

## Kentucky Cancer Consortium Survivorship Committee 2010 Mid-Year “News Update”



**\*\*Reminder:** Our next (semi-annual) meeting will be held **September 14, 2010** in the Lexington offices of the American Cancer Society, next to the Hope Lodge.

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## HEALTHCARE REFORM

### Health Care Reform – Key Provisions for cancer survivors

The National Coalition for Cancer Survivorship (NCCS) states that the new Health Care Reform legislation will bring America's 12 million cancer survivors and the 1.5 million more that are diagnosed each year closer than ever to getting the quality of care they need and deserve.

Some of the key provisions for cancer survivors, which take effect soon after enactment, include the following:

- Coverage would be required for routine patient care costs for those with cancer and life-threatening illnesses who are enrolled in clinical trials.
- Dependent children will be allowed to remain on their parents' health insurance up to age 26.
- Existing insurance plans will be barred from imposing lifetime caps on coverage.
- Insurers will be prevented from canceling insurance retroactively, except for fraud.
- Insurance plans cannot exclude coverage for pre-existing medical conditions for children under age 19.
- Steps will be taken to fix the doughnut hole; in the first year, those who hit the doughnut hole will receive a \$250 rebate.
- Prevention care will be available to Medicare beneficiaries without co-payments or deductibles beginning in 2010.
- People with medical conditions that make them uninsurable may be able to get coverage through a federally subsidized health insurance program, to be established within 90 days. The legislation limits spending for this program to \$5 billion.

Now that the bill has been signed into law, NCCS will be working with policy and other decision makers to ensure that these reforms are implemented. [To read the entire article.](#)

### Resources to Better Understand Health Care Reform's Implications on Cancer

**From the American Cancer Society's Cancer Action Network:**

- ["The New Health Care Reform Law Through the Cancer Lens: Key Provisions Affecting Cancer Patients and Survivors"](#)
- ["Health Care Reform: Timeline for Implementation"](#)
- ["Affordable Care Act and Pain Management"](#)
- ["Affordable Care Act and Medicaid Expansion"](#)

**Washington Post article: "New health-care law might make your doctor more informed, efficient, responsive"**  
**Published on 5/4/10 by Mark Brown**

*In many respects, American doctors today labor much the way their counterparts did 50 years ago.*

*Most are in practices with five or fewer other physicians. They keep their records on paper in longhand. When they need to consult a colleague, they reach for the telephone. They bill for each visit. They have little idea about*

*how their skills compare to those of fellow practitioners, nor do most know what their patients really think about the care they give.*

*The new health-care law aims to change most of that.*

Fifty years from now, it is likely that almost all doctors will be members of teams that include case managers, social workers, dietitians, telephone counselors, data crunchers, guideline instructors, performance evaluators and external reviewers. They will be parts of organizations (which either employ them or contract with them) that are responsible for patients in and out of the hospital, in sickness and in health, over decades.

The records of what they do for a patient -- and what every other doctor does -- will be in electronic form, accessible from any computer. Software will gently remind them what to consider as they treat, and try to prevent, diseases. How the patients fare will be measured and publicized, and used in part to judge practitioners' performance. At the same time, the health-care organizations, aided by the government, will make an effort to let caregivers know the "best practices" they're expected to follow.

Read the entire article: <http://www.washingtonpost.com/wp-dyn/content/article/2010/04/30/AR2010043002007.html>

## RESOURCES

### **Lance Armstrong Foundation announces new free iPhone application**

Lance Armstrong Foundation recently announced a new LIVESTRONG cancer resource for cancer survivors and professionals available for iPhone, iTouch and iPad users. This application is a cancer dictionary that users can download for free through the iTunes app store.

The application provides users quick and easy access to a cancer dictionary in both English and Spanish, and is the only cancer dictionary available through iTunes that is both free and from a reputable cancer organization. The dictionary uses cancer terms and definitions from the National Cancer Institute's Cancer Dictionary and is updated with new terms on a regular basis. Realizing that these definitions may present users with more questions and concerns, LAF has included an option at the bottom of each definition where users can contact LIVESTRONG SurvivorCare, a direct one-on-one support program, with one touch. Through this feature, users will have access to Navigation Coordinators to express their concerns and ask questions about the information they read.

View images of the app by visiting <http://itunes.apple.com/us/app/livestrong-english-spanish/id375144785?mt=8>.

For additional information please contact Haley Justice, **Program** Manager for the Lance Armstrong Foundation at 512.279.8388 or [haley.justice@laf.org](mailto:haley.justice@laf.org)

**Computer-Based Tool Helps Survivors Move Forward After Cancer:**  
***Survivorship Care Planning Program Benefits Survivors of All Types of Cancer***

Citing shortfalls in the care currently provided to the country's 11 million cancer survivors, the [Institute of Medicine](#) recommends that each cancer patient receive a "survivorship care plan." Such plans should summarize information critical to the individual's long-term care, such as the cancer diagnosis, treatment, and potential consequences; the timing and content of follow-up visits; tips on maintaining a healthy lifestyle and preventing recurrent or new cancers; legal rights affecting employment and insurance; and the availability of psychological and support services.

Journey Forward ([www.JourneyForward.org](http://www.JourneyForward.org)), has released a new computer-based tool that enables anyone diagnosed with any type of cancer to have their medical history, cancer treatment summary and a post-treatment survivorship care plan captured in one place.

Journey Forward, a collaboration among the National Coalition for Cancer Survivorship (NCCS), the UCLA Cancer Survivorship Center, WellPoint, Inc., and Genentech, provides a computer-based tool that allows survivors and their cancer team to develop a customized Survivorship Care Plan. These plans improve coordination of care for cancer survivors throughout their lives, and they help survivors and their loved ones understand their cancer treatment and follow-up needs. Survivorship Care Plans also put survivors in a better position to advocate for themselves, monitor their health, and participate in decisions about their future care.

If you would like to spread the word about this tool throughout your organization and to partners, consider this [sample newsletter copy](#) provided by Journey Forward. You can also find a sample *Journey Forward* Survivorship toolkit online at [JourneyForward.org](http://JourneyForward.org) PATIENTS section.

### **Cancer Advocacy Training Webinars**

The National Coalition for Cancer Survivorship offers online webinar trainings to learn about what advocacy is and how you and/or your partners can get involved in making a difference. Currently available on the website: [The Advocacy Continuum: Six Basic Skills to Help You Survive and Thrive — and Improve Cancer Care for Others \(30 min.\)](#)

The next trainings will include:

- **JULY: How to Hold an Effective Meeting with Your Legislator**  
Learn how to arrange an appointment, how to prepare for your meeting, and what to say depending on where your legislator stands on an issue.
- **SEPTEMBER: The Media and the Message: How to Use the Media to Raise Awareness and Stir Action**  
Learn how to share your story or talk about an issue through traditional and new media.
- **NOVEMBER: Building a Movement: How to Recruit Advocates to Your Cause**  
Learn how to use your story and those of fellow cancer survivors to move people to action in support of your cause.

Visit [NCCS's Advocacy page](#) to read more.

### **Patient Advocate Foundation – News You Can Use**

Patient Advocate Foundation received 75,117 calls from Kentuckians and 1,036 received direct case management help in 2009!

Case management includes assistance to patients with specific issues they are facing with their insurer, employer and/or creditor regarding insurance, job retention and/or debt crisis matters relative to their diagnosis of life threatening or debilitating diseases. PAF's professional case managers and attorneys specialize in mediation, negotiation, and education, advocate on behalf of patients experiencing issues with access to care, job retention and debt crisis due to their illness. To learn more go to <http://www.patientadvocate.org/index.php> or contact Luke Barlowe, Kentucky State Policy Liaison for the Kentucky Division of PAF.

Also, PAF has released a new tool entitled "The National Underinsured Resource Directory". The Directory is intended to help **underinsured** individuals and families locate valuable resources and seek alternative coverage options or methods for better reimbursement.

The National Underinsured Resource Directory is available through an online interactive tutorial program, and a written publication that supports this program. The information will also be provided through an easy to manage pocket envelope of resource cards offering suggestions for resolving specific issues as well as a list of national and state specific resources. To access The National Underinsured Resource Directory, visit: <http://patientadvocate.org/help4u.php>. Organizations that want to include this resource on their websites are invited to contact Erin Moaratty, Chief of External Affairs at PAF at (800) 532-5274 ext 1150 or [erin.moaratty@patientadvocate.org](mailto:erin.moaratty@patientadvocate.org).

And lastly, PAF has launched a new program, the CINV (Chemotherapy-Induced Nausea and Vomiting) CareLine. The CareLine is a toll-free hotline, 877-614-9242, designed to provide individualized case management assistance to patients diagnosed with cancer and experiencing chemotherapy-induced nausea and vomiting. The CINV CareLine is staffed by a team of clinical case managers with both nursing and social work background who provide individualized service to patients, their caregivers and providers who are seeking information and/or assistance with the following:

- Navigation and assistance through the reimbursement system, including initial interpretation of the patient's benefit language
- Direct appeals assistance
- Educational resources, including disease specific literature, managed care information and financial resource information
- Referrals and linkage to appropriate educational resources
- Clinical trials education and clinical trials screening
- Connection to all known local, state and/or national resources for financial assistance
- Case management services to uninsured patients, ensuring access to care and enrollment into Medicaid and/or charity care programs, when appropriate

## RESEARCH

### **More Than 1.5 Million Cancer Survivors Have Kids Under 18:**

***Findings may lead to greater assistance for patients and families, researchers say***

6/28/10 (HealthDay News) -- More than 1.5 million adult cancer survivors in the United States are parents who live with one or more children younger than 18 years old, finds a new study.

The researchers analyzed data from 13,385 adult cancer survivors who took part in the United States National Health Interview Survey between 2000 and 2007. They found that about 18 percent of newly diagnosed cancer survivors and 14 percent of all U.S. cancer survivors live with one or more of their minor children. The percentages mean that there are about 1.58 million adult cancer survivors living with 2.85 million children under age 18. An estimated 562,000 minor children are living with a parent in the early phases of cancer treatment and recovery.

A cancer diagnosis poses extraordinary challenges for people with young children, including worries about not living to see their children grow up. "Greater awareness of the number and characteristics of cancer survivors living with minor children may facilitate clinical screening and referral efforts, inform public health planning, and stimulate research on these understudied families," the researchers concluded.

The study appears online June 28 in the journal *Cancer*. [Read more.](#)

### **Study: Millions Of Cancer Survivors Put Off Care They Can't Afford** ***from Kaiser's Health News Daily Report***

A new study says about 2 million of the 12 million cancer survivors in the United States put off medical care because they cannot afford it. The work was based on national surveys of more than 110,000 people, including 6,600 cancer survivors, from 2003 through 2006. It was released online by the American Cancer Society's medical journal, *Cancer*. "Younger cancer patients were more likely to respond they had put off care because of the cost (Associated Press, Stobbe, 6/14).

Hispanic cancer survivors were most likely to skip treatment according to the study. Hispanic and African American cancer survivors were more likely than whites to leave prescriptions unfilled or to forgo needed dental care. ... Because of their experience, researchers say cancer survivors may have a more heightened sense of health and vulnerability and they might be more aware of symptoms indicating something more serious. They may perceive they need more care than the typical person, which may present more opportunities for financial fears to interfere with them getting the care they need" (CNN, Henry, 6/14).

The Wake Forest study found that breast- and prostate-cancer survivors were least likely to forgo services, while cervical-cancer and melanoma survivors were the most likely to forgo services. Also, the most likely survivors to forgo services were those within the first year of post-diagnosis or very long-term survivors. (Winston-Salem Journal, Craver, 6/14).

*This is part of Kaiser Health News' Daily Report - a summary of health policy coverage from more than 300 news organizations. The full summary of the day's news can be found [here](#) and you can sign up for e-mail subscriptions to the Daily Report [here](#).*

### **Yoga Eases Sleep Problems Among Cancer Survivors**

***Study found those who practiced it for four weeks after chemo slept better, used fewer sleep aids***

5/20/10 (HealthDay News) -- Cancer survivors who participated in a month-long program in the ancient art of yoga reported enhanced quality of life, better sleep, less fatigue and less need for sleep medications.

The results of the trial, the largest randomized, controlled study on this topic to date, were presented at the American Society of Clinical Oncology's annual meeting, held in June in Chicago. Some 80 percent of cancer patients have trouble sleeping while undergoing treatment, and about two-thirds say the problems persist after treatment ends. Despite these large numbers, few solutions exist.

[The study](#) authors involved 410 cancer survivors, average age 54, who had finished treatment two to 24 months before and who still reported greater-than-average sleep disruptions. Participants were randomized either to receive regular follow-up care for cancer survivors or to receive regular care plus two 75-minute sessions of yoga per week for four weeks. Key findings included:

- Yoga participants reported an improvement in sleep quality of 22 percent, while controls reported an improvement of only 12 percent.
- Thirty-one percent of participants in the yoga group who had started out with clinically impaired sleep quality recovered vs. only 16 percent in the control group.
- Fatigue in the yoga group was decreased by 42 percent, compared with only 12 percent in the control group.

### **Mastectomy Rates Down Overall, New Comprehensive Study Finds**

***While previous studies show opposite trend, latest one reflects entire U.S. population, experts note***

6/15/10 (HealthDay News) -- While some recent research has documented an upswing in mastectomy rates among women who have been diagnosed with breast cancer; a new study comes to a different conclusion. The report is published in the June 14 online issue of the *Journal of Clinical Oncology*.

Why the discrepancy? Previous studies showing an increase in the drastic procedure, according to the University of Minnesota Med School researchers, have come from leading institutions but drawn all of the patients from a single hospital. "Often single institutions publish research that is not reflective of what is occurring nationwide."

The University of Minnesota researchers looked at the Surveillance, Epidemiology and End Results (SEER) registry. While it includes about 26 percent of U.S. residents, it is representative of the entire population. Researchers zeroed in on 233,754 patients diagnosed between 2000 and 2006 with either ductal carcinoma in situ or stage 1 to stage 3 unilateral breast cancer. "Mastectomy rates decreased, from 41 percent in 2000 to 37 percent in 2006."

Curiously, the researchers found that the rates of women opting to have the opposite, healthy breast removed as a precaution actually rose, going from 2.5 percent in 2000 to 5.7 percent in 2006. [Read all the study's findings and implications.](#)

### **Stress-Relief Program Helped Those Facing Breast Cancer Twice**

***Intervention boosted quality of life, longevity after disease returned, study found***

6/8/10 (HealthDay News) -- A stress-relieving program may boost survival in women with recurrent breast cancer and also improve their quality of life, a new study suggests.

Patients who took part in the program had "significant emotional improvement and more favorable immune responses in the year following recurrence diagnosis," study author Barbara L. Andersen, a psychology professor at Ohio State University, said in a news release from the American Association for Cancer Research.

The researchers followed 227 women who were newly diagnosed with breast cancer in stage 2 or stage 3. The participants were randomly assigned to either take part in an intervention program designed to reduce stress and improve overall health, or to just be assessed without participating in the intervention.

Breast cancer recurred in 62 of the women during the follow-up period. Compared with the non-intervention group, those who had taken part in the anti-stress program were 59 percent less likely to die of breast cancer, according to the report released online June 8 in *Clinical Cancer Research*, the journal of the American Association for Cancer Research. [Read more.](#)

### **Study Finds Video Eases End-of-Life Care Discussions**

Patients with malignant glioma who watched a video that depicts options for end-of-life care were more certain of their end-of-life decision making than patients who only listened to a verbal narrative and were more likely to choose comfort care over aggressive medical care for their end-of-life care preferences, according to an article published online November 30, 2009, in the *Journal of Clinical Oncology*. To read more, visit the National Cancer Institute's Supportive Care Trial Results page at <http://www.cancer.gov/clinicaltrials/results/end-of-life-video0110>

## **National News**

### **CDC's National Comprehensive Cancer Control Program Announces Public Health Needs of Cancer Survivors as a Top Priority**

During the Comprehensive Cancer Control Leadership Institute in Los Angeles June 7-10, Branch Chief Dr. Laura Seeff outlined the National Comprehensive Cancer Control Program's top priorities for the foreseeable future. Among the top three: "Addressing the Public Health Needs of Cancer Survivors". Dr. Seeff discussed potential strategies towards addressing the need, such as:

- Define the scope, needs, and health behaviors of the cancer survivor population
- Enhance survivorship surveillance
- Define health risks from cancer treatment and disseminate clinical management guidelines for cancer survivors
- Ensure that cancer survivors have access to a medical home
- Assess capacity to support survivorship interventions
- Utilize and maintain the BRFSS survivorship module
- Use cancer registry data to define interventions for follow-up treatment and care among cancer survivors
- Develop evaluation measures for survivorship interventions
- Conduct research to assess health risks associated with cancer treatment
- Continue primary and secondary prevention efforts for survivors
- Monitor and track progress of cancer survivors' health, economic, psychosocial issues

Five Kentucky Cancer Consortium Steering Committee and staff attended the Leadership Institute. Katie Bathje will share best practices and strategies from the Institute with the Survivorship Committee at the September meeting.

## Kentucky News

### **Louisville Courier-Journal devotes portion of Sunday newspaper to cancer articles**

The Louisville Courier-Journal's June 20<sup>th</sup> edition included eight news articles and graphics highlighting the burden of cancer in Kentucky, as well as how Kentucky researchers are addressing the burden. Included in the paper was an article on KCC Survivorship Committee member Sister Rita Jarrell entitled "Five-time cancer survivor's 'surprised I'm here'", describing her extensive volunteer work with the American Cancer Society and her inspiring spirit. If you missed this edition, find article titles and links below.

- [Area researchers target 'crisis' of lung cancer: Amid tangible results, many challenges still exist](#)
- [Decades-old war on cancer shows mixed results for nation](#)
- [Lung-cancer survivor feels fortunate 'I am still here'](#)
- [Five-time cancer survivor's 'surprised I'm here' \(article on Sister Rita Jarrell\)](#)
- [Classes and patches help some kick the smoking habit](#)
- [Research being done on various cancers at the universities of Louisville and Kentucky](#)
- [Interactive graphic: Advances in detecting, treating top 10 cancer killers](#)
- [Lung Cancer Signs, Symptoms, Etiology and Statistics](#)

### **Norton Cancer Institute Joins NCI's Program to Enhance Cancer Research and Care at Community Hospitals**

LOUISVILLE, KY. (April, 2010): Norton Cancer Institute in Louisville is among 14 new sites chosen by the National Cancer Institute, part of the National Institutes of Health, to join a national network of community cancer centers offering expanded research opportunities and state-of-the-art cancer care at health care organizations serving largely rural, suburban, small-town, and underserved urban populations. Norton Cancer Institute becomes the first site in Kentucky to be chosen by the NCI for its Community Cancer Centers Program (NCCCP) and one of only 30 sites in the entire country.

The two-year, \$1.6 million NCCCP contract will be supplemented by a \$5 million commitment from Norton Cancer Institute/Norton Healthcare to enhance existing cancer services and programs across the continuum of cancer care, including behavioral oncology, survivorship care, hospice and palliative care, cancer support services, and many others.

In regards to cancer survivorship, NCCCP centers are seeking ways to improve survivorship, palliative care services and patient advocacy. Examples would include establishing survivorship care plans for all cancer patients, integrating palliative care education and initiatives into all cancer care treatment strategies, and developing new efforts to ensure that cancer patients have convenient and effective access to patient advocates.

[Read the press release.](#) For a list of all sites in the network, visit [ncccp.cancer.gov](http://ncccp.cancer.gov).

## **Leukemia & Lymphoma Society**

Do you have Leukemia and Lymphoma Society's Kentucky and Southern Indiana Chapter's most recent contact information on file (see below)? Check your books...

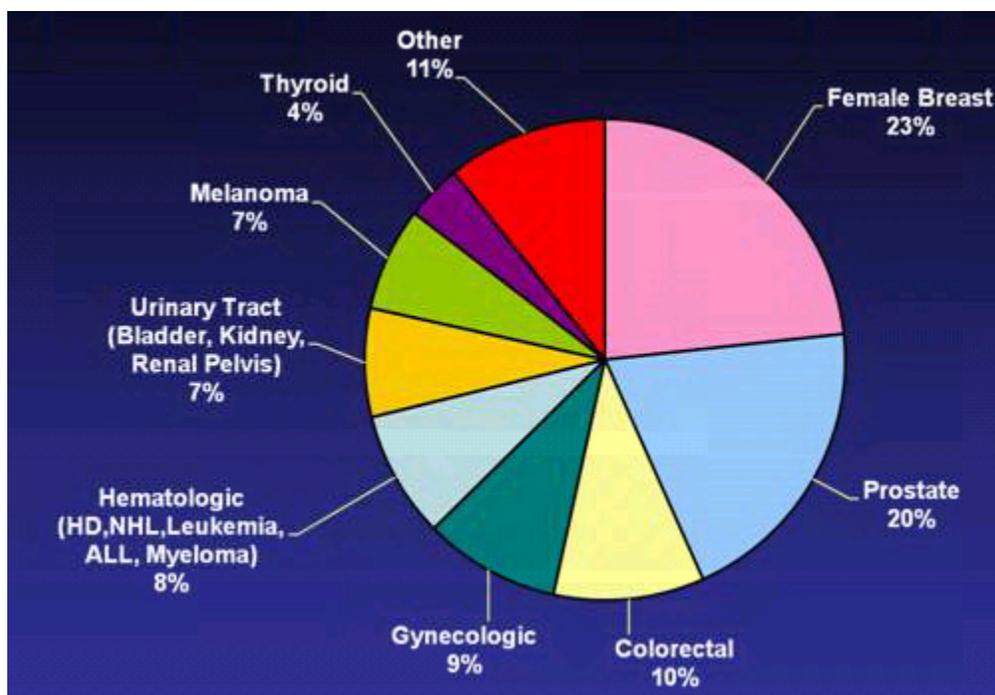
### NCI Survivor FAST FACTS – DID YOU KNOW?<sup>1</sup>

- As of January 1, 2006, it is estimated that there are 11.4 million cancer survivors. This represents approximately 3.8% of the population.
- 60% of survivors are currently 65 years of age and older.
- Approximately 14% of the 11.4 million estimated cancer survivors were diagnosed 20 or more years ago.

<sup>1</sup>Data source: Horner et al. (eds). *SEER Cancer Statistics Review, 1975-2006*, National Cancer Institute. Bethesda, MD, [http://seer.cancer.gov/csr/1975\\_2006/](http://seer.cancer.gov/csr/1975_2006/), based on November 2008 SEER data submission, posted to the SEER web site, 2009.

### Who are the 11.5 million cancer survivors?

Estimated # of Persons Alive in the U.S. Diagnosed with Cancer on 1/1/06 by Site (N = 11.4 Million)



Data source: Ries et al. (eds). *SEER Cancer Statistics Review, 1975-2005*, National Cancer Institute. Bethesda, MD, [http://seer.cancer.gov/csr/1975\\_2005/](http://seer.cancer.gov/csr/1975_2005/), based on November 2007 SEER data submission, posted to the SEER web site, 2008.