



# The Research Connection

The Psychosocial & Nursing Advisory Board to  
the New Jersey Commission on Cancer Research

Editor: Kathleen Neville, Ph.D., RN

Number 1

The Joint Psychosocial and Nursing Advisory Group to the New Jersey Commission on Cancer Research (NJCCR) was appointed to advise the NJCCR of special research needs pertaining to nursing, psychology, sociology, and related disciplines for the purpose of addressing gaps in vital areas of cancer research and cancer care in New Jersey.

## 2008 Psychosocial & Nursing Advisory Group Members

### Chairs

Mildred Ortu Kowalski, PhD, RN, MPA  
Lissa Parsonnet, PhD

Denyse Adler, MA  
Alan Axelrod, MSW  
Cynthia Ayres, PhD, RN  
Wendy Budin, PhD, RN, BC  
Julie A. Fitzgerald, PhD  
Denise C. Fyffe, PhD  
David Gordon, MS  
Ellen Levine, MSW, LCSW, OSW-C  
Ruth Lin, RN, MS, AOCN  
Kathleen Neville, PhD, RN  
Linda J. Patrick-Miller, PhD  
Kathleen Walsh Scura, EdD, RN, GNPC

## Treatment, Clinical Care and Research of Young Adults with Cancer

by

Darlene G. Gibbon, M.D.

Co-Director of Adolescent and Young Adult  
Oncology Clinical Services, Clinical Director,  
Gynecologic Oncology at CINJ and Assistant  
Professor of Obstetrics/Gynecology and  
Reproductive Sciences, UMDNJ-Robert Wood  
Johnson Medical School

In order to fully conceptualize how to design a research and clinical program for Adolescent and Young Adult (AYA) cancers, one must look at several recurring themes throughout the *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer, Report of the Adolescent and Young Adult Oncology Progress Review*

(continued on page 2)

### IN THIS ISSUE

Article 1	Treatment, Clinical Care and Research of Young Adults with Cancer	1
Article 2	Long Term Effects and Follow-Up of Young Adults with Cancer	4
Article 3	Dealing with the Psychosocial Issues as Young Adults with Cancer	7
Article 4	Supportive Services for Young Adults with Cancer	9
Article 5	Survivorship in Young Adults: A Call to Action	10

*Group (PRG).* The recommendations for implementation of the following PRG imperatives that have particular relevance to the treatment, clinical care and research of young adults with cancer are:

1. Ensure excellence in service delivery across the cancer control continuum (i.e. prevention, screening, diagnosis, treatment, survivorship and end of life.)
2. Identify the characteristics that distinguish the unique cancer burden in the AYAO (Adolescent and Young Adult Oncology) patient.
3. Provide education, training and communication to improve awareness, prevention, access and quality cancer care for AYA's.
4. Create the tools to study the AYA cancer problem.

Why is this group underserved? Progress in AYA oncology has been hampered because cancer risk and adverse cancer outcomes have been under-recognized in this population. Several closely interrelated factors may have contributed to the failure to improve the outcomes of AYA's with cancer and can be broken down into what I refer to as the three A's:

**Awareness:** Cancer in this population goes unrecognized by the young individuals affected, the public and even healthcare professionals. Cancer is the leading cause of disease-related death among adolescents and young adults. Diagnosis can be delayed because AYA's typically see themselves as invulnerable to serious disease or injury, causing them to ignore or minimize symptoms and delay seeking medical attention. Additionally, healthcare providers have a low level of suspicion of cancer in this population.

The first step for the organizers of the PRG was to define who AYA patients are. This was

undertaken by looking at empirical and observational research indicating that AYA's with cancer are distinguished by physiologic, developmental, and societal characteristics as well as less improvement in survival that set them apart from younger and older age groups. To prioritize research and health care needs, the population was defined as being between the ages of 15-39. For AYA issues to be addressed effectively, the first critical step is broad acceptance of AYA's as a distinct demographic group with unique needs related to their age and stage of life.

**Access:** Access to care can be restricted or delayed, in part because AYA's have the highest uninsured rate of any age group in this country. AYA's with symptoms of cancer may see a variety of health care providers and once seen, referral patterns for AYA's suspected or diagnosed with cancer varies widely. These patients too frequently fall into a "no man's land" between pediatric and adult oncology. Most AYA's are treated in the community rather than in cancer centers. However, a robust community oncology and primary care infrastructure does not currently exist to enable patient data collection that would support research efforts. Contact with many AYA patients is lost following treatment, complicating collection of late effects and outcome data in this highly mobile population.

**Advances:** Research on AYA's has been further constrained by their exceedingly low participation in the clinical trials available to them. Poor understanding of patient and tumor biology that distinguishes cancers in this population has contributed to minimal advances in treatment. Inconsistency in treatment and follow-up care coupled with insufficient research data has prevented the development of guidelines for treating and monitoring AYA's with cancer and few tools exist to measure the efficacy of treatment and psychosocial interventions delivered in diverse settings.

## RESEARCH

- 1) **Identify the characteristics that distinguish the unique cancer burden in the AYA patient.**
- 2) **Create the tools to study the AYA cancer problem.**

A more robust research effort is needed to better understand tumor biology and human factors that affect aging, disease susceptibility, treatment response and outcome. Factors that characterize and account for disparities experienced by AYA cancer patients and survivors are understood only in the broadest terms. Further research is needed to elucidate in detail the factors contributing to under-service and poorer outcomes among AYA's as a whole and among racial and ethnic subgroups within the AYA population.

Among the 703 active, applicable NCI sponsored trials, only 26 Phase III trials have no age limitations that exclude a portion of the adolescent and young adult patient population. More clinical trials designed specifically for AYA's are needed, as are more trials that include all AYA's in the eligible patient age range. When AYA's are enrolled in trials that include a wide patient age range, separate analyses and reporting of outcomes by age cohort should be conducted whenever possible.

The existing research infrastructure is inadequate to support needed AYA-focused research. The most pressing needs are to create a prospective database on all AYA cancer patients, increase the number of annotated AYA tumor, normal tissue and other biospecimens, improve grant coding and search term standardization and expand the number of clinical trials appropriate for and available to AYA's.

## TREATMENT AND CLINICAL CARE

- 1) **Provide education, training and communication to improve awareness, prevention, access and quality cancer care for AYA's.**
- 2) **Ensure excellence in service delivery across the cancer control continuum (i.e. prevention, screening, diagnosis, treatment, survivorship, and end of life.)**

The AYA's PRG recognized an urgent need for a variety of education, training, and communication activities to raise awareness and recognition of the AYA population at both the public and professional levels as a first step toward increasing national focus and resource allocation to address the AYA cancer problem. Current health care provider training programs generally do not address AYA-specific issues, resulting in poor recognition of AYA's cancer risk and inadequate response to their medical and psychosocial needs. Core competency curricula are needed for inclusion in appropriate training and continuing education programs to ensure that all providers who work with adolescents and young adults have the requisite understanding of the cancers that either peak or occur more commonly in this age group.

Establishment of standards of care for AYA cancer patients must be developed, evaluated and disseminated. Excellence in care may vary not only by cancer diagnosis but also, by age and gender, race/ethnicity/culture, socioeconomic status, access to care, insurance status and this must be addressed to meet the complete spectrum of patient needs. Establishing, disseminating and reinforcing standards of cancer care for AYA's will require an ongoing and concerted collaboration. Health care providers, research sponsors, investigators, regulators, insurers, and patient advocates should expand existing collaborations and establish a national network or coalition committed to

improving the quality of life and outcomes for AYA's with cancer.

New AYA specific clinical programs should be developed based on current knowledge and modeled after successful existing programs. These AYA programs should be evaluated rigorously through a program of health services research to guide future program development. The PRG concurs with the consensus that has emerged among health professionals, health care organizations, patients and advocates that services for AYA's should be based on a patient-centered model of care. AYA patients need access to oncology centers of excellence, access to clinical trials, and a means to obtain appropriate counseling, peer support, and patient navigation/health coaching.

The intent of this synopsis of the PRG Review is to be informational, thought provoking and to initiate a dialogue addressing the strategies necessary to decrease the healthcare disparity in AYA oncology in this country and in the state of New Jersey.

## **Long Term Effects and Follow-up of Young Adults with Cancer**

by

**Generosa Grana, M.D.**

Director, The Cancer Institute of New Jersey  
Head, Division of Hematology & Medical  
Oncology at Cooper University Hospital

As the population of young adults with cancer increases, so too does our evolving understanding of the health issues faced by this population of cancer survivors. Young cancer survivors face four significant issues that have both psychosocial as well as medical implications:

- 1). Risk of late sequelae associated with their cancer treatment
- 2). Risk of disease recurrence
- 3). Risk of new malignancies (due to association, treatment or hereditary factors)
- 4). Impact of their disease on family members

### **Risk of Late Sequelae Associated with Treatment:**

Chemotherapy, radiation therapy and even hormonal therapy, have long-term sequelae that need to be considered. One of the most important issues for young survivors is the fertility effect of systemic therapy. Planning for fertility preservation needs to begin at the time of diagnosis and treatment, if possible and issues to prevent infertility can be considered when choosing a particular chemotherapy regimen or by thinking about sperm and egg cryopreservation. Ultimately, however, the young cancer survivor should be educated about fertility effects of therapy and options with regards to preservation of fertility and assisted reproductive techniques. There is data suggesting that outcomes of pregnancy in cancer survivors are excellent and that there are no increased birth defects or genetic diseases in offsprings conceived after cytotoxic chemotherapy.

Sequelae of cancer treatment can be seen to affect almost every organ system. There is cardiac

toxicity – both acute and delayed - related to various agents (anthracyclines, trastuzumab), pulmonary toxicity (Bleomycin), endocrine effects from hormonal therapies such as tamoxifen and Lupron, neurologic toxicity seen with both platinum compounds and taxanes and a host of other health effects. Awareness of these long term effects of treatment is important for both the patient and the primary care provider in terms of treatment of the specific problem and monitoring for disease, but also in terms of implementing disease prevention strategies such as smoking cessation, and other such health maintenance strategies.

### **Risk of Disease Recurrence:**

This risk varies depending on the particular disease in question. It not only depends on the stage of the tumor, but also tumor pathologic factors. The sites of recurrence also depend on tumor type. For example, breast cancer has a preponderance for metastasis to bone, liver and lung, while colon cancer has a preponderance to liver. For some diseases, five year disease-free survival is a very important end point, while for others such as breast cancer, it carries less significance as patients with breast cancer can have late recurrences (10-15 years or longer). The National Cancer Center Network (NCCN) has published guidelines recommending appropriate screening after initial cancer diagnosis and treatment. These guidelines can be helpful for the primary care provider, the oncologist and the patient in terms of identifying the appropriate management after primary treatment has been completed and implementing appropriate screening strategies.

When focusing on surveillance for disease recurrence, the recommended surveillance varies depending on the disease. For certain cancers such as breast cancer, there tends to be a minimalist approach as data has not demonstrated an impact on survival from aggressive screening, while for other cancers such as colorectal cancer, serial tumor markers and scans are recommended (NCCN guidelines). Currently, the tools available for

surveillance for disease recurrence tend to be limited to x-ray studies, CT scans, MRIs and Pet Scans. Tumor markers have been validated in certain diseases such as colon cancer (CA27), ovarian cancer (CA125) and prostate cancer (PSA). Ultimately, current work being done on molecular genetic markers such as p53 and Kras will lead to significant improvements in this area.

As far as managing risk of recurrence, risk modification can be considered including the use of adjuvant therapy such as chemotherapy, hormone therapy and the use of chemo preventive agents (such as Tamoxifen for breast cancer). While much emphasis is placed on lifestyle modification, the research suggesting that significant changes in lifestyle can ultimately modify disease outcome are less than perfect. Two recent studies have shown conflicting results when looking at breast cancer reoccurrence and lifestyle modification via diet and exercise.

### **Risk of Associated Malignancies:**

Second malignancies in cancer survivors may be due to treatment (carcinogenicity of the individual treatment modality varies), due to association (shared environmental exposures), due to hereditary syndromes that are present or they may simply be due to the aging process itself. Whatever the cause, secondary malignancies have a significant impact on the health of the cancer survivor population. It is important to know that secondary malignancies may depend on the treatment undertaken: sarcomas are associated with prior radiation treatment, tamoxifen use for breast cancer leads to an increased risk of endometrial cancer and a variety of chemotherapeutic agents are associated with an increased risk of secondary leukemias and myelodysplasia. The risk of a secondary cancer varies with the agent used, with the total duration of exposure, as well as the time of exposure in the life cycle.

It is well-established that second primary cancers are a major disease burden for long-term

survivors of Hodgkin's Lymphoma. The specific risk for these individuals depends not only on the type of treatment undertaken (chemotherapy vs. combined chemotherapy and radiation), but also the age at which the cancer was diagnosed. This is important in terms of implementing early detection strategies for these individuals. The 30 year cumulative risk of a second occurrence for men and women diagnosed at 30 years of age were 18% and 26%, respectively in a recent article in (Hodgson, Gilbert, Dores, et al., 2007). This compares to the risk of similar individuals in the population whose risk would be 7% and 9%, respectively. It is also important that these risks were elevated 10-25 years before the age when routine screening would be recommended in the general population, thus forcing the issue of tailored surveillance for this group of survivors rather than just following population cancer screening guidelines. Women with hereditary breast and ovarian cancer syndromes have approximately a 60% risk of developing a new primary contralateral breast cancer, as well as a 20-40% risk of developing a primary ovarian cancer. Clearly, for these individuals, the screening and preventative recommendations will be significantly different from those undertaken for the general population. Again, it is important to be aware of risk of second malignancies due to either treatment association or heredity to make appropriate screening recommendations.

### **Impact of the Disease on Family:**

Family members are impacted not just by the experience of the cancer in the survivor but also by the potential increased risk that they themselves will face due to the cancer in question. First degree relatives of individuals with breast cancer have an increased risk of the disease themselves. This is also the case for a variety of other cancers. Families with multiple cases of cancer or young ages of onset of cancer may represent a hereditary syndrome and face much higher risks not just of the cancer noted in the immediate family member, but of other cancers that are part of the spectrum of disease.

Hereditary syndromes have been identified in breast, ovarian, colorectal, kidney and a variety of other cancers. For some of these syndromes, genetic testing is commercially available and can be used to guide the management of at-risk individuals. If an individual tests positive for a mutation in one of these genes, screening guidelines will be modified, prophylactic surgery can be considered and chemo preventive agents such as tamoxifen may be recommended for the appropriate individual. The potential impact of family history needs to be taken into account when assessing screening and preventive strategies for the family members.

Each of the four issues addressed (sequelae of treatment, risk of recurrence, risk of secondary malignancies and risk to family members) has important implications for the long term management of the young cancer survivor and their family. These implications include different screening strategies, a different – and potentially more focused attention – to health maintenance as well a more careful attention to the family. The patient, the primary care physician and the oncology team all play an active role in implementing a long-term survivorship plan that addresses these issues for the individual and the family. None of this can occur, however, without the understanding of the psychological implications of these issues for the patient and the family.

### **References:**

Hodgson, D., Gilbert, E., Dores, G., et al. (2007). Long-term solid cancer risk among 5-year survivors of Hodgkin's Lymphoma. *Journal of Clinical Oncology*, 25, 1489-1497.

## Dealing with the Psychosocial Issues as Young Adults with Cancer

by

**Kathleen Neville, Ph.D., R.N.**

Professor, Department of Nursing  
Kean University

*Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer, Report of the Adolescent and Young Adult Oncology Progress Review Group* (U.S. Department of Health and Human Services, National Institute of Health, National Cancer Institute, and LIVESTRONG Young Adult Alliance) provides striking evidence of the immediate need for the health care community to develop innovative and more comprehensive oncology services to the underserved population of adolescents and young adults (AYA's), who range from 15 to 39 years of age. While the perception is that cancer is a relatively rare disease in this age group; the incidence of cancer is greater in this age group than children under 15 years of age. As stated in this report in 2002, 68,000 adolescents and young adults developed cancer, and this incidence was eight times higher than the number of children less than 15 years of who were diagnosed with cancer (executive summary, i). Cancer remains the leading cause of disease related deaths in this age group among women and is second only to cardiac disease in men. While older adults and young children have shown substantial improvement in survivorship since 1975, adolescents and young adults have not shown significant improvements in survivorship.

In the report *Closing the Gap*, the need to provide intensive, unique services to individuals in this age group is strongly advocated and improved health care delivery is needed in all aspects of care. Clearly, specialized treatment, increased research and expert health care tailored to the unique needs of AYA's is essential to improving survivorship among this age group. For example, cancers in the AYA possess different biological factors than other age groups, and therefore warrant different specific

treatments. In addition, there are limited opportunities for clinical trials and many health services issues exist such as delayed diagnosis, inconsistent specialist referrals, lack of health issues, and lack of psychosocial research for the AYA population.

While this report addresses the need for increased psychosocial research, specifically psychosocial outcomes, causative factors and survivorship issues, the findings of this report closely parallel the findings of the scant literature specific to this age group.

Adolescence and young adulthood are two unique developmental time spans; adolescents are beyond children, but they are not yet adults, and young adults face many uniquely different developmental tasks as they progress to middle adulthood. Adolescence is a transitional period marked by physical, psychological and social uncertainty, characterized by many changes and the evolution of new relationships with family and peers, which can produce uncertainty and for some, distress. For adolescents and young adults, it is a stressful time in life and a diagnosis of cancer is superimposed on the normal stressful developmental tasks of this age group. It is important to note that chronological age does not precisely define a developmental stage, as adolescents and young adults achieve developmental tasks at an individual pace. How cancer impacts on an individual has been shown to depend on their achievement of development tasks and whether they were in early, middle or late adolescence and not merely age (Neville, 2000).

There are many psychosocial and behavior needs unique to the adolescent and young adult and are categorized in this report by: interpersonal, emotional, intellectual, practical, and existential/spiritual issues, as well as the need for cultural sensitivity among this age group. Interpersonal issues pertain to relationships with family, peers, significant others and health

professionals during the cancer experience. The increased need for and resultant changes in social support and networks as a result of cancer, along with the development of protective communication between parents, and the experience of isolation and loss as a result of lengthy periods away from school, work, or social events are extremely important aspects to this age group.

The emotional impact of cancer during this age group is dramatic. While studies address that many survivors do well and some even grow in their experience (Koocher and O'Malley, 1981; Neville, 2000), there are predictors of those who are at risk for major psychosocial difficulties. In addition, as a result of the cancer experience, identity may need to be redefined, and integrating oneself back into their previous school, work and home life while feeling different, often poses difficulties.

Existentially, individuals with cancer must learn to live with uncertainty and while this can be viewed as a negative outcome, many AYA survivors identify that positive uncertainty results with an increased appreciation of life, meaning, purpose and resilience. In terms of religious perspectives, many AYA's report an increased faith or belief, while others indicate that cancer has challenged their religious beliefs.

In the *Closing the Gap* report, the need for increased education and knowledge pertaining to disease, treatment, and long term effects was identified. Sensitivity in relaying information based on cognitive ability and age in a cultural competent and compassionate manner is essential to improving health care delivery to this age group.

Lastly, the many practical issues of dealing with cancer during the adolescent and young adult years were addressed. The challenges of peer pressure promoting the use of alcohol, tobacco and drugs may influence adherence to treatment. Financial issues such as being uninsured, being a

recent college graduate, and child care responsibilities pose real practical issues that warrant the provision of services to aid AYA's in their cancer experience.

In summary, the need for increased psychosocial research and services specific to the adolescent and young adult with cancer has been identified. Important psychosocial outcomes, such as minimizing social isolation, enhancing family communication and peer relations will contribute to the improved well-being of adolescents and young adults living with cancer.

### References

- Koocher, G., & O'Malley, J. (1981). *The Damocles Syndrome: Psychological Consequences of Surviving Childhood Cancer*. New York: McGraw-Hill.
- Neville, K. (2000). *Mature beyond their years: The impact of cancer on adolescent development*. Pittsburgh: Oncology Nursing Press.

## Supportive Services for Young Adults with Cancer

by

**Julie Larson, LMSW**

Clinical Coordinator for Young Adult Services  
CancerCare, New York

Young adults have the highest percentage, of any age group, of being uninsured or underinsured which can lead to a delayed cancer diagnosis, obstacles in accessing medical care and financial strain. The unique psychosocial concerns and needs of this population are also too often neglected or not understood by the medical oncology community. Developmentally, young adults are focused on establishing long-term intimate relationships, reaching milestones of independence from their parents, family planning and professional development. A diagnosis of cancer, in young adulthood, is more unexpected; the emotional responses often more intense. Young adults feel isolated, “out of synch” with peers and left behind. They tend to struggle with stigma and have difficulty “re-entering” post-treatment. Regardless, these patients are forced to communicate with professionals, manage their care, learn complicated medical information and assume critical responsibilities in more intricate and advanced ways than typical for this age. Beyond understanding the fundamentally distinct issues for this age group, recognition of the need for education, peer-to-peer networking, age appropriate and need specific resources and creative outlets for coping is critical to providing the support and information most beneficial to this age group.

In response to the overarching concerns expressed above and more thoroughly in the *Report of the Adolescent & Young Adult Oncology Progress Review Group*, five recommendations were expressed. Among the five recommendations set forth for improving the outcomes of adolescent and young adults with cancer was the need to strengthen and promote advocacy and support of the

adolescent and young adult (AYA) cancer patient. Two equally important models currently exist: peer-to-peer support programs and patient navigator programs. Both types of support are important and crucial to the appropriate support for AYA’s with cancer.

Within professional patient navigator supportive programs, newly diagnosed patients are able to access timely, current and accurate information related to their diagnosis. Information helps young adults to regain a sense of control and begin to navigate the health care system. Professional support helps to connect young adults to available resources they would otherwise be unaware and allows for a safe space to express questions and concerns. Imperative to the value of professional support for young adults is the knowledge base around the unique issues, concerns and challenges faced by this age group as well as the awareness of appropriate and reliable resources for referral.

Peer-to-peer support is equally powerful and valuable to this age group. Peer support helps to reduce feelings of isolation and provides young adults with the opportunity to more candidly gather information and emotional support. Questions regarding the validity of patient training programs and auxiliary support for peer to peer connections have been raised.

In order to begin addressing the recommendations set forth by the PRG, The LIVESTRONG Young Adult Alliance was developed. The LIVESTRONG Young Adult Alliance is a coalition of organizations with the goal to improve the survival rates and quality of life for young adults with cancer. The Alliance in collaboration with the National Cancer Institute responded to the recommendations outlined in the PRG by writing, *Closing the Gap: A Strategic Plan*.

As stated above, the value of both Patient Navigator/Professional and Peer-to-Peer support for

young adults is clear, however, too little is known about the volume and capacity of any existing program. Currently, no credible resource is available to provide reliable information on the supportive resources that exist to specifically address the unique needs of young adults. A review of existing resources is underway to develop standards of care leading to the development of more need/population specific programming.

#### ANNOUNCEMENT



### *A Resource Book for Cancer Patients in New Jersey*

**has been revised by the Nursing & Psychosocial Advisory Group to the NJCCR.**

**Copies are now available, free of charge, by calling 609-631-4747.**

## **Survivorship in Young Adults: A Call to Action**

by

**Regina S. Cunningham, Ph.D., R.N., AOCN**

Chief Nursing Officer

The Cancer Institute of New Jersey

Approximately 70,000 young adults (aged 20-39) are diagnosed with cancer in the United States every year. Although cancer survival rates have been steadily improving in both children and adults, survival among young adults has lagged behind. For many types of cancer found in this age group, survival rates have remained stable and for others, they have actually declined. Young adults experience a distinct array of cancers and treatments that lead to a variety of physical and psychological issues. Because these issues occur in a particular developmental context, they create unique challenges. Disease- and treatment-related alterations in fertility, cognition, body image, stamina, and other long-term effects may lead to distress and worry in young adult survivors. Long-term survival, the attainment of educational or personal goals, the ability to initiate and maintain partner, marital, and family relationships, and employment and insurance status have all been identified as unique concerns within this survivor population.

How are we currently managing young adult survivors and what are the key issues that we need to focus on to meet the special healthcare needs of this population? How can we extend the lives of young cancer survivors while ensuring the quality of those lives? What steps can we take to ensure the delivery of high quality care to young adults and their families as they face the unique challenges of survival?

i). Develop a research agenda that is specifically focused on addressing the unique needs of young adult cancer survivors.

This agenda should be comprehensive and include the development of knowledge that spans from basic to clinical to population science. Specific areas of focus should include the biology of cancers in young adults, secondary malignancies, therapeutic strategies, late effects, fertility issues, the effects of cancer on relationships, family and parenting issues, employment and insurance concerns, models of care delivery, and psychological and psychosocial sequelae of cancer in young adult survivors.

Little is currently known about interventions to improve outcomes in young adult survivors. One of the reasons for this may be the low accrual of young adults with cancer onto clinical trials. Exploring reasons for these low rates of participation is an essential component of advancing the research agenda. Investigations testing specific strategies to enhance a variety of outcomes in this population are needed and will require young adult survivors to actively participate in studies. Young adult survivorship issues also need to be studied within the context of diverse populations and cultures. Issues of young adult survivorship must be considered from diverse ethnic, racial, and cultural perspectives. Diversity characterizes the State of New Jersey, both in terms of cancer incidence and patient demographics. Given this, we have a unique opportunity to begin to address the complexity of these issues in the young adult survivor population.

ii). Enhancing knowledge of young adult survivorship issues among health care professionals.

Ensuring that quality survivorship care is delivered to young adults poses substantial challenges; one of the most salient of these is that health care professionals are unaware of many of the special needs and care requirements of young adult cancer survivors. Although a relatively new construct, cancer survivorship care represents a distinct phase of the cancer care trajectory. Providers often don't recognize this and as a result don't provide comprehensive care. Several studies

have indicated that professionals providing survivor care are in need of specific education on the topic; this is particularly true for those who are involved in the care of young adult survivors. The Institute of Medicine (IOM) has made recommendations about what essential survivorship content should be provided. How do we ensure that NJ providers have this information? What kind of educational strategies do we need to think about to meet the educational needs of diverse providers? We must develop a comprehensive agenda for survivorship education throughout the state. This education should be intradisciplinary and must involve oncology-specific as well as primary care providers.

iii). Educating and empowering young adult survivors and their family members.

We need to establish systematic approaches to “prepare” young adult survivors who are finishing treatment and entering the survivor phase of their care. Every cancer survivor should have a comprehensive care summary and follow-up plan that reflects their treatment and addresses their post-treatment needs to improve their health and quality of life. Providing them with specific information about the treatments they have received, anticipated sequelae, potential late effects, a risk-based surveillance plan, and information about health maintenance is essential. They need information on possible signs of recurrence and second tumors, on the possible effects of cancer on marital/partner relationships, sexual functioning, work, fertility and parenting, support resources available, and connections to other young adult cancer survivors. They should also be provided with information and resources on potential insurance, and employment, as well as legal aid and financial assistance if needed.



**PO Box 369  
Trenton, NJ 08625-0369**

**FIRST CLASS MAIL  
U.S. POSTAGE  
PAID  
TRENTON, NJ  
Permit No. 21**