

Cancer Survivorship: Moving the Science and Art of Research and Care Beyond Cure

**Statement of
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Good afternoon, Senator Brownback and Senator Feinstein. I am Julia Rowland, Ph. D., Director of the Office of Cancer Survivorship (OCS) at the National Cancer Institute (NCI). I am pleased to appear before you today to describe the history of the National Cancer Institute's Office of Cancer Survivorship and to share with you the breadth of activities currently supported by the NCI addressing the needs of the growing population of individuals living with a history of cancer, and their family members.

As little as 40 years ago, a diagnosis of cancer virtually was a death sentence for most children and usually meant significant periods of pain and suffering for those diagnosed as adults. Outcomes were often uncertain. The majority of the research on the psychosocial and behavioral aspects of cancer was concerned with whether or not to tell the diagnosis, how to prepare for death, how to manage bereavement, and generally, strategies to reduce suffering. The driving impetus behind most cancer research was simply helping a person survive.

Today, the picture is dramatically different. As we race into the new millennium and embrace the post-genome era, we are beginning to see the fruits of the war on cancer launched in 1971. More than half of all adults diagnosed with cancer today will be alive in five years; the figure for those treated as children is even higher. As past and future advances in cancer detection, treatment, and care diffuse into clinical practice, the number of individuals who are cancer survivors is expected to increase. Fewer deaths from cardiovascular disease and the aging of the population will contribute to this trend.

The very existence of this growing population of survivors is a testament to the many successes achieved by NCI. This includes important progress in the delivery and use of cancer screening, enhancement of early detection technologies, discovery and use of more effective and often multimodal therapies, provision of a broadening array of supportive care and rehabilitative options, and, increasingly, wider adoption of active

screening behaviors and healthier lifestyles by those at risk for the disease, as well as by those with a cancer history. At the same time, however, this population of survivors represents a clear challenge to NCI. America's cancer survivors serve as a reminder that we have a role beyond the search for a cure and to address the needs of and provide hope for a valued future to those living with and beyond a cancer diagnosis.

While research on the biology, treatment, and cure of cancer has flourished, we are only just beginning to describe the health status, functioning, and quality of life of most of those who are post-treatment. There are important questions still to answer:

- What are the most common late effects of treatment?
- Who is at risk for developing these and can they be protected?
- How can we follow these survivors for disease recurrence?
- What constitutes optimal surveillance and what is the cost of such follow-up care?
- Do psychosocial or behavioral interventions reduce physical or psychosocial morbidity in these populations?

Survivorship Research at the National Cancer Institute

In June 1996, NCI created the OCS in recognition of the growing population of cancer survivors in the United States and the knowledge gap in cancer survivorship research. Survivors, their family members, and healthcare providers called for more research information about the challenges faced by those living with a cancer history. The OCS was formed in direct response to their articulate and compelling demand. It was specifically to provide a coordinating locus for and to direct the focus of research and care delivered to survivors following the completion of treatment. The goal of the OCS is to improve the health and life of individuals with a cancer history beyond the acute diagnosis and treatment phase, and to identify, examine, prevent, control, or manage adverse illness- and treatment-related outcomes and age-related co-morbidities. This is important because few current cancer therapies are benign, and widely used cancer treatments (surgery, chemotherapy, radiotherapy) are known to carry substantial risk of adverse long-term (persistent) or late effects (occurring months to years after treatment has ended).

The mission of the OCS is as follows:

- Develop an agenda for the continuous acquisition of knowledge concerning the problems and challenges facing cancer survivors and their families.
- Support studies to increase the length of survival for cancer patients and improve the quality of survival of all individuals diagnosed with cancer and their families, including those that involve prevention of subsequent disease and disability.
- Promote the dissemination of information to professionals who treat cancer patients, and the public concerning the problems and needs of cancer survivors and their families.

With the establishment of the OCS, NCI formalized its commitment to understand better and respond to the unique needs of all cancer survivors. Appointment of a specific office to oversee cancer survivorship initiatives sent a strong signal to both the clinical and research community that NCI was committed to advancing the science associated with caring for long-term cancer survivors. The impact of the OCS has been dramatic.

Since its inception, the OCS has been instrumental in realizing a tremendous increase in funding of survivorship-related research in the NIH research portfolio. In FY 2001, the OCS alone supported 57 grants on survivorship. In addition to an expansive grant portfolio, the OCS is engaged in several broad coordination efforts across the survivorship continuum, including palliative care. Activities include the development of evidence-based educational materials, co-sponsorship of scientific meetings with survivorship-relevant organizations (e.g. ACS), and co-management and funding of several grants with the National Institute of Mental Health, the National Institute of Nursing Research, and the National Institute on Aging. In 1996, NCI conducted an internal review of the NIH research portfolio related to cancer survivorship.

The findings of this review helped prompt NCI's strong commitment to promote cancer survivorship research and fill this knowledge gap. Subsequently, the OCS has taken on the role of conducting annual NIH portfolio analyses related to survivorship research. It also reviews the work supported by other organizations that focus on survivorship issues. As a result, the OCS has a unique opportunity to track scientific outcomes and is poised to identify gaps in survivorship research.

The OCS, in partnership with a number of different NCI offices and divisions, has created several products that enable NCI to track more accurately who is surviving cancer, and also to communicate more effectively with diverse audiences about the growing knowledge base regarding the long-term health and care of survivors and their families. Each of these is described briefly below.

- *Prevalence Statistics*
<http://cancercontrol.cancer.gov/ocs/prevalence/index.html>
The OCS Prevalence Statistics Web site provides updated information about cancer survivors in the United States. The site soon will be expanded to track minorities, to provide better information on survivors' second malignancies and quality of life and prevalence data by state.
- *Facing Forward Series*
The Facing Forward Series for cancer survivors, family members, and medical professionals is an NCI product designed to educate and empower cancer survivors as they face the challenges associated with life after cancer treatment. The Series soon will create booklets for family members and healthcare providers.
- Office of Cancer Survivorship Web Site
<http://survivorship.cancer.gov>
The OCS Web site is a comprehensive resource for researchers, advocates, and the public. The site contains a wealth of information for cancer survivors.

Features include current OCS research grants, grant funding opportunities, and post-treatment resources.

The OCS has, since its inception, worked to build strong partnerships across NCI, as well as with other federal and non-governmental cancer-related entities. In addition, the OCS has led several important conferences intended to guide the science of cancer survivorship research and equip survivors and their healthcare providers with up-to-date information critical to achieving the optimal care of those living with a history of cancer.

- *Physical Activity after Cancer:* Recent evidence suggests a protective effect of physical activity against cancers of the colon, breast, and prostate. Plausible mechanisms include the prevention of weight gain or obesity, and thus the modulation of sex hormones or growth factors. In addition, physical activity affects many physiologic systems and may modify the carcinogenic process through many routes and at many stages. To date, this body of research on physical activity has focused largely on the role of exercise as a protective factor in the development of cancer. However, a small but growing body of research is beginning to show that physical activity and exercise interventions may enhance the health and quality of life of those already diagnosed with cancer.

In order to better understand and describe this emerging area of science, NCI convened a January 2002 meeting for researchers involved in studying the psychosocial and health-related effects of physical activity among cancer survivors. Partners from the ACS, the Department of Defense (cancer research program), and the Lance Armstrong Foundation also participated in the meeting.

As a result of the meeting, literature reviews were commissioned on four major topic areas: physiologic and psychosocial outcomes of physical activity interventions among cancer survivors, methodological challenges to conducting physical activity research in this population, issues of special relevance to physical activity research in the older adult cancer survivor population. These papers currently are being considered for publication as a group in a journal. Information from the meeting also is being used to support several NCI-wide initiatives currently under consideration to advance research in the larger areas of diet and physical activity.

- *Biennial Cancer Survivorship Conference:* To keep abreast of the state of the science in cancer survivorship research, the OCS, in collaboration with the American Cancer Society (ACS), established a biennial conference on cancer survivorship. The inaugural conference titled, "Cancer Survivorship: Resilience Across the Lifespan," was held in June 2002. There were over 300 participants - researchers, medical professionals, and cancer survivors - in attendance to hear the 20 guest speakers address such topics as cancer survivorship and aging, promoting post-treatment adaptation, pathways to psychosocial care, family outcomes, and improving survival in the setting of advanced disease. The papers

from this conference are currently under review for inclusion in a special supplement to the journal *Cancer*, expected in early 2004.

Prior to the conference, a town hall meeting was held in celebration of National Cancer Survivors' Day. The town hall was designed to bring the consumer's voice to the scientific proceedings and was attended by over 100 cancer survivors, their loved ones and advocates, and many NCI-funded researchers. The event was Web cast live by the ACS, who, along with the National Coalition for Cancer Survivorship, co-sponsored the event. A panel of survivors, moderated by well-known radio host Paul Berry, provided riveting personal accounts and made for lively open exchange.

The NCI /ACS partnership provides a special opportunity to bring together researchers and clinicians performing cutting-edge cancer survivorship science every other year. It will also provide a venue where we can ascertain where the research gaps remain, and the directions future science needs to take, identify resources and partnerships needed to move forward a strong survivorship agenda, and communicate with and engage survivors, their caregivers and healthcare professionals in our efforts to achieve the NCI's goals of improving both the length and quality of survival for all those affected by cancer.

- *Cancer Survivor Follow-Up Programs and Clinics Meeting*: Most survivors need some manner of cancer-related surveillance and medical care for the balance of their lives. Many cancer centers and academic institutions have developed specialized follow-up care clinics and programs in order to address the follow-up care needs of long-term survivors of childhood cancer. However, to date, there has been little coordination of efforts across centers and no attempt to evaluate their effectiveness. Worrisome also is the realization that these programs may not be taking full advantage of the potential to collaborate, conduct research, and take advantage of the unique potential to prevent or detect early the many persistent or late effects of cancer treatment.

The International Workshop on Long-Term Follow-Up Care Programs for Survivors of Pediatric Cancer was convened in an effort to respond to these issues, and to formulate a research agenda that will advance the science associated with the care and follow-up of the cancer survivor population. The group met in June 2002 and again in February 2003. A significant outcome of these meetings was a clear consensus regarding the desirability of developing a consortium or working group of follow-up care clinics. This request is being actively pursued.

- *State of the Science Meeting: Symptom Management in Cancer: Pain, Depression and Fatigue*: Health care professionals, caregivers, and patients all have an important role in symptom management throughout the course of cancer. Evidence suggests that pain is often under-treated, despite the availability of effective interventions. Cancer-related depression and fatigue are less clearly defined, but are extremely common and have a profound impact on a patients'

well being. A future priority would be to study the occurrence, causes, and impediments to effective treatments of these symptoms. These findings emerged from the NIH Symptom Management in Cancer meeting. The meeting brought together national experts to address key questions regarding the occurrence, assessment, and treatment of these symptoms, barriers to their effective treatment, and directions for future research.

Papers from all of the meeting presentations are currently under review for publication in a supplemental issue of the *Journal of the National Cancer Institute*. In addition, there are two active NCI-wide working groups addressing health-related quality of care research and palliative care issues. Both are moving forward a range of initiatives and activities that respond to the recommendations of the panel.

Highlights of Progress: What Has the Research Shown?

NCI's investment in cancer survivorship research is beginning to reveal a number of facts and trends. Persistent or late effects from cancer treatment include physical symptoms and impairment that may decrease length and quality of life, emotional distress, altered social functioning, and economic hardship. In contrast, studies have shown that many survivors identify their illness experience as an event that has the potential to help them make personally meaningful health and lifestyle changes.

Among pediatric cancer survivors, it is estimated that one-fourth of late deaths among childhood cancer survivors are due to complications of their disease or its treatment (second malignancies, cardiotoxicity). Late cardiotoxicity (heart problems) occurs in 5 percent to 10 percent of long-term cancer survivors 5 to 10 years after therapy, and is often life threatening if not treated by heart transplant. Acute lymphoblastic leukemia survivors are at significant risk of being overweight or obese when compared to sibling controls. As many as one-fourth of pediatric cancer survivors may have incomplete knowledge of the treatments they received. Further, 46 percent of a large sample of pediatric survivors denied that their past therapy could cause a serious health problem with the passage of time. Post-traumatic stress disorder may occur in as many as one-fifth of pediatric cancer survivors. Rates of this disorder are even higher among parents (in particular, mothers) of children treated for cancer, affecting as many as one-third or more of parents even years after treatment has ended.

Among survivors of adult-onset cancers, breast and lymphoma survivors exposed to systemic chemotherapy are at increased risk for neuro-cognitive deficits (e.g., problems with memory, concentration, attention). Long-term breast cancer survivors as a group, and in particular those who are younger at age of diagnosis and/or receive systemic therapy (chemotherapy or hormonal therapy), are at increased risk for functional and physical limitations when compared to women without a cancer history. Up to 44 percent of head and neck survivors able to eat by mouth experience chronic laryngeal aspiration that places them at significant risk for pulmonary complications such as pneumonitis. African American survivors experience poorer functional health after cancer; they also

report being less concerned about a recurrence and are less likely to follow routine screening guidelines than white survivors. Among the larger population of survivors, those working at the time of diagnosis may experience significant reduction in annual market earnings compared to age-matched cancer-free controls.

There are some promising interventions in development. Use of the drug dexrazoxane (DEXRA or Zinecard) during active treatment may prevent or reduce acute cardiac injury associated with doxorubicin therapy. Methylphenidate (more familiar to some as Ritalin) may provide short-term benefit in childhood cancer survivors who experience clinically significant learning problems. Daily consumption of aspirin by breast cancer survivors may result in a significant reduction in relative risk of death from breast cancer.

Where Do We Go From Here?

We have identified several directions for future development in research on post-treatment survivorship issues. First among these is the need for more descriptive and epidemiologic research on the chronic and long-term impact of cancer on survivors.

Few of our current cancer treatments are benign. There is the hope that in the near future, more molecularly targeted therapies will be identified and used. Until then, however, the oncologic community must work with drug and treatment modalities that carry the risk of mild to substantial risks of adverse chronic or late effects. As children and adults with a history of cancer live longer, and data from research studies supported by NCI mature, more of these risks are being documented and reported: neurocognitive problems, premature menopause, cardiorespiratory system dysfunction, sexual impairment, infertility, chronic fatigue and pain syndromes, and second malignancies. The risks are not limited to physical and functional problems. Research shows that many survivors experience significant adverse psychosocial outcomes: fear of recurrence, poor self-esteem, anxiety and depression, employment and insurance discrimination, body-image disturbances, relationship difficulties. It is clear that for those post-treatment, being disease-free does not mean being free of their disease.

The need to identify those at increased risk for complications of treatment, and interventions to reduce that risk (e.g., use of cardio-protective agents during herceptin or anthracycline-based chemotherapy), is becoming increasingly urgent. Access to information about treatment-related risks is also critical if we are to help patients and their providers negotiate the treatment decision-making process, especially when different options may exist. It is expected that with the decoding of the human genome, our ability to identify hereditary cancer risk patterns (e.g., BRCA1/2, Li-Fraumeni syndrome) and oncogenes (erb-B, HER-2/neu, myc, p53) will accelerate. What impact these genetic characteristics have on treatment and subsequent patient outcomes is still in its infancy. Using survivors' tissue and blood samples to track outcomes holds the promise of helping us to understand how these genes operate and what therapies may be effective in controlling cancer.

A second vital area of focus is on the development and application of interventions that will prevent or reduce the adverse sequelae of cancer and its treatment on survivors' physical, psychological and social functioning. Almost half of the grants in the survivorship area contain an intervention component.

In addition to these two large areas of research focus, the OCS has identified an additional five areas for future investment. These include:

- *Underserved and poorly studied populations of survivors.* A number of recent reports highlight the unequal burden of cancer faced by those from low-income backgrounds, diverse ethnocultural minorities, and rural communities. New initiatives to address these health disparities will necessarily include research on the survivorship experience of these previously neglected groups. In addition, information about our older survivors and those with some of the most common malignancies (e.g., colorectal cancer, gynecologic cancer, lymphoma) is also surprisingly limited. If we are to understand and advance the care of all of those diagnosed, we must expand our research to include the full representation of all constituent members of those living with a history of cancer.
- *Economic outcomes, patterns of care and service delivery.* Determining the personal and social costs of cancer on individuals, their families, and society at large remains a challenge. More research could be done on the impact of cancer on work and economic status; insurability; and the impact of patterns of follow-up care on survivors' health status, morbidity, and mortality.
- *Focus on family.* We are only just beginning to appreciate the impact cancer has on the functioning and well-being of the millions of family members affected by this illness, many of whom may themselves be at increased risk for cancer due to shared cancer-causing genes, lifestyle, and/or toxic exposures. As cancer care is pushed into the outpatient setting, the economic, physical, and emotional burden on family members is increasing. We need to acknowledge this additional at-risk population and take advantage of the opportunity to provide these vital caregivers with supportive or health-promoting interventions as part of standard cancer care.
- *Instrument development.* The past decade has seen the introduction of a host of well-developed measurement tools to describe the impact of cancer diagnosis and treatment on individuals' health-related quality of life. As this population lives longer following treatment, new tools will be needed to accurately describe the late effects of treatment and to compare the well being of those living with and without a history of cancer.
- *Education.* As we learn more about the cancer survivorship experience and the interventions or care needed to optimize outcomes, we must find ways to communicate this knowledge to those in most need of the information. Patients, families, healthcare providers, and cancer advocates and policy makers are important audiences to educate. At the same time, we need to mentor and train the next generation of clinicians and researchers to study and deliver state-of-the-art cancer care.

NCI is uniquely poised to champion significant advances in our capacity to understand and enhance cancer survivorship. A number of recent initiatives including our Cancer Care Outcomes Research and Surveillance Consortium, SEER Expansion, Extraordinary Opportunity in Cancer Communication, and NCI Special Populations Networks, will provide us with a rich source of data and direction for future research. They will tell us which ethnic groups may have poorer cancer survival and why, what instruments are being used to assess health-related quality of life and satisfaction with care among survivors, and what types of information cancer survivors are looking for and where they search to find this. Importantly, we are in a time when we have a strong and articulate survivor community. We intend to share broadly the cutting-edge information that is being generated by our research community.

NCI, in its budget proposal for fiscal year 2004, has identified cancer survivorship as a scientific priority. Our strategy, outlined in *The Nation's Investment in Cancer Research for Fiscal Year 2004: Plans and Priorities for Cancer Research*, serves as a blueprint for - as well as a means to track our success in delivering on - NCI's intent to champion the aggressive expansion of cancer survivorship.

It is clear that cancer survivors face unique, multifaceted and, in many cases, uncharted consequences of their illness and treatment. It is also clear that responding to the needs of this diverse population demands an interdisciplinary approach that includes clinicians and researchers, experts from the biomedical and social sciences, ethicists, statisticians, epidemiologists, economists, health policy experts, and consumers. Information about our survivorship community is critical if we are to help patients make decisions now about treatment options that will affect their future; tailor therapies to maximize cure while minimizing adverse treatment-related effects; develop and disseminate evidence-based interventions that reduce cancer morbidity and mortality and facilitate adaptation among cancer survivors; and improve the quality of care being delivered, control the cost of that care, and equip the next generation of healthcare professionals to provide not just the science but also the art of comprehensive cancer medicine. NCI is committed to increasing its investment in survivorship research, one that both acknowledges and strives to learn from the growing numbers of cancer survivors.

Thank you for this opportunity to speak with you today. I would be pleased to answer any questions you may have.