early diagnosis and treatment of the long term effects (physical, neurocognitive and psychosocial) of childhood/adolescent cancer.

#### **Objective 1.4:**

All children/adolescents in Tennessee will have the opportunity to benefit from basic research and to enroll in clinical trials designed to maximize therapeutic efficacy while minimizing toxicity.

#### Strategies:

- Support research/clinical trials for novel therapies, rather than solely relying on new combinations of existing drugs.
- Promote and support funding for basic research that addresses the potential role of both genetics and environmental causes of childhood/adolescent cancer.
- Support research/clinical trials to identify best treatment plans for adolescent/young adult populations.
- Promote "consumer-friendly" explanations of clinical trials and informed consent forms.
- Identify funding sources to support research on late effects of treatments and long-term follow-up survivor care.

#### **Objective 1.5:**

Raise awareness of childhood/adolescent cancer and advocate for policies, laws, and practices that meet the needs of survivors and their families.

#### Strategies:

- Obtain and display Proclamations signed by the Governor and local Mayors recognizing September as Childhood Cancer Awareness Month.
- Develop Childhood Cancer Awareness Month web pages publicizing local and statewide events and community partners.
- Submit Letters to the Editor of major publications statewide to increase awareness.
- Advocate for passage of legislation for increased funding for research.
- Advocate for services related to long-term survivorship such as psychosocial support, education, employment, and insurance.
- Work with a national Advisory Committee to replicate the TC2 Childhood Cancer Committee model (www.tncancercoalition.org/childhood) in other states and build statewide coalitions that include all stakeholders (healthcare providers, community organizations, individual activists, survivors, and their families).
- Work collaboratively with local, regional, and national organizations related to childhood cancer advocacy, awareness, prevention, research, treatment, and support.
- Develop a statewide advocacy network to improve benefits/programs/services. Create a campaign that will: a) increase grassroots awareness of the need to find a cure for every child, and b) include a call to action.

#### **Objective 1.6:**

Optimize each child's quality of life through symptom control beginning at the time of diagnosis and continuing throughout the child's life.

#### Strategies:

- Establish and make easily accessible a statewide inventory identifying existing local/state/national resources for home health and hospice care.
- Educate both health care providers and parents about communicating candidly and proactively regarding minimizing the symptoms associated with cancer diagnoses and treatments.
- Promote adequate reimbursement for home/hospice care and bereavement support for families.

#### **Objective 1.7:**

All children/adolescents/family members in Tennessee will have equal access to educational, rehabilitative, and psychosocial services both during and after treatment.

#### Strategies:

- Conduct baseline and ongoing neuropsychological testing for preschool through college age students.
- Implement the services necessary for each child as indicated by testing.
- Recognize the necessity for all patients/families to meet with a Pediatric Oncology Social Worker for ongoing counseling/emotional support and for a psychosocial assessment to determine emotional and developmental impact of diagnosis/treatment, work/school concerns, patient/family coping, family dynamics, cultural differences, and need for resources from the hospital, government, or other outside agencies.
- Educate health care providers about the necessity of cross-cultural awareness and strategies when communicating with culturally diverse survivors/families of childhood/adolescent cancer.
- Develop programs that address disparities and gaps in care due to age, diagnosis, education level, and rural/urban settings.

The Childhood Committee welcomes your comments and questions. Please go to http://cancercoalition.org/childhood and contact the committee chair

#### **References:**

- 1. National Cancer Institute, www.cancer.gov
- 2. Centers for Disease Control and Prevention, www.cdc.gov
- 3. National Cancer Institute Cancer Trends Progress Report 2009-2012, www.progressreport.cancer.gov/
- 4. Surveillance Epidemiology and End Results, www.seer.cancer.gov/
- 5. Children's Oncology Group Guidelines, www.survivorshipguidelines.org

## **Carolyn Hale's Childhood Challenge**



I am a 24 year old graduate student and athlete, and I like to think I am the picture of health – but this was not always so. I was 13 years old when I was introduced to the world of childhood cancer. On April 17th 2000, doctors found a mass on my thoracic spine and within that same week I underwent a biopsy and was diagnosed with precursor B-cell non-Hodgkin lymphoblastic lymphoma, stage III. As with most anyone who has heard the words, "You have cancer," my family and I can remember every minute quite vividly. I was thrown into a rigorous, two-year chemotherapy protocol, during which time I

endured 19 spinal taps, 56 blood transfusions, 25 hospital admissions, and over 150 visits to Vanderbilt's outpatient clinic. Not surprisingly and like most childhood cancer patients, throughout the course of my treatment I experienced significant and life altering side effects.

I am now 10 years post-treatment and cancer-free! While I am very blessed to be a survivor, I have a long list of issues that have resulted or could occur as a consequence of my cancer treatment. With the excitement and relief of being told, "You've reached remission; no signs of cancer exist," comes the potential for physical, cognitive and emotional issues that childhood cancer survivors can face throughout the remainder of their lives. It is for this reason that I am so grateful for the cancer community's focus on survivorship care. With the help of the medical community and related organizations devoted specifically to outreach and advocacy efforts, cancer survivors have united to become a powerful voice and I am proud to be one of thousands of those voices.

## Chapter 4

## **COLORECTAL CANCER**

#### **Primary Prevention**

#### Goal 1:

To reduce the risk of developing colorectal cancer through healthful lifestyle choices including healthy eating habits and regular physical activity.

#### **Objective 1.1:**

Increase the proportion of persons who eat five or more servings of fruits and vegetables daily to 25.3% by 2017 (Tennessee baseline is 23.3%, Behavioral Risk Factors Surveillance System).

#### **Strategies:**

- Advocate for coverage of nutrition counseling as part of the comprehensive benefits packages under TennCare and private insurance carriers.
- Collaborate with successful health education providers such as University of Tennessee (UT) educators and Coordinated School Health Education to provide culturally appropriate nutrition education as it relates to cancer health education.
- Collaborate with A-B-C- 1-2-3 Healthy Kids in Tennessee, Eat Smart, Play Hard, United States Department of Agriculture (USDA), and Get FitTN programs to provide nutrition education to daycare enrolles, staff and parents.
- Increase public awareness of existing programming resources such as the American Cancer Society's Eat Right/Get Active, Body and Soul, Healthy Body, Healthy Spirit, as well as Great American Get Checked Program. Additionally, work with community based nutrition and physical activity programs of the University of Tennessee Extension and other credible sites such as Fruit andveggiesmatter.gov, girlshealth.gov, eatrightgetactive.org, choosemyplate.gov and nutrition.gov.
- Collaborate with state nutrition programs to ensure appropriate funding for nutrition education across the state.
- Provide easy links to reputable websites on our Tennessee Cancer Coalition (TC2) website.

#### **Objective 1.2:**

Decrease the proportions of adults who report no sustained physical activity to 27% by 2017. Current BRFSS reports a rate of 31% in 2009.

- Encourage employers to support employees' physical activity such as wellness programs that include workout facilities, workout credits, and incentives for increasing exercise, fitness breaks, and access to available built environments for physical activity.
- Support existing stage and community-based physical activity initiatives such as University of Tennessee's physical activity programs. Some examples of programs include Walk Across Tennessee Program, Tai Chi, Master Your Body, and Get Fit TN.
- Participate in the development of new physical activity initiatives both state and community based as appropriate.
- Promote culturally appropriate physical fitness educational programs with particular focus on reaching the underserved and at risk populations.

#### **Early Detection**

#### Goal 2:

Reduce colorectal cancer (CRC) mortality through screening and early detection. Colorectal cancer is the 4th leading cause of cancer incidence in Tennessee and the second leading cause of cancer-related deaths among Tennesseans.

#### **Objective 2.1:**

By 2017, increase by 25% the proportion of Tennesseeans, age 50 and older, who had a blood stool test within the past two years. Increase the public knowledge of colorectal cancer risk factors, symptoms, screening recommendations and options. The baseline is 20.1% of individuals state they have had a blood stool test in the last two years (BRFSS 2010), by 2017 increase this to 25.1% per BRFSS data.

#### Strategies:

- Utilize state CRC mortality data to target counties or regions with rates of colorectal cancer mortality higher than the national average. Collaborate with successful and comprehensive health education providers such as county University of Tennessee Extension (UT) educators, regional health councils, and professional organizations.
- Develop, implement, disseminate and evaluate cancer prevention and screening programs, with particular focus on reaching the Medicare and underserved populations.
- Participate in the development of partnerships between community education organizations and the cancer centers across the state as appropriate.
- Collaborate with work sites to promote CRC early detection and screening initiatives.
- Support community, state and national agendas for increasing awareness of CRC issues.
- Utilize established and evaluated messages and marketing materials from national organizations to promote CRC screening and early detection.
- Advocate for grassroots fundraising in each community to help fund screenings where they live.
- Replicate evidence-based public colorectal cancer education interventions statewide using the train-the-trainer sessions.

#### **Objective 2.2:**

Increase the number of primary care providers by 50% who recommend CRC screening to their high risk and/or adult patients over 50 years of age by 2017 through conducting one education session in each of the TC2 regions by June 30, 2017.

- In partnership with professional organizations, offer primary health care providers continuing education courses focusing on CRC screening recommendations, evidence-based best practice strategies and skills for communicating with patients in a culturally sensitive manner that takes into consideration the patient's health literacy level.
- Through TC2 website direct healthcare professionals to online continuing medical education opportunities focusing on CRC as well as national researche based screening guidelines.
- Utilize state CRC mortality data to identify counties or regions with rates of CRC mortality higher than the national average. Provide outreach to healthcare professionals in that county/region with educational programs that focus on clarifying and promoting understanding of current screening guidelines.
- Random survey conducted through professional organizations of health providers regarding CRC screening practices.

#### **Objective 2.3:**

By June 30, 2017, increase access to routine colorectal screenings and early detection for those age 50 and older, uninsured, underinsured Tennesseans' access to routine colorectal screenings and early detection by 50%.

#### Strategies:

- Use the Tennessee Breast and Cervical Screening Program as a model for the promotion and development of a CRC early detection and screening program targeting low income and medically underserved Tennesseans.
- Work with other advocacy organizations to educate and encourage the Tennessee State Legislature to increase funding for CRC control.
- Engage state-based health insurers in a dialogue to discuss methods to increase CRC screening rates among their insured populations.
- Promote and encourage local grass roots local initiatives to help fund the uninsured and underinsured in need of CRC screenings (Undy 500, Skivy Scoot).
- Increase utilization and awareness of genetic counseling for families with high risk CRC and primary care providers (PCP) awareness of genetic counseling.

## **A Couples Journey**



I've never been a big doctor guy. Growing up on a farm, cuts, colds and any number of aches and pains were just something you dealt with until they were 'all better'. But when my wife Nan asked me to feel a knot in her neck in April of 2008, I immediately scheduled an appointment for her. Three weeks later, after visits with an otolaryngologist (ENT), oncologist and radiologist, she began 8 months of chemo and radiation treatments for Hodgkin's Lymphoma. We were told that if she could get through the treatments, if we had insurance, she would be fine and we'd be ok financially. We have insurance,

but the bills started coming in for our 20% along with all our regular monthly bills. It became difficult to keep track of everything.

Eventually we got behind with the utility bills in order to cover the medical bills! We made it through and in October Nan finished up the last of her radiation treatments and was cancer free...she was anyway.

From a routine colonoscopy in November I was diagnosed with colon cancer. After the shock, we prepared ourselves for another bout with cancer...and bills. Thankfully I was diagnosed at Stage 1, making surgery the only needed treatment. Lying in the hospital after having nearly a foot of my colon removed, I was overwhelmed with the financial burden that comes with cancer. We had insurance, but between the two of us we could have bought a pretty nice car with the out-of-pocket expenses! So, in my morphine-induced haze, I thought if there was a way to take care of a utility bill for a month or two that we could take one less bill off the plate of someone fighting to simply stay alive.

I became a national board member of the Colon Cancer Alliance and together we created the Blue Note Fund. In my line of work, music production and songwriting, blue notes are the ones used to create emotion. Nothing is more emotional than cancer! In its first year of existence, the Blue Note Fund helped 400 families. Nan and I are both cancer free four years later and now realize the gifts that come with cancer - the gifts of appreciation for second chances, new life missions and most importantly, the gifts that come from giving.

## Chapter 5

## DISPARITIES

#### **Definition:**

The National Cancer Institute defines cancer health disparities as adverse differences in incidence, prevalence, mortality, cancer survivorship, and the burden of cancer or related health conditions that exist among specific population groups in the United States<sup>1</sup>. Nationally, during the period 2005-2009, Tennessee ranks 19th in cancer incidence and 3rd with the highest in cancer deaths when all races and sexes are combined<sup>2</sup>. Many factors contribute to the complexity of the disparate populations with ranks and ratings varying by race, ethnicity, geography, gender, age, and socioeconomic status. Some differences in rates are known, but the identity of specific factors that cause disparities and how these factors are interrelated is complex and poorly understood. Viewing cancer as a community health issue can lead to greater involvement in local implementation of this Plan. Communities across the state can identify themselves using the characteristics that define the disparities they suffer (e.g., race and place). Public involvement in cancer issues will lead to more engagement of communities with their health systems and patients with their providers to improve cancer action and outcomes as defined in the state Plan.

#### Goal 1:

Educate Tennesseans by conducting at least one presentation regarding regional disparities in each of the Tennessee Cancer Coalition (TC2) regions by June 30, 2017.

#### **Objective 1.1:**

To understand the dynamics of cancer-related health disparities in Tennessee.

#### **Strategies:**

- Prepare a report that identifies populations across the state that suffer from cancer disparities using the steps in the continuum of cancer care as a framework.
- Assemble interdisciplinary teams of professional and community representatives in each region to further investigate and describe Tennessee's cancer-related health disparities.
- Disseminate information about regional cancer-related health disparities.
- Convene meetings of health providers and communities to discuss specific population-based cancer disparities, best practices and resource tools available for stakeholders working in Tennessee to reduce and eliminate cancer morbidity and mortality.

#### **Objective 1.2:**

To strengthen a culture of collaborations to reduce cancer-related health disparities.

- Use the Intercultural Cancer Council's "Cultural Competence in Cancer Care: A Health Care Professional's Passport" as the framework to define aspects of culture that influence cancer care outcomes for different populations in the state.
- Offer statewide and local cultural competency training opportunities for community leaders and health professionals serving populations which suffer from cancer-related disparities (e.g., African Americans, Appalachians, Hispanics, rural residents, the poor and uninsured) through regional work shops and online training.
- Increase awareness and utilization of existing tools and resources that impact cancer-related health disparities.

• Collaborate with currently funded health disparities programs throughout Tennessee to provide additional services and raise awareness.

#### **Objective 1.3:**

To address public policy as it relates to Tennessee's cancer-related health disparities

#### **Strategies:**

- Review current health policies as they relate to Tennessee's cancer related health disparities
- Disseminate findings, recommendations, and best practices to Tennessee stakeholders.
- Collaborate with partners across the state to advocate for more effective public policy addressing cancer-related health disparities.

#### **References:**

- 1. National Cancer Institute, fact Sheet: Cancer Health Disparities 3/11/08
- 2. Cancer in Tennessee 2005-2008. Office of Cancer Surveillance, Tennessee Department of Health



## Chapter 6

## **GENETIC TESTING for HEREDITARY CANCER**

#### **Definition:**

Hereditary cancer risk assessment and genetic testing is now standard of care for certain families that may require aggressive medical management for early detection and prevention of cancer. Approximately 5-10% of cancers are caused by a damaged gene that is being passed in the family. Accurate identification of individuals who carry these "deleterious" genetic mutations will result in overall decreased morbidity and mortality from cancer. Genetic testing is recommended in a setting where pre- and post-test genetic counseling is provided to ensure that (1) patients receive appropriate testing, (2) results are interpreted accurately, and (3) undue financial burden is avoided for the patient and third party payers.

#### Goal 1:

Educate healthcare providers and consumers about the availability of genetic counseling and testing for hereditary cancer and improve appropriate utilization and reimbursement for services available in TN.

#### **Objective 1.1:**

Improve provider and patient education regarding benefits and limitations of hereditary cancer-risk assessment and genetic testing.

#### Strategies:

- Add hereditary genetic testing information to the Tennessee Cancer Coalition (TC2) website.
- Create a webinar for healthcare professionals to educate them regarding the purpose of genetic testing and alert them to genetics information and resources available in TN.
- Construct and distribute a genetics referral guide to mail to healthcare providers in TN to help them recognize appropriate referrals.
- Create a patient and provider information sheet to be distributed at TC2 meetings and at the TC2 information table during healthcare events.
- Seek out and utilize radio and television opportunities for educating the public about genetic counseling and testing for hereditary cancer.

#### **Objective 1.2:**

Promote utilization of genetics professionals in provision of genetics services to increase the appropriate use of genetic testing, thus avoiding emotional, physical and financial harm to patients.

#### Strategies:

- Include patient interviews, vignettes and stories in TC2 materials and on the website to illustrate possible harm to patients when genetics professionals are not utilized.
- Discuss importance of pre- and post-test genetic counseling in the proposed healthcare provider webinar as well as radio and television educational opportunities.

#### **Objective 1.3:**

Increase access to genetic testing for hereditary cancer and to licensed genetic counselors or individuals trained in cancer genetics. The American College of Surgeons 2012 Commission on Cancer Accreditation (CoC) standards

requires that "genetic risk assessment, genetic counseling and testing services are provided to patients either on site or by referral, by a qualified genetics professional." The National Accreditation Program for Breast Centers (NAPBC), various medical genetics organizations, and insurance company guidelines also require that genetic risk assessment, counseling and testing be provided by trained genetics professionals.

#### Strategies:

- Provide a current listing of cancer genetics service providers on the TC2 website. Include a listing of professional societies that provide policy statements regarding the use of genetics-trained professionals for provision of hereditary cancer-risk assessment and genetic testing.
- Link the National Society of Genetic Counselors and Tennessee Genetic Counseling Association websites to the TC2 website.
- Work with the TN legislature to gain better support for billing and reimbursement of genetic counselors in TN.
- Work with the TN legislature to improve TennCare coverage of genetic testing for appropriate patients.

## Vickie Leonard Proclaims: Therefore I Am a Previvor!!!!!



My previvor journey began four years ago, when I started working in an oncology office, of all places. Every day I was surrounded by patients with cancer and I started thinking about my own family history and what could be lurking in the background for me in my future. I was very fortunate because our office has a genetic counselor and so I started talking with her about my family history of breast cancer and wondered if I would be a good candidate for genetic testing. After discussing the cancer on both sides of my family we decided yes, this was something I needed to do. I was a single mom of a 10 year old boy at the time and having lost my mom

to breast cancer at the age of 11, I didn't want to take the chance of that ever happening to my son, especially if I could prevent it.

I had blood drawn for BRCA genetic testing to see if I carried the gene for breast and ovarian cancer and it turns out I did! This meant that I had up to a 90% risk of developing breast cancer. I then began making plans and speaking to family members, friends and even some of our own patients about my results. Shortly after finding out I carried this genetic mutation, my older sister chose to do testing and she is a BRCA1 mutation carrier as well.

About a year ago, I chose to have a double mastectomy and I am doing very well. Yes, it has been a long process to recreate what I had, but it has been worth it. I can still do the same things that I was able to do prior to the surgery and I don't have to worry as much about developing breast cancer. My risk has gone down to less than 5%. I now advocate along side our genetic counselor on the benefits of knowing your family history and being tested. We can't prevent all bad things in life but if there is an opportunity to, I will certainly try. My son is now 15 years old and because I was proactive about my family history, he will have a much better chance of having his mom around for many years to come.

## Chapter 7

## **HEALTH LITERACY**

#### **Definition:**

Health literacy is the degree to which individuals can obtain, communicate, process, and understand the basic health information and services they need to make appropriate health decisions. However, literacy goes beyond the individual. Literacy depends upon the skills, preferences, and expectations of health information and health care providers, doctors, nurses, administrators, home health workers, the media and others.

#### Limited health literacy affects people's ability:

- To navigate the healthcare system, including filling out complex forms and locating providers and services;
- To adopt healthy and preventive health care behaviors, such as using sunscreen and healthy eating;
- To act on important health recommendations, such as cancer screenings.

In 2003, the most recent year data is available, twelve percent (12%) of people were considered proficient in health literacy<sup>1</sup>. This means that 88% of people may lack the skills needed to manage their health and prevent disease. Limited health literacy is associated with increased preventable hospital visits and higher use of the emergency room, and has been found to be even greater with older adults, minorities and the poor<sup>2</sup>.

#### Goal 1:

To promote activities related to issues of health literacy within the Tennessee Cancer Coalition (TC2).

#### **Objective 1.1:**

To ensure the products and programs of the TC2 are developed and assessed in respect to appropriate health literacy.

#### Strategies:

- Adopt a health literacy standard for communications and products created and disseminated by TC2 and subsequently implement a health literacy review process.
- Encourage TC2 members to participate in health literacy training.
- Provide health literacy resources to the TC2 membership.

#### Goal 2:

To improve health literacy in the state of Tennessee.

#### **Objective 2.1:**

To impact health literacy specific to cancer prevention, control, treatment and survivorship within the state of Tennessee beyond the coalition membership.

- Identify and raise awareness of health care professionals to best practices and resources that address the issues of health literacy (i.e., teach-back, using living room language with patients.)
- Engage the media as a mechanism to increase professional and public awareness of health literacy as an issue. Assist the media in communicating and translating cancer information to the public.

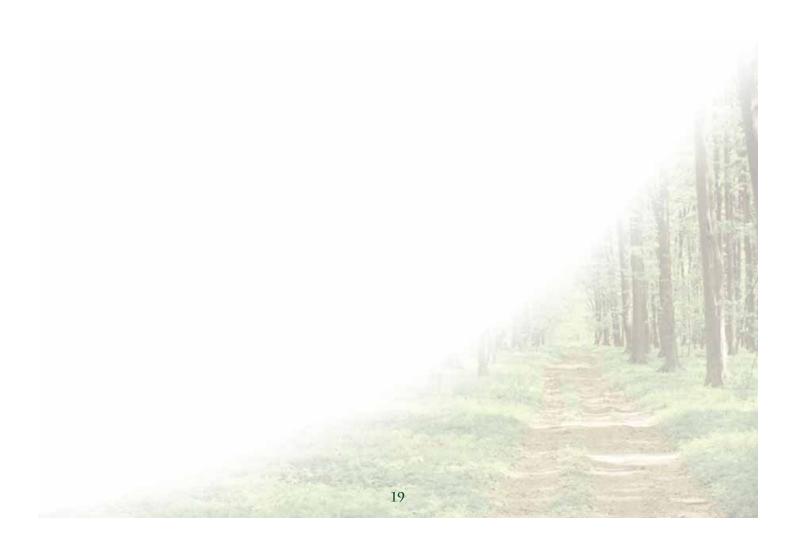
- Develop and provide professional education on TC2 website related to health literacy issues in TN including how to evaluate the quality and reliability of health information that is provided by websites and other resources related to cancer information.
- Identify and develop linkages to community-based organizations and promote ways they can help improve health literacy among the people they serve. (i.e., adult education programs, parent resource centers, etc.)

#### **References:**

1. American Medical Association Foundation,

http://www.ama-assn.org/ama/pub/about-ama/ama-foundation/our-programs/public-health/health-literacy-program.page

2. United States Department of Health and Human Services; www.hhs.gov/



## Chapter 8

## **HEMATOLOGICAL CANCERS**

#### **Definition:**

Hematological cancers are also referred to as blood cancers.

These cancers begin in blood-forming tissue, such as the bone marrow, or in the cells of the immune system. Examples of hematologic cancer are leukemia, lymphoma, and multiple myeloma.

#### Goal:

To reduce morbidity and mortality associated with hematologic malignancies, myeloproliferative neoplasms and myelodysplasia.

#### **Objective 1.1:**

Increase awareness of hematologic malignancies by invoking a statewide effort to help interpret the complexities of bone marrow and lymphatic cancers.

#### **Strategies:**

- Collaborate with Leukemia Lymphoma Society (LLS), the Multiple Myeloma Foundation (MMF), the Myelodysplastic Syndrome Foundation, the Minnie Pearl Foundation and other partners, to develop and distribute appropriate informational material to primary care physicians and extenders, nurses, and patients.
- Further publicize current activities organized in the State of Tennessee to promote awareness of hematologic malignancies.
- Develop a continuing medical education program for primary care providers with a faculty of medical, surgical and radiation oncologists, to stress the practical screening tools and to promote guidance for referral to oncology care.
  - o Promote early recognition of myelodysplasia a neoplastic disorder expected to have increased incidence in the coming decade.
  - o Advocate for thoughtful blood transfusion practices and care to protect from iron-overload syndromes.
- Engage Tennessee medical students to further involvement in partner fundraising events, and commence a reciprocal plan for involvement of medical students in further work to promote awareness of hematologic malignancies.

#### **Objective 1.2:**

Increase funding for leukemia-focused clinical research and patient care.

#### **Strategies:**

- Expand current fundraising campaigns through state partners.
- Promote advocacy for funding of Tennessee-based clinical research programs.
- Encourage of expansion of funding to cover insurance gaps for patients with acute leukemia through advocacy with partners patients' assistance programs as well as state-based insurers.
- Formalize a state-driven hematologic malignancy tissue repository for further research.

#### **Objective 1.3:**

Improve access to clinical trials for patients with hematologic malignancies.

#### **Strategies:**

- Consolidate, collate and maintain the clinical trial offerings from Tennessee-based clinical researchers into a web-based tool run by the Tennessee Cancer Coalition (TC2).
- Publish fact sheet for patients on the reality of clinical trials, for all of cancer care, in the 21st Century.
- Engage partners to serve as referral network for clinical trials in Tennessee.

#### **Resource:**

1. National Cancer Institute; http://www.cancer.gov/cancertopics/types/cancersbodylocation/hematologic



## Chapter 9

## LUNG CANCER

Lung cancer represents the number one cause of cancer death by far, for both men and women in Tennessee, and the number of deaths from lung cancer exceed that of female breast, colorectal, prostate, and pancreas, combined. Nationwide, approximately 160,000 people will die from this disease annually. Any attempt to reduce the state burden of cancer must prioritize reducing the impact of this disease. Fortunately, new discoveries in lung cancer give us specific leads on how to accomplish this. In this plan, we have targeted 3 general areas: primary prevention, early detection, and genetically informed therapy.

#### **Primary Prevention:**

While approximately 10,000 to 15,000 patients nationwide die from lung cancer who have no known environmental exposure, the majority of patients with lung cancer have a significant smoking history, either past or present. Thus the impact of preventable addiction and exposure to tobacco smoke remains the first priority in this plan. In addition, it is now clear that high environmental levels of radon are prevalent in Tennessee. Encouraging testing and remediation of radon exposure should also be a priority.

#### Goal 1:

Reduce the incidence of lung cancer by decreasing tobacco use reported on BRFSS from 23% (2011) to 18% by 2017 and limiting exposure to known carcinogens including secondhand smoke and radon gas.

#### **Objective 1.1:**

Support the reduction of tobacco use in Tennessee.

#### Strategies:

• See Tobacco-Related Cancers Section.

#### **Objective 1.2:**

Increase the proportion of persons to 100% who are covered by the State's indoor worksite policy to prohibit smoking, called the Tennessee Non-smokers Protection Act of 2007.

#### Strategies:

• Advocate for the protection and expansion of the Tennessee Non-smokers Protection Act 2007.

#### **Objective 1.3:**

Reduce the incidence of lung cancer associated with radon gas exposure by reducing the number of homes with radon levels higher than the Environmental Protection Agency (EPA) has deemed safe (4 picocuries per liter, or pCi/L, or higher).

- Work in conjunction with the Tennessee Department of Environment and Conservation (TDEC) using the EPA's zone classification system, to educate homeowners throughout the state on the importance of testing their homes for radon gas levels.
- Promote access to radon testing kits through the Tennessee Radon Program as administered through the Office of Environmental Assistance.
- Provide a complete listing of certified measurement and mitigation professionals on the Tennessee Cancer Coalition (TC2) website.
- Advocate to mandate radon testing for all residential real estate transactions in the Tennessee.

#### **Early Detection:**

The majority of lung cancers are detected when they are in advanced, incurable stages. Until recently, there was no data to support the application of any screening procedure for the early detection of lung cancer, as is universal for breast, colorectal, prostate and cervical cancers. With the recent publication of the National Lung Screening Trial, in which a 20% reduction in lung cancer mortality was observed with the application of annual low dose, non-contrast screening computerized tomography (CT) scans compared to chest x-rays in high risk populations, and in fact a reduction in all-cause mortality in this population as well, population screening has become a reasonable goal.

#### Goal 2:

Reduce lung cancer mortality by 5% through the use of low-dose CT (LDCT) screening and early detection by the year 2017.

#### **Objective 2.1:**

Promote LDCT screening of Tennesseans who are at high risk (55 years or older with a 30 year pack history or 50 years or older with a 20 year pack history and one additional risk factor) as reported by the National Lung Screening Trial (NLST).

#### Strategies:

- Educate the public on their risk factors and what to do if they are at risk.
- Identify at-risk populations throughout Tennessee and provide tailored information.
- Educate PCPs of the risks associated with LDCT and encourage best practices among cancer centers/hospitals.
- Provide comprehensive listing of all sites throughout the state that are following best practices for lung cancer screening via the TC2 and the Department of Health websites

#### **Objective 2.2:**

Increase access to LDCT screening for those at high risk.

#### Strategies:

- Provide mobile screenings in areas with high-risk populations through the Tennessee Department of Health and US Department of Energy.
- Advocate for policy to ensure that TennCare covers lung cancer screenings and any follow-up care that may result. Identify potential funding for the underinsured including partnering with tertiary care centers to establish low-cost lung cancer clinics.
- Advocate to increase the tobacco tax in Tennessee and mandate that a portion goes to pay for screenings, diagnosis and treatment for those at high risk.
- Recognize medical centers and institutions providing low-cost LDCT scans via TC2 website.

#### **Objective 2.3:**

Ensure that best practices for LDCT screening and follow-up care are utilized at hospitals, cancer centers and imaging centers throughout the state.

- Utilize scan and evaluation of detected nodules in accordance with guidelines established by the National Lung Screening Trial (NLST). National Comprehensive Cancer Network (NCCN), The American Thoracic Society (ATS) and The American College of Chest Physicians (ACCP)
- TC2 and Department of Health promote agreed-upon best practices and recommendations for screening per NLST.

#### **Objective 2.4:**

Document outcomes of screening in Tennessee by establishing a Tennessee Registry of CT-screened patients to determine real-world costs and benefits.

#### Strategies:

- Institute a state-wide repository for LDCT scan sharing by radiologists.
- Encourage Radiologists to register all LDCT scans for lung cancer screening.
- Develop protocols for use in evaluating scan results. Establish radiation settings for LDCT scans.

#### **Objective 2.5:**

Legislate for a framework of funding for lung cancer screening. Advocate for 3rd party coverage.

#### Genetically informed therapeutic decision-making

Molecular analysis of lung cancer tumors in the last decade has uncovered at least two specific acquired abnormalities that make a major difference in the type and outcomes of treatments for this disease. Very clear evidence from multiple large randomized trials shows the superiority of choosing therapy based on the genetic abnormalities present in the tumor, and particularly in the epidermal growth factor receptor (EGFR) for erlotinib, the Anaplastic Lymphoma Kinase gene (ALK) for crizotinib. These therapies are also oral and less toxic than standard therapies for lung cancer, making them more convenient, more tolerable, and more effective. Analysis of these lesions in advanced non-small cell lung cancer can thus no longer be considered a research activity, and should be considered standard of care. However genetic testing is not uniformly offered to all patients in the state.

#### Goal 3:

Educate and inform individuals about genetic testing by hosting one informational session in each of the TC2 regions by 2017 by partnering with the TC2 Genetics Committee.

#### **Objective 3.1:**

Advocate for universal genetic testing of patients with advanced non-small cell lung cancer, and evidence-based selection of therapies based on these results.

#### Strategies:

• Increase the number of patients with advanced disease undergoing appropriate genetic testing from 40% to 80% in the three major metropolitan Areas. Advocate adequate third party payer assistance for genetic testing.

#### **Objective 3.2:**

Legislate for oral chemotherapy parity so that third-party reimbursement for oral chemotherapy regimens is equivalent to that currently available for intravenously administered chemotherapy drugs.

- Partner with American Cancer Society to insure this measure becomes law.
- Partner with Tennessee Cancer Coalition (TC2) Advocacy Committee.

## **Teri Simon's Story**



The course of my life changed completely on December 2, 2009, when my pulmonologist called and told me, "Teri, it's adenocarcinoma. It's lung cancer." I said, "Well, that's just wrong!" And he said, "I know!"

For almost a month, I had been undergoing medical testing after a tumor, believed to be a retinal melanoma, was found in my left eye. The CT scan looked the same as the chest x-ray, pneumonia, so the bronchoscopy was ordered, and in one short sentence, I got a life sentence.

I have participated in a successful clinical trial, an unsuccessful clinical trial, undergone a radiological stereotactic procedure, and some intense chemotherapy. My metastases includes both of my eyes, liver, bones, brain, and other lung. I believe that the healthy lifestyle I engaged in prior to my diagnosis has kept me strong and helped manage this disease.

Today, over half of new cases of lung cancers diagnosed in this country are in female patients who never smoked. It is far less important to ask "why" someone has lung cancer than it is to ask "What can be done about it?" My hope is that by sharing my story and working together, we can make that change.

Teri lost her battle in December 2012. She remains in our thoughts.

## Chapter 10

## MELANOMA & NON-MELANOMA SKIN CANCERS

#### Goal 1:

Decrease the incidence and improve outcome of melanoma and non-melanoma skin cancers by increasing education regarding prevention, early detection, and treatment.

#### **Objective 1.1:**

By 2017 develop at least one public education program addressing risk factors for melanoma and non-melanoma skin cancers, as well as comprehensive prevention strategies and early detection methods in each of the TC2 regions.

#### Strategies:

- Collaborate with the Tennessee public school system and the media to implement a sun safety curriculum for students.
- Develop partnerships with agencies that offer established programs on awareness, prevention, and early detection of melanoma and non-melanoma skin cancer to augment public health education through the use of illustrative teaching materials and utilization of evidence-based programs and media campaigns such as "Slip, Slap, Slop" (American Cancer Society).
- Provide specific information on the risk of developing melanoma and non-melanoma skin cancers associated with indoor tanning (i.e., tanning bed use).
- Explore extramural funding opportunities like the American Academy of Dermatology (AAD) Shade Structure grant program for use in non-profit organizations and schools.

#### **Objective 1.2:**

By 2017 develop at least one no-cost or low-cost screening for melanoma and non-melanoma skin cancer in each of the TC2 regions.

- Promote participation by dermatologists and clinicians across Tennessee in the AAD's Melanoma Monday Screening campaign, which encourages Academy members to conduct free skin cancer screenings during May (Skin Cancer Awareness Month).
- Collaborate with state/local organizations and community agencies to hold free screenings.
- Because studies show that men over 50 experience the highest incidence of advanced melanoma, target this demographic by providing educational materials on early detection of melanoma and non-melanoma skin cancer to gyms, senior centers, country clubs, nursing home workers, and family members of nursing home patients.
- Implement media and community-based programs to promote and educate the public on the benefits of sun protection, utilize existing programs like "Go Sun Smart" (NCI) and the SunWise Program (Environmental Protection Agency-EPA).
- Focus efforts on occupational groups that are at increased risk of ultra violet radiation (UVR) exposure due to time spent working outdoors (i.e., farmers, construction workers, fishermen, landscapers, and public works employees).
- Work with health care providers to promote education and counseling regarding sun protection to patients.
- Seek sunscreen sample donations from manufacturers to distribute at local outdoor activities such as sporting events, festivals, amusement parks, and fairs.

#### **Objective 4:**

Reduce the proportion of Tennessee adults who engage in indoor tanning to less than 5% by 2017. Tanning beds were recently linked to melanoma and classified as "carcinogenic to humans" by the International Agency for Research on Cancer (IARC) [El Ghissassi F et al.; A review of human carcinogens- part D: radiation. Lancet Oncol. 2009 Aug;10(8):751-2]. Tennessee legislation bans indoor tanning for youth under the age of 14 and prohibits youth between the ages of 14 and 18 from indoor tanning without written parental consent, [Tenn. Code Ann. §68-117-104].

#### Strategies:

- Utilize locally-based programs and policies to promote the dangers of indoor tanning at health clubs, workplaces, churches, and community events.
- Implement anti-tanning messages into sun safety school curricula detailing current statistics and risk factors.
- Work with media to create public service announcements featuring melanoma survivors (particularly young women, since recent studies show rising melanoma incidence in the 15-39 age group) to showcase the importance of prevention and early detection.

## **Survivor Story**



"We better keep an eye on that mole", PCP to Dick Boland, Melanoma Survivor, 1994

Many people refer to their diagnosis of cancer and the subsequent events that follow as their 'journey". To me it's more like a series of train wrecks. It was late 1994. During an annual physical my Primary Care Physician spotted a mole on my left side. He said, "We better keep an eye on that mole." To this day, I do not understand why I did not insist we do something about it then. In February the following year a dermatologist diagnosed melanoma. Surgery followed. The protocol was alternating PET and CAT scans every three months for the next two years and then chest X-rays for the next three

years. Five years from the date of surgery I was declared cancer free- it was time to break out the champagne.

The next six years were uneventful as far as the cancer was concerned. In October 2006 I felt a lump in my left breast. It felt like a small pecan (with the shell on) about a half inch under the skin. I contacted my cancer doctor and the diagnosis was male breast cancer. A few days before my surgery I got a call- "... it's not breast cancer, your melanoma is back." The treatment was the same, cut it out.

After the November 2006 surgery I changed my strategy. I started a search for doctors and institutions that were specifically in existence to treat melanoma. I selected a team at Vanderbilt in Nashville, TN.

July 2007- I got the news that my PET scans showed the cancer was back. Another surgery followed and for the first time the melanoma had spread to my lymph nodes in my left underarm.

My cancer team decided the best course of action was a clinical trial. The clinical trial was completed in December 2007.

Today I am classified as a "NED", no evidence of disease.

My advice about cancer- be aggressive in your treatment. Find a team that specializes in treating your specific cancer- you are in the fight of, and for, your life.

## Chapter 11

## PALLIATIVE CANCER CARE

#### **Definition:**

The Health Resources and Services Administration has defined palliative care as a patient-and-family-centered care that optimizes quality of life by active participation, prevention, and treatment of suffering. It emphasizes the use of an interdisciplinary team approach throughout the continuum of care, placing critical importance on building respectful and trusting relationships. Moreover, the provision of palliative care is not dependent upon prognosis and can and should be used alongside curative or life-prolonging treatments. Palliative care addresses physical, intellectual, emotional, social, and spiritual needs for patients of all ages and their loved ones, facilitating patient autonomy, access to information and choice.

#### Goal 1:

To increase the awareness of, accessibility to and value of palliative care programs both in institutions who have palliative care programs and those who do not through education, outreach, and positive performance. Provide coordinated care through an interdisciplinary team approach. In providing palliative care programs, a large percentage of hospice patients will be identified earlier in their eligibility window, and will potentially have an extended time frame to take advantage of these valuable services.

#### **Objective 1.1:**

To increase individual and community awareness of the meaning of palliative care and how it differs from hospice care.

#### Strategies:

- To inform individuals about their right to discuss palliative care with healthcare providers and to request palliative care.
- Empower patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.

#### **Objective 1.2:**

Increase access to and awareness of palliative and hospice care.

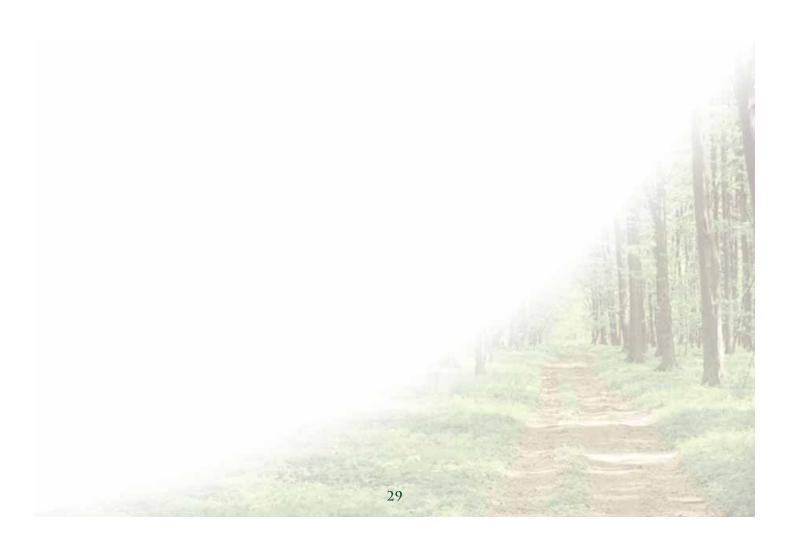
#### **Strategies:**

- Work in areas with already established palliative care programs to assure that care is equitable and accessible in a collaborative approach. This can be accomplished by organizing services across all levels of care, educating the general public, caregivers and policymakers. By increasing awareness, patients can be screened earlier so that recommendations can be made for hospice care, when appropriate.
- Education of patients, caregivers and health care providers of the role of palliative vs. hospice care for those with chronic, potentially life-limiting diagnoses through in services, pamphlets, public service announcements and frequent reinforcement, social media and the internet.

#### **Objective 1.3:**

All patients who are experiencing complex, chronic health issues related to cancers that are affecting the quality of life should be offered palliative care as an option.

- It is vital to offer each patient the option of palliative care. Patients have the right to all resources that help maximize their quality of life. Create programs/order sets that require as per policy that potential palliative care population are identified upon admission to the hospital.
- Palliative care should be addressed throughout the patient's cancer journey as an additional support for symptom management, psychosocial support and holistic, comprehensive care for patients and families.
- Create a screening tool upon admission to flag "at risk" patients for referrals based on disease characteristics, hospital utilizations and symptom management issues to identify those who would most benefit from a palliative care consult.
- Provide access to palliative and hospice care that is responsive to the patient and family 24 hours per day, 7 days a week.



## Chapter 12

## **PATIENT NAVIGATION**

#### **Definition:**

Patient navigation in cancer care refers to individualized assistance offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality medical and psychosocial care. Cancer patient navigation can be provided by culturally competent professionals (nurses, social workers) or peers (lay) from pre-diagnosis through all phases of the cancer experience. Cancer patient navigation can and should take on different forms in different communities as dictated by the needs of patients, their families, and their communities within the context of the health care environment<sup>1</sup>.

#### Goal 1:

Increase awareness and utilization of patient navigation systems to facilitate optimum cancer care for all Tennesseans.

#### Goal 2:

Develop a health care provider resource guide on navigation services located in healthcare facilities and cancer treatment centers.

#### **Objective 2.1:**

Disseminate resource guide of healthcare facilities and cancer treatment centers that provide navigation services to 10% of Tennesseans by June 30, 2017.

#### Goal 3:

Develop a peer resource guide on navigation services located in the healthcare facilities and cancer treatment centers.

#### **Objective 3.1:**

By 2017, increase Tennessee Cancer Coalition website navigation resource materials for primary care providers, survivors, and Tennesseans by 15%.

#### **Strategies:**

- Establish state wide resource committee of navigators to plan and implement objectives as well as provide opportunity for networking and education.
- Facilitate educational opportunities for healthcare providers to learn about American College of Surgeons, C-Change, Centers for Disease Control (CDC) and other best practice and evidence-based guidelines and recommendations for patient navigation processes.
- Provide navigation "best practice" information on Tennessee Cancer Coaliton (TC2) website.
- Identify and disseminate a list of existing navigation models and navigator roles throughout the state.
- Identify and provide list of existing Commission on Cancer (CoC) accredited cancer programs on the TC2 website.
- Develop and implement community education programs about the role of patient navigators.
- Facilitate and support navigation speaker(s) at TC2 annual Summit.

#### **References:**

1. C-Change; http://c-changetogether.org/

## Chapter 13

## **PRIMARY PREVENTION**

Scientific evidence suggests that an estimated 75%-80% of cancer cases and deaths in the US are related to environmental factors which include behavioral choices that are potentially modifiable. These environmental factors include tobacco use, poor nutrition, physical inactivity, obesity, certain infectious agents, certain medical treatments, excessive sun exposure, and exposures to carcinogens (cancer-causing agents) that exist as pollutants in our air, food, water, and soil<sup>1</sup>.

Being obese or overweight has been linked to cancers of the colon, rectum, esophagus, kidney, endometrium, postmenopausal breast, thyroid, liver, gallbladder, pancreas, stomach and prostate as well as non-Hodgkin's lymphoma and multiple myeloma. One-third of the cancer deaths in the United States are due to poor nutrition and lack of physical activity. Poor nutrition habits start in youth and often continue into adulthood, increasing a person's risk for malnutrition, obesity, cancer and other serious chronic health conditions<sup>1</sup>.

#### **Definition:**

To prevent the occurrence of cancer through healthy lifestyle choices, through control of environmental health and societal risk factors can be defined as primary prevention of cancer.

#### Goal 1:

To raise awareness of actions that can be taken by individuals, communities, government, or other groups to prevent the occurrence of cancer through healthy lifestyle choices.

#### **Objective 1.1:**

Increase the proportion of persons aged two and older who eat five servings of fruits and vegetables daily to 25.3%, by 2017. Tennessee baseline consumption of fruits and vegetables five or more times daily is 23.3%, versus the 23.5% nationwide baseline consumption, Behavioral Risk Factor Surveillance Survey (BRFSS), 2009].

#### Strategies:

- Advocate for food desert relief legislation to improve accessibility to affordable healthy foods in areas that lack access.
- Use existing social marketing campaigns (5 A Day, etc.) to promote healthy eating.
- Implement effective community-based programs statewide that address one or more of the Dietary Guidelines for Americans.
- Collaborate with public schools to plan and implement programs to increase healthy eating using the CDC's School Health Index and collaborate on implementing comprehensive school health programs.
- Promote the adoption of state standards for healthy eating in Child Care centers and school-age child care programs based on the Tennessee Office of School Readiness and Early Learning, Office of School-based Support Services.

#### **Objective 1.2:**

Increase the proportion of adults who engage at least 5 days per week, preferably daily, in sustained moderate physical activity for at least 30 minutes per day to 40% by 2017. Tennessee baseline for moderate intensity of physical activity is 36.0%. Tennessee baseline for vigorous intensity physical activity at least 20 minutes three or more days per week is 17.2%, [Behavioral Risk Factor Surveillance Survey (BRFSS), 2009].

#### Strategies:

- Engage companies to implement evidence-based worksite model programs statewide to promote physical activity.
- Implement effective community-based programs statewide that promote daily physical activity.
- Promote governmental, state, voluntary and local policies that promote daily physical activity.
- Expand worksites' and faith-based physical activity and weight management programs and help them establish nutrition guidelines for meetings and events.
- Ensure that adequate opportunities for safe physical activity are available (e.g. built environments, green spaces, community recreation facilities, walking trails and safe sidewalks).
- Advocate for Complete Streets legislation where streets are designed to enable safe access for all users. This may include bike lanes, sidewalks, bus lanes, frequent and safe crossing opportunities, and median islands.

#### **Objective 1.3:**

Increase the proportion of children who engage regularly, preferably daily, in sustained physical activity for at least 60 minutes per day to 60% by 2017. Tennessee baseline for physical activity 60 minutes per day on five or more days per week is 47.2%. [Tennessee Youth Risk Behavioral Survey, 2011].

#### **Objective 1.4:**

Decrease the proportion of adults who are overweight (body mass index of 25-29.9Kg/m2) to 30% by 2017. Tennessee baseline is 36.1% of adults reported being overweight and 31.7% of adults reported being obese (body mass index greater than or equal to 30Kg/m2). [Behavioral Risk Factor Surveillance Survey, 2010].

#### **Objective 1.5:**

Decrease the proportion of individuals in grades 9-12 who are clinically overweight (body mass index 25-29.9Kg/m2) to 10 % by 2017. Tennessee baseline is 17.1% of males and 17.5% females reported being overweight and 17.9% of males and 12.4% of females reported being obese (body mass index greater than or equal to 30Kg/m2) [Tennessee Youth Risk Behavioral Survey, 2011].

#### Strategies:

- Same as Objective 1.1 and 1.2.
- Encourage health care providers to routinely track body mass index and offer appropriate counseling and guidance to children and their families.
- Partner with school health advisory committees to educate key decision makers in the school setting on the benefits of a coordinated school health model approach and its link to academic achievement.
- Partner with school decision makers to increase the proportion of schools that eliminate unhealthy food and beverage options in cafeterias, vending machines, and other sources.
- Educate food service staff, teachers, and school administrators on the impact of obesity among children and ways to encourage healthy eating and increased physical activity.

#### **Environmental Pollutants**

Through surveillance and tracking, scientists have shown changing trends in cancer that sometimes are associated (this term would be preferred as this is the usual term used in epi studies) with the presence of certain environmental pollutants. This association does not rule out other causes, but does suggest that environmental factors may increase the risk for particular cancers. One environmental factor related to an increased risk of lung cancer is radon. Radon is a naturally occurring radioactive gas. Radon has no color, odor or taste and results from the decay of uranium, which is a radioactive element found naturally in the earth's crust.

There are no known health effects connected with brief exposure to radon. Breathing air with too much radon over a lifetime, however, increases a person's risk of getting lung cancer. The risk is increased even more for a smoker

exposed to radon. According to a report by the National Academy of Sciences, radon is estimated to cause about 21,000 lung cancer deaths per year. About 2,900 of these deaths occur among people who have never smoked. It is the second leading cause of lung cancer after smoking and the number-one leading cause of lung cancer among non-smokers<sup>2</sup>.

Testing for radon in the home is the only way of knowing if radon is present. The Tennessee Department of Environment and Conservation (TDEC) operates a statewide indoor radon program as part of the Office of Environmental Assistance emphasizing mitigation efforts for those homes that test higher than safe guidelines. The U.S. Environmental Protection Agency (EPA) has established 4 pCi/L as an action level in which one should initiate measures to reduce the amount of radon in a home<sup>3</sup>.

#### Goal 2:

By 2017, reduce Tennessean's population risks associated with environmental exposures to known or likely environmental risk factors for cancer through reduction of exposure to environmental hazards and risk factors.

#### **Objective 2.1:**

Increase the number of households tested for radon gas to 40,000 by June 2017. As of 2007, 28,306 home radon tests have been conducted [Tennessee Department of Health, Tennessee Radon Program, 2007].

#### **Objective 2.2:**

Increase the percentage of households initially testing high for radon gas that are mitigated through appropriate actions. As of 2007, 67% of homes had a radon level above the EPA recommended limit of 4pCi/L [Tennessee Department of Health, Tennessee Radon Program, 2007].

#### **Strategies:**

- Expand research into the risks associated with environmental and occupational exposures and promote strategies to reduce elevated exposures.
- Improve Tennesseans' understanding of the risks of exposures to environmental hazards and continue outreach efforts to promote the effective dissemination of information to Tennesseans.
- Partner with federal, state and local governments, businesses, and communities to reduce elevated exposures to known or likely environmental risk factors for cancer.
- Establish links on the Tennessee Cancer Coalition web site to information resources on cancer-related environmental exposures.

#### **References:**

1. American Cancer Society. Cancer Facts & Figures 2012. Atlanta: American Cancer Society; 2012.

2 Environmental Protection Agency. (2011) Radon Health Risks. Retrieved January 30, 2012 from http://www.epa.gov/radon/healthrisks.html

3.Tennessee Department of Environment and Conservation, Office of Environmental Assistance Radon Program(2012) Retrieved January 27, 2012 from www.tn.gov/environment/ea/radon

#### **Other references:**

Behavioral Risk Factor Surveillance System (BRFSS) (2010) Retrieved January 30, 2012 from http://health.state.tn.us/statistics/brfss.htm

Calle EE, Rodriguez C, Walker-Thurmond K, Thun MJ. Overweight, obesity, and mortality from cancer in a prospectively studied cohort of U.S. adults. New England Journal of Medicine; 2003(348): 1625-1638.

Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Data. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2009, 2010].

Fair AM, Montgomery K. Energy balance, physical activity, and cancer risk. Methods of Molecular Biology. 2009(472):57-88.

National Complete Streets Coalition. (2010). Complete Streets FAQ. Retrieved January 30, 2012 from http://www.completestreets.org/complete-streets-fundamentals/complete-streets-faq/

T.C.A. § 49-1-302(l).

The State Board of Education Office of the Commissioner Standards for Child Care Centers and School-Age Child Care Programs Chapter 0520-12-1-.12.

Tennessee Department of Environment and Conservation, Office of Environmental Assistance Radon Program Retrieved January 27, 2012 from http://health.state.tn.us/environmental/radon.htm

Youth Risk Behavior Survey Results (2011). Retrieved January 30, 2012 from

http://www.tn.gov/education/yrbs/11/index.shtml



# Chapter 14

## **PROSTATE CANCER**

### Goal 1:

To promote informed decision-making regarding issues associated with prostate cancer and prostate cancer screenings.

### **Objective 1.1:**

Identify disparities in prostate cancer incidence and mortality among population groups in Tennessee.

### Strategies:

- Regularly review data provided to the TC2 surveillance committee by the Tennessee Cancer Registry and/or obtained from the State Cancer Profiles web site to identify disparities in prostate cancer incidence and mortality.
- Collaborate with Tennessee Cancer Coalition (TC2) regional coalitions to plan educational programs to address regional disparities.

### **Objective 1.2:**

Increase educational opportunities for all citizens of Tennessee related to prevention, detection, and treatment of prostate cancer by hosting one activity in each of the TC2 regions by 2017.

### Strategies:

- Work with Tennessee Department of Health Minority Health Office, Tennessee Men's Health Network, UsToo and others to present culturally appropriate, informed decision-making programs to minority population males on the need and effectiveness of prostate cancer screening.
- Work with the TC2 advocacy committee to support a legislative action to provide printed material on the risks and benefits of screening and treatment choices to all men diagnosed with prostate cancer.

### **Objective 1.3:**

Increase primary care physician knowledge of the risks and potential benefits of prostate cancer screening and encourage discussion with appropriate male patients.

### Strategies:

• Facilitate distribution to and understanding by primary care physicians of the American Cancer Society's "New Prostate Cancer Screening Guidelines for Health Professionals" in the state of Tennessee.

### **Objective 1.4:**

Facilitate partnership with churches within the African American community to encourage physician/patient dialogue about the appropriateness of prostate cancer screening.

### Strategies:

- Work with pastors from primarily African American congregations to encourage physician dialogue regarding prostate cancer screening.
- Utilize CDC Prostate Cancer Screening: A Decision Guide For African Americans as an educational tool. http://www.cdc.gov/cancer/prostate/pdf/aaprosguide.pdf

• Meet with the "Ladies Circle groups" to educate them about the importance of the men in their lives discussing prostate cancer screening with their physicians.

### **Objective 1.5:**

Establish funding for Prostate Cancer Awareness and Treatment.

#### **Strategies:**

- Facilitate advocacy for Prostate Cancer at the state and national level.
- Advocate at the state and national level for additional funding to improve the lives of men with prostate cancer and raise awareness to decrease the death rate.
- Advocate nationally to bring an increased awareness in the federal government and increase needed resources for the state of Tennessee to fight Prostate Cancer.



### Family Ties of Ted, Charles and James Jr. Harris



Ted Harris and brothers Charles Harris and James Harris, Jr., Prostate Cancer Survivors. In 2000, my father James A. Harris, Sr. was diagnosed with prostate cancer. He took treatment for the disease and was given a clean bill of health. In April 2003, the doctors informed my father that the cancer had come back and there was nothing else he could do. This was bad news that my family did not want to hear, but as children of God, we, as his

family agreed that we would trust the Lord that his will be done.

On August 22, 2003 my father lost his battle with prostate cancer. However before he passed, he requested that all his sons, promise to continue to get their prostate's checked. In March 2004, the company, Shaw Industries (where my brother James, Jr. worked) offered a free prostate screening for all their employees. James, Jr. decided to be tested.

A few days later the medical staff who did the prostate screening notified my brother that his results were positive and he would have to have surgery immediately. As a family, this was not good news because we had lost our father the year before from prostate cancer. We did not want to lose our brother too.

With this news, my sisters began to search all over the country for the best urologist we could find to do the surgery.

My mother, brother and I talked with the doctor to see if he could do the surgery. During our conversation, he asked my mother about our family medical history and asked if she had other sons. She informed him that she did. The doctor told my mother that all her sons needed to have their prostate's checked. We scheduled an appointment to see him. He asked that my brothers and I come to see him together so we all could have our prostates checked. I informed him that I had regular prostate checks and I should be fine. He stated that due to my strong family history of prostate cancer, he wanted me to have my prostate checked as well. So I did.

The results from our test came back positive for prostate cancer. We were truly in shock. I could not begin to tell you the stress that was on my family; more importantly my mother, wife and children. Again, as a family we were faced with a battle for our lives with prostate cancer. We as a family knew that again we would place our faith in God's hand.

On April 22, 2004, my brother James, Jr. had his surgery. Six days later on April 28th my oldest brother Charles had his surgery. Six days later on May 4, 2004, I had my surgery.

After our surgeries we all were informed by our doctor that the surgeries went very well and he wanted to closely monitor us for the next five to seven years.

The year now is February 2012. I can tell you that we are blessed to say that all three of us brothers are doing well. I will never forget the years of 2003 - 2004, because even though my brothers and I are still alive, we lost 13 other family members to different types of cancer.

## Chapter 15

### **SCREENING and EARLY DETECTION**

#### **Definition(s):**

Screening for cancer means using strategies to look for a cancer in people who do not have any symptoms of cancer. Early detection means finding a cancer through this process.

Individuals can reduce their chance of dying from cancer by finding cancerous changes in the early stages of a disease when it can be treated most effectively, individuals can reduce their chance of dying from cancer. Strategies may include clinical examination, x-rays, laboratory analysis, endoscopic technologies or a combination of procedures.

#### **Guidelines:**

There are specific screening guidelines recommended by the American Cancer Society (ACS), the National Cancer Institute (NCI), and the National Comprehensive Cancer Network for cancers of the breast, colon, rectum, cervix, prostate, testes, oral cavity, lung, and skin.

Screening guidelines may differ dependent upon the assessed risk of the individual. A thorough health, social, behavioral, psychosocial, family and medication history as well as a physical examination estimate risk. Genetic testing may be beneficial in selected individuals to estimate risk.

#### Goal 1:

Increase detection of cancer at acceptable rates when disease is not causing a symptom and when treatment is more likely to be successful. Increase awareness regarding family history and risk factors for cancer.

#### **Objective 1.1:**

Promote knowledge of guidelines by creating a fact sheet on published resources describing cancer screening guidelines that is distributed to health care professionals and the public.

#### Strategy:

• By December 2017, develop and publish information on resources and risk factors for cancer on the Tennessee Cancer Coalition (TC2) website at tncancercoalition.org.

#### **Objective 1.2:**

By June 30, 2017 promote and disseminate access to cancer screening resources to the coalition members, health care institutions, legislative members, policy makers, and citizens of TN. By 2017, publish this information on the Tennessee Cancer Coalition website at tncancercoalition.org.

#### Strategies:

- By 2017, identify deficits in screening prevalence in each of the TC2 regions in comparison to the State and National prevalence data for breast, colon, rectum, prostate, testicular, oral, lung, skin and cervical cancers.
- By 2017, increase a single disease-specific screening program in each of the TC2 regions by 15% that was identified as having a screening prevalence below the State and/or national median.

#### **Objective 1.3:**

Assess information available on screening rates, changes in screening rates and trends in Tennessee.

38

### **Strategies:**

- By 2017, identify details in screening prevalence for economic disparate populations within each of the TC2 regions in comparison to State and National Prevalence data for breast, colon, rectal, cervical, prostate, testicular, oral cavity, lung, and skin cancers.
- By 2017, increase a single disease specific screening program for socioeconomic disparate population within each of the TC2 regions by 15% identified at or below State and national medium.

### **Objective 1.4:**

Identify disparities in screening and early detection for low income, uninsured and underinsured individuals in Tennessee.

### Strategy:

• By December 2015, conduct a review of existing documents and reports to identify problems and possible solutions for people in Tennessee.



## Chapter 16

## **SURVEILLANCE and EVALUATION**

#### **Surveillance Definition:**

Accurate and timely reporting of cancer diagnoses to the Tennessee Cancer Registry for the purpose of using the data to evaluate the burden of cancer and direct interventions towards reducing this burden in the state of Tennessee.

#### Goal 1:

To utilize the Tennessee Cancer Registry to assess the incidence and impact of cancer within the state and direct interventions towards prevention and reduction of cancer-related morbidity and mortality

#### **Objective 1.1:**

Build awareness of the existence and applicability of the Tennessee Cancer Registry.

#### **Objective 1.2:**

Improve utilization of the Tennessee Cancer Registry data to promote cancer-related education, research and policy development.

#### **Objective 1.3:**

Create opportunities for cancer-related education, research, and policy development by improving access to the state registry.

#### Strategies:

- Maintain affiliation with the Tennessee Cancer Registry
- Update Tennessee Cancer Registry brochures
  - o Emphasize purpose, content, applicability to cancer-related education, policy and research activities.
- Develop relationship with State Institutional Review Board (IRB) to facilitate utilization of patient identifiable data for research purposes
- Improve relationship and communication with the American College of Surgeons Commission on Cancer (CoC) physician liaisons.
  - o Promote the Tennessee Cancer Registry within Tennessee CoC-affiliated sites & programs.
- Promote the Tennessee Cancer Registry at coalition-related activities.
- Promote the Tennessee Cancer Registry among state cancer-related organizations.
  - o Personal communication
  - o Public appearances/presentations
  - o Printed materials

#### **Evaluation Definition:**

Utilization of cancer-related data to assess, target, support and improve coalition-based interventions and activities focusing on the reduction of cancer incidence, morbidity and mortality in the state of Tennessee.

#### Goal 2:

To evaluate the impact of interventions on the reduction of cancer incidence, morbidity and mortality in the state.

### **Objective 2.1:**

Improve the utilization of data to direct initiatives, activities and interventions within the coalition.

### **Objective 2.2:**

Improve evaluation tools.

### **Objective 2.3:**

Education of coalition members regarding the essential role and use of evaluation in sustaining the mission of the coalition.

### **Objective 2.4:**

Educate coalition members about the availability of Tennessee Cancer Registry data.

### Strategies:

- Educate coalition members about the accessibility & content of Tennessee Cancer Registry data.
- Redesign coalition implementation documents to incorporate uncomplicated evaluation processes & methods.
- Emphasize evaluation process as a requirement.
- Provide/facilitate educational opportunities on the purpose & implementation of evaluation in coalition activities.
  - o Workshops
  - o Lectures/Webinars
  - o Maintain standard in all coalition activities and interventions
- Provide/facilitate educational opportunities on importance of evidence-based activities that have evaluable outcomes.
  - o Personal communication
  - o Lectures/Webinars
  - o Workshops
  - o Printed materials
  - o Maintain standard in all coalition activities and interventions

### Partricia Brown - A Survivor!



My first diagnosis of cancer was in 2003 when I discovered a mass in my abdomen. I made an appointment with my doctor. After being examined and undergoing a MRI the results showed that I had ovarian and kidney cancer. I underwent surgery and had a total hysterectomy and my left kidney was removed. After this I underwent six rounds of chemotherapy and was cancer free for five and 1/2 years.

In 2009 cancer again invaded my life. This time, cancer was diagnosed in my large and small intestines, colon, pelvic area, and spots were discovered on my liver and bladder. My oncologist wanted to do surgery, however I wanted a second opinion. I went to see another oncologist who affirmed my oncologist diagnosis. I came back home and underwent surgery and had six rounds of chemotherapy.

In January 2010 I found lumps in my abdomen. I contacted my oncologist and scheduled an appointment to see him. He did biopsies of my abdominal area. The result was cancer for a third time now with metastases, however it was a slow growing cancer and surgery was not an option.

In February 2011, I was evaluated and underwent several tests and chemotherapy. The chemotherapy did not work. Today I am taking cancer medication every day. My battles with cancer have been an up-hill journey; however, I am not giving up this battle without a fight. It is through God's grace and mercy that I am still here living my life fully each day. I thank God for what he has done for me and my family.

# Chapter 17

## SURVIVORSHIP

### **Definition:**

Survivorship focuses on improving the quality of life for children and adults diagnosed with cancer. The term 'survivor' includes the one living with cancer from the time of diagnosis, family members, friends and caregivers.

### Goal:

Improve TN cancer survivors' quality of life through education and advocacy initiatives that address the physical, emotional, and practical challenges of cancer survivorship.

### **Objective 1:**

Increase cancer survivors' awareness of/access to survivor resources and services by June 30, 2017 by publishing the childhood cancer resource guide available on-line at tncancercoalition.org by June 30, 2017. Also develop an adult cancer resource guide that will be available on-line by June 30, 2017.

### Strategies:

- Develop ,disseminate, and maintain an existing survivorship resource database and services at local, state, and national levels
- Provide education regarding the survivorship resource database to Tennessee residents and academic cancer centers

### **Objective 2:**

Educate health care providers at one major hospital in each Tennessee region about the long-term needs of cancer survivors by June 30, 2017.

### Strategies:

- Development of educational materials and tools on survivorship via trainings, the TC2 Summit and website; as well as electronic and print media
- Implement a hard copy of the TC2 adopted survivorship care plan (i.e. OncoLife and Children's Oncology Group guidelines) that may be used by cancer survivors discharged from cancer treatment

### **Objective 3:**

Identify and collaborate with three key community contacts in each region to increase awareness about cancer survivorship issues and impacts among the general public, policymakers, survivors, providers, and other parties by June 30, 2017.

### Strategies:

- Partner with regional and community cancer centers and nonprofits to offer survivorship seminars
- Identify and educate legislators of each region regarding the survivorship needs of cancer survivors by June 30, 2017.

### **Objective 4:**

Encourage and promote cancer survivorship research projects and grants by June 30, 2017.

43

#### Strategies:

- Encourage and promote cancer survivorship research projects and grants by June 30, 2017. Develop a database of potential cancer survivorship research funding mechanisms available via the federal government, private voluntary organizations, and private health insurers.
- Educate researchers and providers in each region about funding opportunities focused on cancer survivors.

### But...I never smoked!



I am a non-smoking survivor of lung cancer.

I am one of the lucky few whose lung cancer was found in stage 1. Lung cancer is found in stage 1 only 15% of the time. Mine was discovered on a chest x-ray to check for chemically induced pneumonia, which might have been the result of a "home cleaning accident".

My "accident" happened when I decided to take action to rid our bathroom of mold growing on the ceiling of the shower. I intended to do this one time and one time only! I thought what better way to fight mold than with bleach and an ammonia-based product. For those of you who don't know, like me, bleach and ammonia, when mixed together, are quite toxic. I gassed myself.

I went for a chest x-ray. The good news was no pneumonia. The bad news was that my doctor noticed a nodule on the right upper lobe of my lung. I followed up with a PET scan which was negative and since I had no risk factors, as in I have never smoked, the protocol was to watch it with a series of CT scans. If there was no change in size after 2 years of scans, the nodule would be considered benign.

After 3 CT scans over a 9 month period, the nodule grew by 30%. So on October 5th 2010, I underwent video-assisted thoracic surgery to biopsy the nodule. Again, I did not smoke!! It turned out to be a stage 1A adenocarcinoma. The cells were lung primary with no lymph nodes involved. The surgeon removed my right upper lobe and I was considered cancer free. Unfortunately, I now have to admit that bathroom cleaning saved my life.

I didn't smoke, I exercised, I tried to eat right. I ran a ½ marathon 2 weeks before surgery. And I had lung cancer. I have done a lot of reading on lung cancer since then. What I have learned is that nearly 80% of new lung cancer cases are a combination of former smokers and those who have never smoked. 80%!! Over 25,000 women who have never smoked will be diagnosed with lung cancer this year and lung cancer now claims the lives of more women each year than breast, ovarian and cervical cancers combined. Lung cancer is still the leading cause of cancer death in every ethnic group.

Lung cancer is the second leading cause of death in the US. While other cancer survival rates have improved, the survival rate for lung cancer is still very low because so few cases are diagnosed at an early stage when cancer is most curable. I am thankful to be one of the lucky few.

## Chapter 18

# TOBACCO

### Goal 1:

To achieve a tobacco-free Tennessee in collaboration with the Tobacco Use Prevention and Control Program at the Tennessee Department of Health. By preventing the initiation of tobacco use among young people, promoting quitting among tobacco users, and eliminating exposure to secondhand tobacco smoke.

### **Objective 1.1:**

Prevent tobacco use among young people and decrease youth smoking rates by 9% by 2017 (Healthy People 2020, TU-2). Among Tennessee youth surveyed in 2011, 30% reported using some type of tobacco product at least once during the previous 30 days, with 10% reporting using cigarettes on 20 or more days during the previous 30 days.

### Strategies:

- Use evidenced-based interventions, implement community-based tobacco prevention and control programs that engage schools, youth, and parents, thereby improving anti-tobacco attitudes.
- Support the Campaign for a Healthy and Responsible Tennessee (CHART) in advocating for monitoring and enforcement of laws restricting youth access to tobacco products and raising the tobacco excise tax to the national average or above.

### **Objective 1.2:**

By 2017, reduce the proportion of Tennesseans aged 18 or older who use tobacco products to 17%. Tennessee current cigarette smoking prevalence rates for individuals 18 years and older was 23.0% in 2010, with more males reporting smoking than females (24.8% vs. 21%, respectively; BRFSS 2011).

### Strategies:

- Continue promotion of the Tennessee Tobacco Quitline throughout the state (1-800-QUIT-NOW). This phone number links Tennesseans with resources throughout the state of Tennessee.
- Promotion and access to materials providing a step-by-step guide to quitting smoking through the website http://www.smokefree.gov.
- Promote and access materials specifically tailored towards women through http://women.smokefree.gov.
- Connect military personnel and their families with access to smoking cessation programs through http://www.ucanquit2.org, a site tailored to military personnel and their families. Tennessee military families may also call the TRICARE® Smoking Quitline at 1-877-414-9949.

### **Objective 1.3:**

Increase insurance coverage of evidence-based treatment for nicotine dependency (Healthy People 2020, TU-8).

### Strategy:

• Work with the 10 largest employers on worksite wellness, encouraging employers to adopt healthy policies while creating and maintaining healthy work environments.

### **Objective 1.4:**

Increase the proportion of persons covered by indoor worksite policies that prohibit smoking to 100% (Healthy People 2020, TU-12). As of October 1, 2007, the Tennessee Non-smoker's Protection Act makes smoking illegal in all enclosed public places within the state, with a few exceptions.

### Strategies:

- Investigate state agency monitoring of daycare compliance with current Tennessee smoke-free air laws.
- Support Campaign for a Healthy & Responsible Tennessee (CHART) in advocating for state policies that restrict smoking in worksites to 100%.

### Goal 2:

Identify and eliminate tobacco-related health disparities among population groups.

### **Objective 2.1:**

Promote innovative demonstration and research projects to prevent youth tobacco use, promote cessation, promote tobacco-free communities, and reach diverse populations (CDC, 2011).

### **Prevalence:**

Smoking prevalence rates are higher for males (21.7%), whites (21.7%), those with less than a high school education (33.7%) and those with an annual household income of less than \$25,000 (CDC, 2010).

### Strategy:

• Promote and access materials specifically tailored toward disparate populations

### References

Centers for Disease Control and Prevention (n.d.). Tobacco use and Tennessee students. Retrieved from http://www.cdc.gov/healthyyouth/yrbs/pdf/tobacco/tn\_tobacco\_combo.pdf

Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Data. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2010.

Centers for Disease Control and Prevention (CDC, 2011). CDC health disparities and inequalities report – United States, 2011. MMWR, 60(Suppl.), 109-113.

Institute of Medicine. (2007, May). Ending the tobacco problem: A blueprint for the nation (Report Brief). Washington, DC: Author.

U.S. Department of Health and Human Services, Office of Disease Control and Health Promotion (2010). Healthy people 2020. Retrieved from http://www.healthypeople.gov/2020/default.aspx

### **Bill Pressly: A Victim of Second Hand Smoke**



I was 55 years old, looking forward to retirement and hopefully some grandkids when I was diagnosed with stage 4 throat cancer. My doctors told me that the most likely cause of my cancer was tobacco smoke which was a shock inasmuch as I had not smoked cigarettes since my impressionable teenage years. This news also brought back sad memories of my Mom who died days before her 60th birthday from emphysema. My Mom smoked Camel cigarettes for most of her short life. And here I was a non-smoker but another victim of tobacco smoke nevertheless and I was not even going to come close to my 60th birthday.

Thanks to advances in cancer research and blessings from above, I not only got to celebrate my 60th birthday, I now am enjoying retirement and spending time with my two beautiful grandkids. My 60th birthday wish was

and remains that my grandkids will never have to go through what I and millions of other cancer victims have had to endure. I am fortunate but know that many victims of tobacco smoke never will enjoy another birthday, retirement, grandkids or other blessings of life. That is why I have dedicated much of my retirement time to the war on cancer. The time to take drastic action against this killing stick is now!

### Chapter 19

### WOMEN'S CANCERS

### Goal 1:

Reduce female breast, cervical, ovarian and uterine cancer mortality through increased awareness, early detection, diagnosis and treatment. Mortality rates for 2005-2009 and reduction goal by June 2017: Breast rate of 24.0, reduce to 22.0; Cervical rate of 2.8, reduce to 1.8; Ovarian rate of 8.1, reduce to 7.1; and Uterine rate of 3.8, reduce to 2.8.

### **Objective 1.1:**

Increase awareness of these cancers, current incidence rates, current mortality rates and screening guidelines and to promote access to services and increase screenings by conducting annual updates on the rates to each of the TC2 regions.

#### **Strategies:**

- Develop and promote public information campaigns with state partners (American Cancer Society (ACS), the six Susan G. Komen affiliates, family practice physicians, OB/GYN physicians, mammography facilities, etc.).
- Identify counties with the highest rates of breast and cervical cancer for special community-based campaigns through the work of the regional Tennessee Cancer Coalition (TC2) coalitions.
- Continue to emphasize targeted outreach to underserved groups through the University of TN Extension statewide, county-based educational delivery systems, The Witness Project of Davidson County, Komen grantees and other local initiatives for breast and cervical cancer awareness and screening.
- Promote awareness in January (Cervical Cancer prevention Month), September (Gynecological Cancer Awareness Month), and October (Breast cancer Awareness Month) through TC2 regional coalitions.
- Work with medical and health care practitioner societies to encourage members to promote regular, periodic screening for breast and cervical cancer.
- Review trends in ovarian and uterine cancer, at least bi-annually, and advocate for screening if evidence-based screening methods become available before 2017.

### **Objective 1.2:**

By June 2017, increase funding for breast and cervical cancer screening.

### **Strategies:**

- Advocate for expansion of state funding to improve TN's incidence and mortality rates for these two highly treatable cancers, if the cancers are caught early.
- Support local Susan G. Komen Affiliates fund raising activates which in turn support local education and screening services.
- Advocate for an increased appropriation from the federal government so that all states have additional resources for their state breast and cervical screening programs.

### **Objective 1.3:**

By June 2017, endorse and support activities of the Tennessee Cervical Cancer Elimination Plan.

### **Strategies:**

- Inform all TC2 members of the release of the TN Cervical Cancer Elimination Plan by June 2017.
- Encourage regional TC2 coalition implementation of those components that can be included in routine regional coalition activities.
- Advocate for funding of the Plan as outlined to reach cervical cancer elimination by 2040.

### **Objective 1.4:**

By June 2017, increase HPV vaccine uptake for all three doses to 30% of female adolescents receiving HPV from 15.2% (HEDIS, 2012) to 30% and determine a baseline for male vaccination completion..

### **Strategies:**

- Promote vaccination against HPV through available vaccine programs, insurance plans and a targeted social marketing campaign.
- Partner with the Cervical Cancer Free American Initiative to support HPV vaccination.

### If only HPV vaccine had been available!



At age twenty-six, Michelle L. Whitlock thought she had it all: she was in the best physical shape of her life, she had a promising career, and she had a budding romance that looked like it could finally be the real thing. Then doctors informed her that she had HPV. Weeks later her worst nightmare became her reality: she was diagnosed with invasive cervical cancer.

Michelle took charge of her healthcare and pursued an experimental surgery that treated the cancer while preserving her fertility. The surgery was a success, but just years later—a week after the love of her life proposed—Michelle discovered her cancer was back.

Michelle is a two time survivor of cervical cancer, mother of a child born via gestational carrier, an advocate for women's health and fertility options, a public/motivational speaker, and an author.

### Glossary

Technical terms are used in presenting the information within this plan. The following are definitions to assist the reader.

### **Incidence Rates**

An incidence rate is the number of new cases of a disease that occur in a specific time period, within a specific population, divided by the size of the population at risk.

**Example:** 10 residents of a county with 20,000 residents at risk for the disease are diagnosed within a single year, then the incidence rate for that county for that year is .0005. Cancer incidence rates are usually expressed per 100,000 population; therefore, .0005 would be multiplied by 100,000 to yield a rate of 50 per 100,000 per year.

The term "at risk" above is an important distinction. The "at risk" population is not necessarily the total population.

**Example:** When calculating rates for uterine cancer, the "at risk" population in the denominator would be the total population of women with a uterus; therefore, women who have had a hysterectomy would be excluded. In practicality, though, usually all women would be included in the denominator and men would be excluded. Men would not be included since they cannot develop uterine cancer.

### In situ

Cases diagnosed as "in situ" include malignant tumors that are confined to the cell group/layer of origin, and have not penetrated the supporting structure of the organ/cell layer in which they arose.

### Mortality Rate (Death Rate)

A mortality rate is the number of deaths that occur in a specific time period within a specific population, divided by the size of the population at risk for the disease. Only those persons whose death certificate lists cancer as the underlying (primary) cause of death are included in a cancer mortality rate. Like incidence rates, mortality rates are usually expressed as the number of deaths per 100,000 population.

### Age-adjusted rate

Age adjustment is a statistical process used to calculate a weighted average of the rates for two or more different populations based on the different age distributions of the populations of interest. Almost all diseases or health outcomes vary according to age groups. Most chronic diseases, including most cancers, occur more often among older populations. Other outcomes, such as many types or injuries, occur more often among younger populations. The age distribution determines what the most common health problems in a community will be.

### **Selected References/Resouces**

American Cancer Society Facts and Figures http://www.cancer.org/research/cancerfactsfigures/indes

Behavioral Risk Factors Surveillance System http://www.cdc.gov/brfss/

> CDC Cancer Control http://www.cdc.gov/cancer/ncccp/

**Cancer Control P.L.A.N.E.T.** http://cancerplanet.cancer.gov

Centers for Disease Control http://www.cdc.gov/cancer/

Clinical Trials www.clinicaltrails.gov

The Community Guide http://www.thecommunityguide.org/index.html

> National Cancer Institute http://www.cancer.gov

**Tennessee Cancer Coalition** http://www.tncancercoalition.org

**Tennessee Cancer Registry** http://health.state.tn.us/TCR/index.htm

Tennessee Comprehensive Cancer Control Program http://health.state.tn.us/CCCP/

Tennessee Department of Health, Smokefree Tennessee http://health.state.tn.us/smokefreetennesseee

> Smokefree Tennessee Campaign http://www.smokefreentn.org

### The Burden of Cancer in Tennessee

The Tennessee Cancer Registry (TCR) was established in 1983 by an act of the Tennessee General Assembly, TCA 68-1-1001. The TCR is responsible for collecting data on all cancer cases diagnosed in Tennessee. The Tennessee Cancer Coalition is a collaborative group of individuals who use the data of the Tennessee Cancer Registry and other data sources to target cancer prevention and control activities to areas of Tennessee that experience a high cancer burden. Cancer is the second leading cause of death in Tennessee.

### **Cancer Incidence**

Cancer incidence is the number of newly diagnosed cases of cancer occurring in a population during a specific time. The overall cancer incidence rate of the state of Tennessee for the years of 2005-2009 including all races and both males and females is 470.5 per 100,000. This is above the US rate of 465.0 per 100,000 (see table...). The four leading cancer diagnoses in Tennessee by number of newly diagnosed cases during 2005-2009 and in decreasing order were: lung, prostate, female breast and colorectal cancers.

### **Cancer Deaths**

Cancer mortality is the number of deaths due to cancer in a given period of time. For the years 2005-2009 Tennessee's overall mortality rate was 200.6 per 100,000. This was above the US rate of 178.7 per 100,000. The four leading causes of cancer death in Tennessee by number of deaths during 2005-2009 and in decreasing order were: lung, colorectal, female breast and pancreatic cancers.

### **Cost of Cancer**

According to the National Cancer Institute, the cost of medical expenditures associated with cancer in the U.S. is projected to reach \$158 billion by 2020 (in 2010 dollars, so this expenditure estimate is not adjusted for projected inflation). This is a 27% increase over actual direct costs recorded in the U.S. for the 2010 diagnosis year. NCI researchers stated that if cancer diagnostic tools, treatment and follow-up continue to increase in cost and do not remain stable that medical costs for cancer could be as high as \$207 billion.

http://www.2.state.tn.us/health/CCCP/index/htm http://www.cancer.gov/aboutnci/servingpeople/cancer-statistics/costofcancer

## **U.S./TN Comparison**

### Table 1

2005-2009	Overall	Males	Females	White Males	Black Males	White Females	Black Females
Ranking							
TN Incidence	470.5 (468.2, 472.9)	559.1 (555.1, 563.0)	409.5 (406.6, 412.5)	552.7 (548.6, 556.9)	603.9 (591.3, 616.8)	411.3 (408.1, 414.6)	395.3 (387.3, 403.5)
US Incidence	465.0 (464.7, 465.4)	540.7 (540.2, 541.3)	412.0 (411.6, 412.4)	532.3 (531.7, 532.8)	613.9 (611.8, 615.9)	416.3 (415.8, 416.8)	390.8 (389.5, 392.1)
TN Mortality	200.6 (199.0, 202.1)	257.9 (255.2, 260.7)	162.0 (160.1, 163.8)	250.3 (247.5, 253.2)	339.4 (329.3, 349.8)	157.9 (155.9, 159.9)	195.5 (189.7, 201.3)
US Mortality	178.7 (178.4, 178.9)	219.4 (219.0, 219.7)	151.1 (150.8, 151.3)	216.7 (216.3, 217.1)	288.3 (286.8, 289.8)	150.8 (150.5, 151.1)	174.6 (173.7, 175.4)
TN Lung Incidence	80.3 (79.4, 81.3)	106.1 (104.4, 107.9)	61.5 (60.4, 62.7)	106.1 (104.3, 107.9)	109.1 (103.7, 114.7)	62.4 (61.2, 63.6)	56.8 (53.7, 60.0)
US Lung Incidence	67.2 (67.1, 67.4)	82.9 (82.7, 83.1)	55.7 (55.6, 55.9)	82.2 (82.0, 82.5)	100.0 (99.2, 100.9)	57.3 (57.1, 57.5)	51.3 (50.8, 51.8)
TN Lung Mortality	65.7 (64.9, 66.6)	91.5 (89.9, 93.1)	47.2 (46.2, 48.2)	90.6 (88.9, 92.3)	104.7 (99.2, 110.3)	47.7 (46.6, 48.8)	45.7 (42.9, 48.6)
US Lung Mortality	50.6 (50.5, 50.7)	65.7 (65.5, 65.8)	39.6 (39.5, 39.8)	65.3 (65.1, 65.5)	82.6 (81.8, 83.3)	40.8 (40.6, 40.9)	38.0 (37.6, 38.4)
TN Female Breast Incidence	119.6 (118.0, 121.2)	NA	119.6 (118.0, 121.2)	NA	NA	118.8 (117.0, 120.5)	120.7 (116.4, 125.2)
US Female Breast Incidence	122.0 (121.8, 122.2)	NA	122.0 (121.8, 122.2)	NA	NA	123.0 (122.7, 123.2)	118.0 (117.3, 118.7)
TN Female Breast Mortality	24.0 (23.3, 24.7)	NA	24.0 (23.3, 24.7)	NA	NA	22.2 (21.5, 23.0)	36.2 (33.8, 38.7)
US Female Breast Mortality	23.0 (22.9, 23.1)	NA	23.0 (22.9, 23.1)	NA	NA	22.4 (22.3, 22.5)	31.6 (31.2, 32.0)
TN Colorectal Incidence	47.7 (47.0, 48.5)	56.2 (54.9, 57.4)	41.3 (40.4, 42.3)	54.6 (53.3, 55.9)	67.5 (63.3, 72.0)	39.6 (38.6, 40.6)	52.1 (49.2, 55.1)
US Colorectal Incidence	46.2 (46.1, 46.3)	53.8 (53.6, 53.9)	40.2 (40.0, 40.3)	52.5 (52.3, 52.7)	65.1 (64.4, 65.7)	39.0 (38.9, 39.2)	48.0 (47.5, 48.5)
TN Colorectal Mortality	18.2 (17.7, 18.7)	22.4 (21.5, 23.2)	15.1 (14.6, 15.7)	20.9 (20.1, 21.7)	36.4 (33.1, 39.9)	14.1 (13.6, 14.7)	23.2 (21.2, 25.3)
US Colorectal Mortality	16.7 (16.6, 16.8)	20.2 (20.0, 20.3)	14.1 (14.0, 14.2)	19.5 (19.4, 19.6)	29.8 (29.4, 30.3)	13.6 (13.5, 13.7)	19.8 (19.5, 20.1)
TN Prostate Incidence	145.6 (143.6, 147.6)	145.6 (143.6, 147.6)	NA	136.4 (134.4, 138.4)	216.1 (208.5, 223.8)	NA	NA
US Prostate Incidence	151.4 (151.1, 151.7)	151.4 (151.1, 151.7)	NA	140.8 (140.5, 141.1)	228.6 (227.4, 229.9)	NA	NA
TN Prostate Mortality	25.3 (24.4, 26.2)	25.3 (24.4, 26.2)	NA	21.8 (20.9, 22.7)	61.9 (57.2, 66.9)	NA	NA
US Prostate Mortality	23.6 (23.5, 23.7)	23.6 (23.5, 23.7)	NA	21.7 (21.6, 21.8)	53.1 (52.4, 53.8)	NA	NA
TN Cervix Incidence	8.7 (8.3, 9.2)	NA	8.7 (8.3, 9.2)	NA	NA	8.3 (7.8, 8.8)	10.5 (9.3, 11.9)
US Cervix Incidence	8.0 (8.0, 8.1)	NA	8.0 (8.0, 8.1)	NA	NA	7.7 (7.6, 7.8)	10.3 (10.1, 10.6)
TN Cervix Mortality	2.8 (2.5, 3.1)	NA	2.8 (2.5, 3.1)	NA	NA	2.4 (2.1, 2.6)	5.4 (4.6, 6.5)
US Cervix Mortality	2.4 (2.4, 2.4)	NA	2.4 (2.4, 2.4)	NA	NA	2.2 (2.1, 2.2)	4.3 (4.2, 4.4)
TN Melanoma Incidence	20.5 (20.0, 21.0)	26.4 (25.5, 27.2)	16.6 (16.0, 17.2)	29.5 (28.6, 30.5)	*	19.3 (18.6, 20.0)	1.3 (0.9, 1.8)
US Melanoma Incidence	19.2 (19.2, 19.3)	24.4 (24.3, 24.5)	15.6 (15.5, 15.7)	27.0 (26.9, 27.2)	1.1 (1.0, 1.2)	17.8 (17.7, 17.9)	1.0 (0.9, 1.1)
TN Melanoma Mortality	3.0 (2.8, 3.2)	4.6 (4.2, 5.0)	1.8 (1.6, 2.0)	5.1 (4.7, 5.5)	*	2.1 (1.8, 2.3)	*
US Melanoma Mortality	2.7 (2.7, 2.8)	4.1 (4.0, 4.1)	1.7 (1.7, 1.8)	4.6 (4.6, 4.7)	0.5 (0.5, 0.6)	2.0 (1.9, 2.0)	0.4 (0.3, 0.4)

\* - represents surpressed data which is determined by less than 16 cases.

### **Reference:**

State Cancer Profiles;

http://statecancerprofiles.cancer.gov/index.html

# Counties with Higher Mortality Rates All Cancers - Both Sexes

### Table 2

All Cancer Sites	Lung & Bonchus Prostate		Female Breast	Colorectal	Cervix	Melanoma
Lake County	Scott County	Lauderdale County	Grundy County	Fentress County	Madison County	Jefferson County
Macon County	Campbell County	Macon County	Grainger County	Lincoln County	Shelby County	Monroe County
Fentress County	Claiborne County	Shelby County	Morgan County	Smith County	Hamilton County	Montgomery County
Marion County	Lake County	Grainger County	Haywood County	Gibson County	Knox County	Blount County
Scott County	Fentress County	Weakley County	Henderson County	Lauderdale County	Davidson County	Sumner County
Morgan County	Stewart County	Marion County	Gibson County	Macon County	*	Sevier County
Perry County	Trousdale County	Dickson County	Shelby County	Lewis County	*	Sullivan County
Smith County	Smith County	Hardeman County	DeKalb County	Polk County	*	Washington County
Claiborne County	Polk County	Fayette County	McNairy County	Jackson County	*	Williamson County
Lewis County	Carroll County	White County	Marshall County	Carroll County	*	Knox County
Lauderdale County	Macon County	McNairy County	Hawkins County	Hardeman County	*	Rutherford County
Tipton County	Greene County	Henry County	Bradley County	Crockett County	*	Davidson County
Campbell County	Weakley County	Hamilton County	Smith County	McNairy County	*	Hamilton County
Gibson County	Morgan County	Obion County	Fayette County	Morgan County	*	Shelby County
Polk County	Perry County	Lawrence County	Coffee County	Tipton County	*	*
Wayne County	Overton County	Claiborne County	Scott County	Shelby County	*	*
Overton County	Hickman County	Gibson County	Marion County	Weakley County	*	*
Carroll County	Hancock County	Greene County	Wilson County	Obion County	*	*
Benton County	Hardin County	Davidson County	Lauderdale County	Haywood County	*	*
Greene County	Marion County	Montgomery County	Tipton County	Hamblen County	*	*

\* - represents surpressed data which is determined by less than 16 cases.

#### **Reference:**

State Cancer Profiles; http://statecancerprofiles.cancer.gov/index.html

### What Can You Do To Fight Cancer in Tennessee?

# If You Are a **Community-Based Health Care System...**

#### **Primary Prevention**

**Goal:** To raise awareness of actions that can be taken by individuals, communities, government, or other groups to prevent the occurrence of cancer through healthy lifestyle choices.

- Provide education on what a healthy lifestyle includes.
- Disseminate information on how to adopt a healthy lifestyle and how this will assist in the prevention of cancer.
- Promote the importance of the HPV vaccine and it's relationship to cervical cancer prevention and potentially the prevention of other forms of cancer.
- Promote and disseminate information regarding tobacco use, cessation, and treatment options.

#### **Early Detection**

**Goal:** Increase detection of cancer at acceptable rates when disease is not causing a symptom and when treatment is more likely to be successful. Increase awareness regarding family history and risk factors for cancer.

- Provide education on the importance of cancer screening options for breast, cervical, prostate, and colorectal cancers.
- Provide education on the use of genetics in management of cancer risk.
- Encourage and support use of evidenced-based screening guidelines.

#### **Survivorship**

**Goal:** Improve TN cancer survivors' quality of life through education and advocacy initiatives that address the physical, emotional, and practical challenges of cancer survivorship.

- Promote and encourage participation in clinical trials.
- Disseminate information about survivorship resources.
- Promote, use, and support the use of survivorship care plans.

#### **Policy and Systems Change:**

- Support and encourage partnerships that promote changes promoting the adoption of a healthy lifestyle.
- Implement and promote changes within your organization to support healthy lifestyles.
- Evaluate your systems change, educate and inform local/state policy makers and leaders of the effectiveness of your interventions.

# If You Are an **Organization Representing a Disparate Population...**

### **Primary Prevention**

**Goal:** To raise awareness of actions that can be taken by individuals, communities, government, or other groups to prevent the occurrence of cancer through healthy lifestyle choices.

- Provide education on what a healthy lifestyle includes.
- Disseminate information on how to adopt a healthy lifestyle and how this will assist in the prevention of cancer.
- Promote the importance of the HPV vaccine and its relationship to cervical cancer prevention and potentially the prevention of other forms of cancer.
- Promote and disseminate information regarding tobacco use, cessation, and treatment options. Early Detection

**Goal:** Increase detection of cancer at acceptable rates when disease is not causing a symptom and when treatment is more likely to be successful. Increase awareness regarding family history and risk factors for cancer.

- Address barriers to accessing screenings in the disparate population.
- Provide education on the importance of cancer screening options for female breast, cervical, prostate, and colorectal cancers.
- Provide education on the use of genetics testing in the management of cancer risk.
- Encourage and support use of evidenced-based screening guidelines.

### Survivorship

**Goal:** Improve TN cancer survivors' quality of life through education and advocacy initiatives that address the physical, emotional, and practical challenges of cancer survivorship.

- Promote participation in clinical trials.
- Encourage and support the use of community health workers/navigators to assist the disparate in obtaining needed services.

### **Policy and Systems Change:**

- Promote the equal distribution of health care services and resources meeting the needs of the disparate population.
- Establish and sustain partnerships that serve the disparate populations.
- Improve methods to identify the disparate populations.

# If You Are a **Health Education Organization...**

### **Primary Prevention**

**Goal:** To raise awareness of actions that can be taken by individuals, communities, government, or other groups to prevent the occurrence of cancer through healthy lifestyle choices.

- Provide education on what a healthy lifestyle includes.
- Disseminate information on how to adopt a healthy lifestyle and how this will assist in the prevention of cancer.
- Promote the importance of the HPV vaccine and its relationship to cervical cancer prevention and potentially the prevention of other forms of cancer.
- Promote and disseminate information regarding tobacco use, cessation, and treatment options.

### **Early Detection**

**Goal:** Increase detection of cancer at acceptable rates when disease is not causing a symptom and when treatment is more likely to be successful. Increase awareness regarding family history and risk factors for cancer.

- Provide education on the importance of cancer screening options for female breast, cervical, prostate, and colorectal cancers.
- Provide education on the use of genetics testing in the management of cancer risk.
- Encourage and support use of evidenced-based screening guidelines.

### Survivorship

**Goal:** Improve TN cancer survivors' quality of life through education and advocacy initiatives that address the physical, emotional, and practical challenges of cancer survivorship.

- Promote participation in clinical trials.
- Promote the assessment of barriers to participation in screenings and clinical trials.
- Encourage and support the use of community health workers/navigators to assist with obtaining needed services.

### **Policy and Systems Change:**

- Support and encourage partnerships promoting the adoption of healthy lifestyles.
- Implement and promote changes within your organization to support healthy lifestyles.
- Evaluate your systems change, educate and inform local/state policy makers and leaders of the effectiveness of your interventions.

# If You Are a **Health Insurance Plan...**

### **Primary Prevention**

**Goal:** To raise awareness of actions that can be taken by individuals, communities, government, or other groups to prevent the occurrence of cancer through healthy lifestyle choices.

- Promote prevention messages that are consistent with healthy lifestyle choices.
- Promote and provide access to the HPV vaccine.
- Provide education on what a healthy lifestyle includes.
- Disseminate information on how to adopt a healthy lifestyle and how this will assist in the prevention of cancer.

### **Early Detection**

**Goal:** Increase detection of cancer at acceptable rates when disease is not causing symptoms and when treatment is more likely to be successful. Increase awareness regarding family history and risk factors for cancer.

- Provide education on the importance of cancer screening options for female breast, cervical, prostate, and colorectal cancers.
- Provide education on the use of genetics testing in the management of cancer risk.
- Encourage and support use of evidenced-based screening guidelines.
- Provide reimbursement for cancer screening services.

### Survivorship

**Goal:** Improve TN cancer survivors' quality of life through education and advocacy initiatives that address the physical, emotional, and practical challenges of cancer survivorship.

- Promote and support participation in clinical trials.
- Promote assessment of barriers to participation in screenings and clinical trials.
- Encourage and support the use of community health workers/navigators to assist with obtaining needed services and provide reimbursement.

### **Policy and Systems Change:**

- Support and encourage partnerships promoting the adoption of a healthy lifestyle.
- Implement and promote changes within your organization to support healthy lifestyles.
- Evaluate your systems change, educate and inform local/state policy makers and leaders of the effectiveness of your interventions.
- Promote and support medical homes for ALL Tennessee residents.

# If You Are a Local Public Health Organization...

### **Primary Prevention**

**Goal:** To raise awareness of actions that can be taken by individuals, communities, government, or other groups to prevent the occurrence of cancer through healthy lifestyle choices.

- Promote prevention messages that are consistent with healthy lifestyle choices.
- Promote and provide access to the HPV vaccine.
- Provide education on what a healthy lifestyle includes.
- Disseminate information on how to adopt a healthy lifestyle and how this will assist in the prevention of cancer.

### **Early Detection**

**Goal:** Increase detection of cancer at acceptable rates when disease is not causing a symptom and when treatment is more likely to be successful. Increase awareness regarding family history and risk factors for cancer.

- Provide education on the importance of cancer screening options for female breast, cervical, prostate, and colorectal cancers.
- Provide education on the use of genetics in management of cancer risk.
- Encourage and support use of evidenced-based screening guidelines.
- Develop and implement a reminder system to ensure screening compliance.

### Survivorship

**Goal:** Improve TN cancer survivors' quality of life through education and advocacy initiatives that address the physical, emotional, and practical challenges of cancer survivorship.

- Promote participation in clinical trials.
- Encourage and support the use of community health workers/navigators to assist with obtaining needed services.
- Disseminate information regarding survivorship resources.

### **Policy and Systems Change:**

- Establish and maintain diverse partnerships and cancer coalition involvement.
- Implement and promote changes within your organization to support healthy lifestyles.
- Evaluate your systems change, educate and inform local/state policy makers and leaders of the effectiveness of your interventions.

# If You Are an **Employer...**

### **Primary Prevention**

**Goal:** To raise awareness of actions that can be taken by individuals, communities, government, or other groups to prevent the occurrence of cancer through healthy lifestyle choices.

- Provide and promote healthy food selections in machines and cafeterias.
- Collaborate with local health facilities and promote health screenings for employees. Promote and disseminate information regarding tobacco use, cessation, and treatment options.
- Establish your organization as a tobacco-free campus.
- Disseminate information on how to adopt a healthy lifestyle and how this will assist in the prevention of cancer.

### **Early Detection**

**Goal:** Increase detection of cancer at acceptable rates when disease is not causing a symptom and when treatment is more likely to be successful. Increase awareness regarding family history and risk factors for cancer.

- Provide education on the importance of cancer screening options for female breast, cervical, prostate, and colorectal cancers.
- Provide education on the use of genetic testing in the management of cancer risk.
- Provide health care coverage for employees.

### Survivorship

**Goal:** Improve TN cancer survivors' quality of life through education and advocacy initiatives that address the physical, emotional, and practical challenges of cancer survivorship.

- Support participation in clinical trials.
- Disseminate information regarding survivorship resources.

### **Policy and Systems Change:**

- Establish and maintain diverse partnerships and cancer coalition involvement.
- Implement and promote changes within your organization to support healthy lifestyles.
- Evaluate your systems change, educate and inform local/state policy makers and leaders of the effectiveness of your interventions.

# If You Are a **Faith Based Organization...**

### **Primary Prevention**

**Goal:** To raise awareness of actions that can be taken by individuals, communities, government, or other groups to prevent the occurrence of cancer through healthy lifestyle choices.

- Provide education on what a healthy lifestyle includes.
- Disseminate information on how to adopt a healthy lifestyle and how this will assist in the prevention of cancer.
- Promote the importance of the HPV vaccine and cervical cancer prevention.
- Open your facility and establish walking clubs to promote an increase in physical activity.

### **Early Detection**

**Goal:** Increase detection of cancer at acceptable rates when disease is not causing a symptom and when treatment is more likely to be successful. Increase awareness regarding family history and risk factors for cancer.

- Provide education on the importance of cancer screening options for female breast, cervical, prostate, and colorectal cancers.
- Provide education on the use of genetic testing in management of cancer risk.
- Encourage membership to obtain screenings as recommended.
- Assist in overcoming barrier to obtaining screenings.

### Survivorship

**Goal:** Improve TN cancer survivors' quality of life through education and advocacy initiatives that address the physical, emotional, and practical challenges of cancer survivorship.

- Support participation in clinical trials.
- Disseminate information regarding survivorship resources.
- Encourage and support the use of community health workers/navigators to assist in obtaining needed services.
- Establish and promote local support groups and provide meeting locations.

### **Policy and Systems Change:**

- Implement and promote changes within your membership to support healthy lifestyles.
- Evaluate your systems change, educate and inform local/state leadership of the effectiveness of your interventions.
- Establish and maintain diverse partnerships with all faith-based organizations.

# If You Are a **Policy Maker...**

### **Primary Prevention**

**Goal:** To raise awareness of actions that can be taken by individuals, communities, government, or other groups to prevent the occurrence of cancer through healthy lifestyle choices.

- Ensure appropriate funding is available for comprehensive cancer control.
- Sponsor and/or support legislation that promotes cancer prevention and control.
- Raise awareness of cancer incidence and mortality rates in the State of Tennessee.
- Direct tobacco settlement funds for use in tobacco and cancer control efforts.
- Provide and promote healthy food selections in machines and cafeterias.

### **Early Detection**

**Goal:** Increase detection of cancer at acceptable rates when disease is not causing a symptom and when treatment is more likely to be successful. Increase awareness regarding family history and risk factors for cancer.

- Ensure that all Tennesseans have access to health care and to early cancer detection, i.e. cancer screening.
- Gain awareness of the barriers to obtaining screening services in Tennessee.
- Assist in overcoming the barriers that exist to health care in Tennessee.

### Survivorship

**Goal:** Improve TN cancer survivors' quality of life through education and advocacy initiatives that address the physical, emotional, and practical challenges of cancer survivorship.

- Support the use of community health workers/navigators to assist in obtaining needed services.
- Advocate for funding to support research on the effects of treatment and long-term follow-up survivor care.

### **Policy and Systems Change:**

- Obtain and understand incidence and mortality rates for the State of Tennessee.
- Promote awareness and support for decreasing the rates in the State of Tennessee.
- Ensure that YOU are a Champion for reducing the burden of cancer in Tennessee.

# If You Are a **Tennessean...**

### **Primary Prevention**

**Goal:** To raise awareness of actions that can be taken by individuals, communities, government, or other groups to prevent the occurrence of cancer through healthy lifestyle choices.

- Stop or never begin tobacco use.
- Increase your fruit and vegetable intake.
- Increase your physical exercise.
- Promote HPV vaccination for appropriate age groups.
- Promote tobacco cessation programs

### **Early Detection**

**Goal:** Increase detection of cancer at acceptable rates when disease is not causing a symptom and when treatment is more likely to be successful. Increase awareness regarding family history and risk factors for cancer.

- Know when to be screen for female breast, cervical, prostate, and colorectal cancers.
- Obtain appropriate screenings.
- Know your biological family history.
- Share with policy makers barriers YOU face to obtaining screening services.

### Survivorship

**Goal:** Improve TN cancer survivors' quality of life through education and advocacy initiatives that address the physical, emotional, and practical challenges of cancer survivorship.

- Become a community health worker/navigator to assist others in obtaining needed services.
- Establish and facilitate local support groups for survivors, friends and family.

### **Policy and Systems Change:**

- Promote and support medical homes for ALL Tennessee residents and ALL cancer.
- Promote the equal distribution of health care services and resources that meet the needs of all Tennesseans.
- Promote and support the availability of screening services for ALL Tennessee residents.

### Acknowledgements:

A special thank you to the following people. Each of these individuals volunteered numerous hours to ensure the production of the State of Tennessee Comprehensive Cancer Control Plan for 2013 -2017. Thanks to each of you for all of your efforts.

Lee Ambrose Wellmont Cancer Institute

Tara Bankes Knoxville Dermatopathology

Susan Barker Kirkland Cancer Center

Vickie Bilbrey Livingston Regional Hospital

**Teresa Bailey** Wellmont Cancer Institute

**Dick Boland** 

#### **Edith Cook**

**Rob Clark** St. Jude Children's Research Hospital

Kay Delfino Vanderbilt Medical Center

Jan Emerson Tennessee State University

Alecia Fair Vanderbilt Institute for Clinical Translational Research

Jenna Finch

Carrie Heuer Baptist Memorial Hospital

Susan Hosbach Minnie Pearl Cancer Foundation

Mohana Karlekar

Jane Kennedy Vanderbilt Ingram Cancer Center

**Audrey Larsha** 

Jennifer Louis Candlelighters of Middle Tennessee

**Robin Matulick** 

**Ingrid Meszoely** Vanderbilt University Medical Center

**Sterling, McNeal** Church Health Center - Memphis

### **Larraine Naylor**

### **Christine Partlow**

**Deborah Pencarinha** Wellmont Cancer Institute

Helen Pinkerton Southside Dodson Avenue Center

#### **Bill Pressly**

Megan Quinn East Tennessee State University

**Cindy Rhea** Middle Tennessee State University

### Linda Reddick

Michael Savona Sarah Cannon Research Institute

Alicia Small Shelby County Health Department

**Paul Terry** University of Tennessee – Knoxville

Judy Togbo Tennessee Men's Health Network

Anne Washburn Vanderbilt-Ingram Cancer Center

Mary Winslow Leukemia & Lymphoma Society

Jenny White Lung Cancer Advocate Michelle Whitlock Cervical Cancer Advocate

Debbie Wujcik Vanderbilt University

Kathryn Visneski Wellmont Cancer Institute

Martha Shrubsole Vanderbilt University

Wendy Vogel Wellmont Cancer Insitute

Special Thanks to the following who so graciously shared their stories with us. Each is a reminder of why the Tennessee Cancer Coalition exist.

Dick Boland John Chiarmonte Ned Harris Vickie Leonard Teri Simon Michelle Whitlock Patricia Brown Caroline Hale Nan and Charlie Kelley Bill Pressly Jenny White

### **TC2** Leadership

Co-Chair: Ingrid Meszoely, MD, Vanderbilt University Co-Chair: Patricia Kassebaum, Austin Hatcher Foundation for Pediatric Cancer Vice-Chair: Jason Searcy, MBA, MHA, FACHE, Houston Valley Medical Center Secretary/Treasurer: Bill Pressly, Statewide Cancer Advocate Past Chair: Alecia Fair, Dr PH, Vanderbilt Institute for Translational Research

Katie Baker, East Tennessee State University Teresa Bailey, BSN, RN OCN, Kingsport Hematology Oncology **Tara Bankes**, Knoxville Dermatopathology Laboratory Sheila Bates, BA, MSSW, Vanderbilt-Ingram Cancer Center Vanessa Bramble, Mountain States Health Alliance Chelsea Brandon, Jackson-Madison County Regional Health Department Rob Clark, St Jude Children's Research Hospital Pam Chesser, RN, Laughlin Memorial Hospital Joyce Clem, Ph.D., Tennessee Department of Health, Southeast Region Tanyelle Dunlap, Christ Community Health Services Jan Emerson, MS, Ph.D., Tennessee State University Sandra Hamilton, RN, FNP, ME, National Black Leadership Initiative Brandi Haynes, Cancer Advocate Nancy Judd, MSN, Cookeville Regional Medical Center Brenda Kyles, B.S., Memphis-Shelby County Health Department Jennifer Louis, Candle Lighters of Middle Tennessee Jennifer Murray, Research Evaluation & Consulting for Healthcare, LLC Debbie Pencarinha, MS, CGC, Wellmont Health Systems Helen Pinkerton, MPH, Southside-Dodson Ave Health Centers Cindy Rhea, Middle Tennessee State University Michael Savona, MD, Sarah Cannon Research Institute Beth Simpson, Chattanooga-Hamilton County Health Department Alicia Small, MPH, CHES, Memphis - Shelby County Health Department Tara Smith, Cancer Advocate Paul Terry, Ph.D., M.P.H, University of Tennessee, Knoxville Judy Togbo, Tennessee Men's Health Network Jenny White, Lung Cancer Advocate Zebedee Williams, MPA, Chattanooga State Community College and Karen Shayne, Survivor Advocate Mary Winslow, Leukemia & Lymphoma Society

### **Regional Coordinators**

Cindy Chafin, M.Ed/MCHES, Middle Tennessee Region Magdaline Hatzikazakis, BS, Northeast Tennessee Region Faye Hollowell, BS, Memphis Tennessee Region Pam Isom, RN, MPH, Upper Cumberland Tennessee Allison Sepulveda, MPH, Southeast Tennessee Region Rachel Thomas, BS, CHES, Jackson Tennessee Region Betti Wilson, MS, East Tennessee Region

### **Tennessee Department of Health**

Kathy Childress, Administrative Assistant, Tennessee Comprehensive Cancer Control Program Pam Isom, RN, MPH, Program Manger, Tennessee Comprehensive Cancer Control Program Martin Whiteside, DC, PhD, MSPH, Director, Office of Cancer Surveillance

