



## National Cancer Survivors Day

### The Cancer Institute of New Jersey Celebrates on June 7, 2009



#### What Is National Cancer Survivors Day?

National Cancer Survivors Day (NCSA) is an annual, worldwide Celebration of Life that is held in hundreds of communities throughout the United States, Canada, and other participating countries. NCSA is the world's largest and fastest-growing annual cancer survivor event. The National Cancer Survivors Day Foundation defines a "survivor" as anyone living with a history of cancer – from the moment of diagnosis through the rest of life. During this event, participants unite in a symbolic event to show the world that life after a cancer diagnosis can be a reality. In most areas, National Cancer Survivors Day is traditionally observed on the first Sunday in June, although this is not always possible due to scheduling conflicts and time differences. The Cancer Institute of New Jersey will be celebrating this day on June 7, 2009. This year's event will feature a special guest speaker and cancer survivor, Connor Cunneen. He will discuss *The gift of gab: How goals attitude, and behavior can provide a top o' the morning feeling*". The event will take place 10:30 a.m. at the Hyatt Regency, located in New Brunswick. To make a reservation, please call The Cancer Institute of New Jersey (CINJ) at 732-235-9891.

#### What Are the Key Statistics about Cancer Survival?

The National Cancer Institute estimates that about 11.1 million Americans with a history of cancer were alive in January 2005. Some of these people were cancer-free, while others still had signs of cancer and may have been undergoing treatment. About 1,479,350 new cancer cases are expected to be diagnosed in 2009. In addition, 1 million new cases of skin cancer are expected to be diagnosed this year.

#### Cancer Survivorship

As difficult as treatment is, thousands of cancer survivors have said that the experience led them to make important changes in their lives. Taking the time to appreciate each new day, learning to take better care of themselves, learning the value how others care for them, or becoming national advocates for better cancer research, treatment, and care were some of these significant changes.

The National Cancer Institute has developed a booklet called *Facing Forward: Life After Cancer Treatment*. The information in this booklet is designed mainly for cancer survivors who have recently completed their cancer treatment, but you may find the information helpful even if you were treated a long time ago. Its purpose is to give cancer survivors and their loved ones a better idea of what to expect after treatment ends. It covers what may happen with:

- Your medical care
- Your body
- Your mind and your feelings
- Your social relationships
- Practical matters such as job and insurance issues

You can receive a copy by calling 1-800-4CANCER or visiting this Web site:

<http://www.cancer.gov/cancertopics/life-after-treatment>

## **Cancer Clinical Trials**

If you would like further information about clinical trials (available in New Jersey) for cancer, please call toll-free New Jersey Cancer Trial Connect at 1-866-788-3929 or visit the Web site at [www.njctc.org](http://www.njctc.org). You can also call The Cancer Institute of New Jersey at 1-866-654-9898. For additional information about nationwide cancer trials, you can call the National Cancer Institute at 1-800-4 CANCER or visit their Web site at [www.cancer.gov](http://www.cancer.gov).

## **Where Can I Find Further Information About Survivorship?**

The Resource and Learning Center

732-235-9639

<http://www.cinj.org/rlc>

American Institute for Cancer Research

1-800-843-8114

<http://www.aicr.org>

Beyond the Cure

800-5-FAMILY

<http://www.beyondthecure.org>

Cancer Survival Toolbox

301.650.9127

<http://www.canceradvocacy.org/toolbox>

Cancer Survivors Network, The American Cancer Society

1-800-ACS-2345

<http://csn.cancer.org>

Cancer Survivors Project

<http://www.cancersurvivorsproject.org>

Cancer Survivorship Research

301-402-2964

<http://dccps.nci.nih.gov/ocs/index.html>

The LITE Program

732-235-KIDS

[http://www.cinj.org/documents/pdf/The\\_LITE\\_Program.pdf](http://www.cinj.org/documents/pdf/The_LITE_Program.pdf)

Livestrong  
866.467.7205  
<http://www.livestrong.org>

National Cancer Survivors Day  
615- 794-3006  
<http://www.ncsdf.org>

National Coalition for Cancer Survivorship  
1-877-NCCS-YES  
[www.canceradvocacy.org](http://www.canceradvocacy.org)

National Institute of Health  
301-496-4000  
<http://www.nih.gov>

The Ulman Cancer Fund for Young Adults  
1-888 393-FUND  
<http://www.ulmanfund.org>

National Cancer Institute  
1-800-4-CANCER  
[www.cancer.gov](http://www.cancer.gov)

New Jersey Cancer Trial Connect  
1-866-788-3929  
[www.njctc.org](http://www.njctc.org)

## **The Cancer Survivors' Bill of Rights**

The National Coalition for Cancer Survivorship presents this new version of the Survivors' Bill of Rights to call public attention to survivor needs, to enhance the quality of cancer care, to empower cancer survivors, and at the same time bring greater satisfaction to them and their physicians, employers, families, and friends.

1. Survivors have the right to continuous lifelong medical care, as needed. The physicians and other professionals involved should make every effort to be:
  - Sensitive to cancer survivors' lifestyle choices and their need for self-esteem, dignity and privacy of the information trusted to them;
  - Careful, no matter how long these patients have survived, to take symptoms seriously and not to dismiss aches and pains, for fear of recurrence is a normal part of survivorship;
  - Vigilant to watch for any long-term and late effects of cancer and its treatment in follow-up clinics and offices;
  - Informative and open, providing survivors with as much or as little candid medical information as they wish, and encouraging informed participation but not expecting survivors to manage that care on their own;
  - Knowledgeable about counseling and rehabilitation resources, and willing to refer survivors and their families as appropriate for emotional support and therapy aiming to improve the texture as well as the quantity of time that is theirs to live.
2. No matter in which setting their care is offered--be it fee-for-service or some sort of managed care system--survivors have the right to quality care emphasizing:
  - Informed choice--choice of the setting in which care is delivered, choice of primary physicians and specialists delivering that care, as well as choice of appropriate, effective and safe treatments (including ongoing clinical trials);
  - Efficient yet humane management of such unfortunate by-products of disease as fatigue and pain--pain control management, for example, which approaches survivors more as partners in identifying the proper amount of medication needed at any given time than as potential drug addicts;
  - Appropriate use of hospital and other facilities, wherein cost effectiveness and patient-centered care are balanced so that no survivor is dismissed--after a mastectomy, for example--unable to care for her or himself or secure the care needed to avoid dangerous and painful situations;
  - Constant respect for survivors' wishes as to when and how to discontinue treatment should that time arise, including the scrupulous honoring of "living wills" and similar documents.
3. In their personal lives, survivors, like other Americans, have the right to the pursuit of happiness. This means they have the right:

- To talk with their families and friends about their cancer experience if they wish, but to refuse to discuss it if that is their choice, and not to be expected to be more upbeat or less blue than anyone else;
  - To be free of the stigma of cancer as a "dread disease" in all social relations, wherever they may take place--from home to work or market-place;
  - To be free of blame for having the disease and of guilt for having survived it;
  - To participate in support groups and other survivor support and/or advocacy activities as they wish, for in such settings they usually feel less isolated, more informed, and more able to express their feelings, be they feelings of hope or of despair, without fear of being regarded as "bad" or "ungrateful" or simply "uncooperative" patients.
4. In the work place, survivors have the right to equal job opportunities. This means they have the right:
- To aspire to jobs worthy of their skills, and for which they are trained and experienced, and thus not to have to accept jobs they would not have considered before their cancer experience;
  - To be hired, promoted, and accepted on return to work, according to their individual abilities and qualifications, and not according to "cancer" or "disability" stereotypes with "reasonable accommodation," under federal and state law, such as changes in duties or hours, which allows them to work while receiving medical treatment without falling into a survivors' "Catch-22"--too ill to work, but too healthy to qualify as "disabled" and so entitled to protection under the Americans with Disabilities Act;
  - To privacy about their medical histories.
5. Since health insurance is an urgent survivorship concern, every effort should be made to assure all survivors decent affordable coverage, whether public or private, or provided under managed care or fee-for-service systems. This means:
- For employers, that survivors have the right to be included in group health coverage regardless of health history;
  - For physicians, counselors, and other professionals concerned, that they keep themselves and their survivor-clients informed and up-to-date on the dangers of health insurance discrimination.
6. For social policy makers, both in government and in the private sector, that they seek both to broaden insurance programs to include diagnostic procedures and treatments which help prevent recurrence and ease survivor anxiety and pain, as well as to lower the unfair barriers often imposed by the accidents of race, minority culture, age, or plain lack of means to pay for adequate health insurance coverage.

In sum, cancer survivors have the overriding right to access quality health care. Implicit in that right is universal access to adequate health insurance coverage. For "quality" becomes an empty word without the means to achieve such coverage. A cancer may not even be discovered. And if it is, care may be sub-optimal, no one will be accountable for it, and the whole society will be the losers.