

Addressing the Unmet Needs of Young Adults with Cancer:

A Dialogue for Action

**A Summary Report:
Annual Retreat on
Cancer Research in New Jersey,
Public Forum**



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Cancer in young adults (ages 21-39 years) represents a significant health problem and presents a broad range of challenges. A recent National Cancer Institute Progress Review Group Report entitled “Closing the Research Gap: Adolescents and Young Adults with Cancer” highlighted the complex and special issues common to this group including poorer survival rates, serious gaps in research, late or missed diagnosis and inconsistent care patterns, long term late effects, substantial psychosocial barriers, unmet support needs and diminished quality of life for survivors to name a few. An interactive public forum, as part of the Annual Retreat on Cancer Research in New Jersey, was designed to develop a framework for action so that New Jersey can begin to better address the needs of young adults with cancer. This report includes a summary of presentations by panel experts who underlined the key issues from the Closing the Gap report, a brief overview of the audience dialogue, and a summary of the most critical unmet needs identified by participants. An organized and collaborative effort must now be launched at a state level if we are to reverse the uneven burden carried by young adults with cancer. A DVD of the complete program is also offered in this package.

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- **NJ Cancer Education and Early Detection Program**
- **Office of Cancer Control and Prevention**
- **Office of Cancer Epidemiology Services**

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**EXCERPT FROM MATT ZACHERY,
Founder of Steps for Living,
KEY NOTE ADDRESS:**

“Cancer, at least for me, was not a death sentence. It was a life sentence of vigilant self-advocacy navigating the chronic conditions that continue to befall me in the wake of my simply not dying from cancer 11 years ago. There are 10,000,000 like me living with, through and beyond cancer in the United States, 600,000 of whom are still under 40 and have the rest of their lives to consider the impact of their survivorship long-term. Think about what “cure” means in 2007.”

Life is about choice.

Remission is not a cure.

Survivorship is all the rage.

This is why we fight.

This is life + cancer. No cure.

Cancer Incidence, Survival and Mortality in Young Adults

Betsy A. Kohler, M.P.H.

Director, Cancer Epidemiology Services, New Jersey Department of Health and Senior Services

According to the *Closing the Gap* report, nearly 68,000 people aged 15 to 39 are diagnosed each year with cancer, and excluding homicide, suicide and unintentional injury, cancer is the number one cause of death for this age group. The most common cancers for this age group are breast, lymphoma, melanoma, thyroid, female genital system, and male genital system. A gender gap in incidence exists with male adolescents having slightly higher incidence rates, but this gap narrows with age, until cancer becomes more common for females ages 30 – 39 years. Data also indicate that adolescents and young adults with cancer have suffered from a lack of progress in survival compared to children and adults over 40 years+.

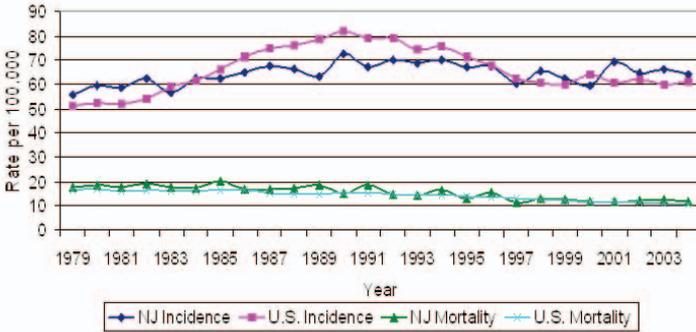
Overall, cancer incidence and mortality among young adults in New Jersey follow the national trends. There are approximately 1,950 young adults (ages 20-39) diagnosed in New Jersey annually and around 380 deaths per year. Young men in New Jersey have had slightly lower cancer incidence for all cancer sites combined while young women in New Jersey have had slightly

higher cancer incidence rates than the US comparison group over the period 1979-2004. Mortality rates for New Jersey young men and women were the same as the US mortality rates for this group. In terms of cancer survival, young US women tend to have slightly better survival rates than NJ women, and young NJ men show the same survival rates as men nationally. Young NJ women tend to have higher rates of breast, cervical, and thyroid cancer than the US population, but less melanoma. Young men in NJ showed more colorectal, testicular, bladder, and Hodgkin lymphoma, but less melanoma.

The Cancer Epidemiology Services (CES) Program is in the New Jersey Department of Health and Senior Services and is comprised of the New Jersey State Cancer Registry that houses more than 1.1 million cancer records (since 1979) and the Cancer Surveillance Program that monitors cancer trends in New Jersey, promotes cancer research, responds to cancer concerns, educates the public about cancer, provides data for cancer control and prevention and shares/compares cancer data with other states and the U.S.

Data Presented during Ms. Kohler's Presentation follow:

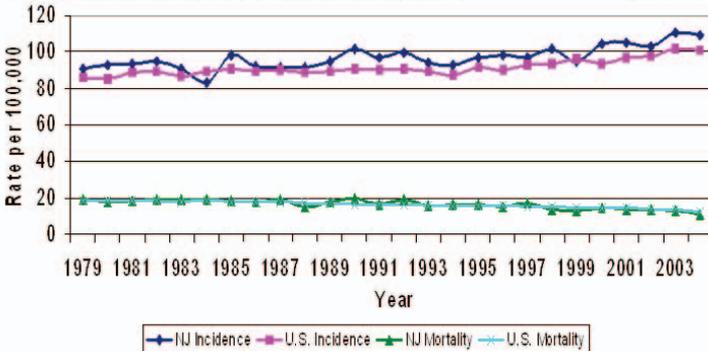
Total Male Cancer Incidence & Mortality among Young Adults, all cancers combined, New Jersey and U.S., 1979-2004



Rates are age-specific

Source: New Jersey State Cancer Registry and Incidence-SEER 9 Regs Limited-Use, Nov 2006 Sub (1973-2004) – Linked to County Attributes – Total U.S., 1969-2004 Counties, National cancer Institute, DCCPS, Research Program, Cancer Statistics Branch, released April 2007, based on the November 2006 submission, Mortality-All COD, Public-Use With State, total U.S. (1969-2004), National Cancer Institute. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

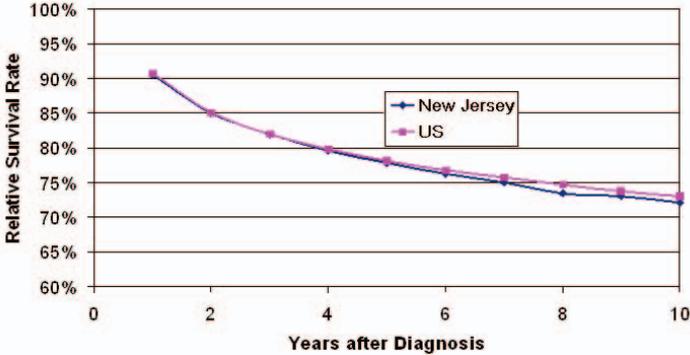
Total Female Cancer Incidence & Mortality, All Sites combined among Young Adults, New Jersey and U.S., 1979-2004



Rates are age-specific

Source: New Jersey State Cancer Registry and Incidence-SEER 9 Regs Limited-Use, Nov 2006 Sub (1973-2004) – Linked to County Attributes – Total U.S., 1969-2004 Counties, National cancer Institute, DCCPS, Research Program, Cancer Statistics Branch, released April 2007, based on the November 2006 submission, Mortality-All COD, Public-Use With State, total U.S. (1969-2004), National Cancer Institute. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

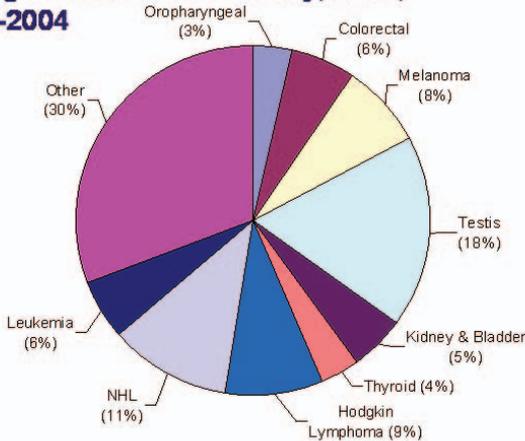
Total Cancer Survival Rates for Young Adults, New Jersey and U.S., 1995-2003



Rates are age-specific

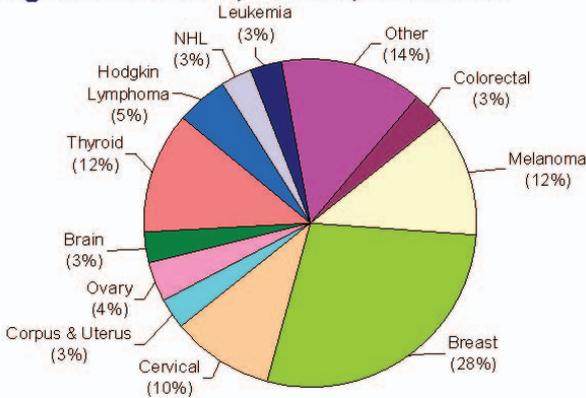
Source: New Jersey State Cancer Registry and Incidence-SEER 17 Regs Limited-Use, Nov 2006 Sub (1973-2004 varying), Linked To County Attributes – Total U.S., 1969-2004 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2007, based on the November 2006 submission.

Distribution of cancers by site among Young Adults in New Jersey, Male, 1979-2004



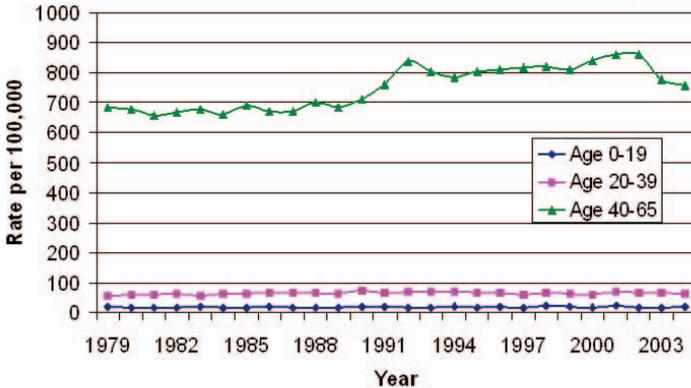
Source: New Jersey State Cancer Registry, New Jersey Dept of Health and Senior Services

Distribution of cancers by site among Young Adults in U.S., Female, 1979-2004



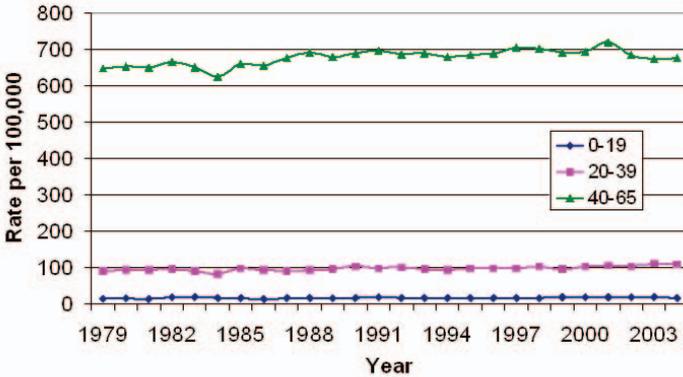
Source: U.S. Incidence-SEER 9 Regs Limited-Use, Nov 2006 Sub (1973-2004) - Linked to County Attributes - Total U.S., 1969-2004 Counties, National Cancer Institute, DCCPS, Research Program, Cancer Statistics Branch, released April 2007, based on the November 2006 submission

New Jersey male cancer incidence by age group, all cancers combined, 1979-2004



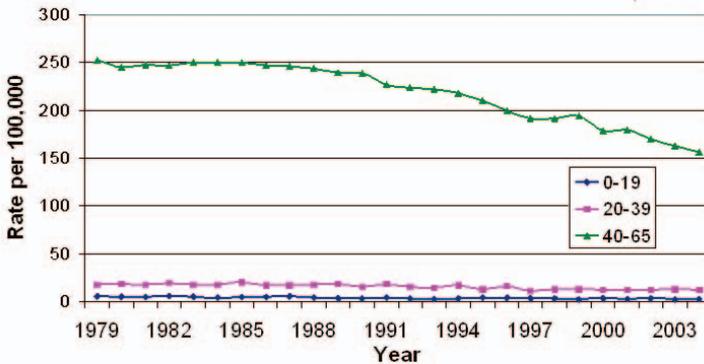
Source: New Jersey State Cancer Registry, New Jersey Dept of Health and Senior Services

New Jersey female cancer incidence by age group, all cancers combined, 1979-2004



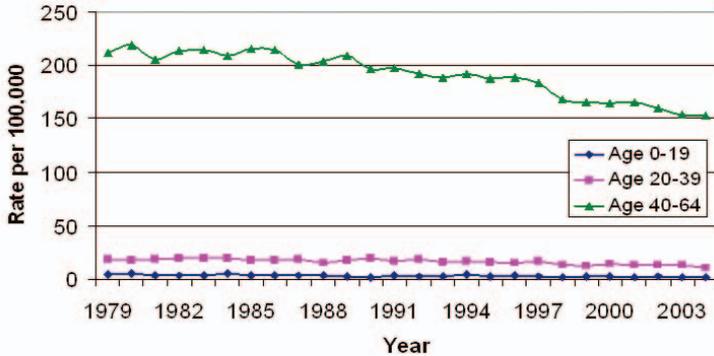
Source: New Jersey State Cancer Registry, New Jersey Dept of Health and Senior Services

New Jersey male cancer mortality by age group, all cancers combined, 1979-2004



Rates are age-specific
 Source: New Jersey State Cancer Registry and Mortality-All COD, Public-Use With State, total U.S. (1969-2004), National Cancer Institute. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

New Jersey female cancer mortality by age group, all cancers combined, 1979-2004



Rates are age-specific
Source: New Jersey State Cancer Registry and Mortality-All COD, Public-Use With State, total U.S. (1969-2004), National Cancer Institute. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

Treatment, Clinical Care and Research of Young Adults with Cancer

Darlene G. Gibbon, M.D

Clinical Director of Gynecologic Oncology, The Cancer Institute of New Jersey

Assistant Professor, UMDNJ-Robert Wood Johnson Medical School

As the *Closing the Gap* report indicated, progress in Adolescents and Young Adults (AYA) oncology has been hampered because cancer risk and adverse cancer outcomes have been under-recognized in this population. While cancer is the leading cause of disease-related death among adolescents and young adults, its diagnosis is often delayed, care patterns are inconsistent and research/evidence based practices are limited. Three major themes, referred to as the 3 As, arise when trying to address the unmet needs involving research and treatment of this group. They are:

- **Awareness:** Cancer in this population goes unrecognized by the young individuals affected, the public and even healthcare professionals.
- **Access:** Access to care can be restricted or delayed, in part because AYAs have the highest uninsured rate of any age group in this country. AYAs with symptoms of cancer may see a variety of health care providers and once seen referral patterns for AYAs

suspected or diagnosed with cancer varies widely.

- **Advances:** Research on AYAs 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.

MAJOR RESEARCH PRIORITIES include:

Identify the characteristics that distinguish the unique cancer burden in the AYA patient.

- A better understanding of the tumor biology and human factors that affect aging, disease susceptibility, treatment response and outcome is needed.
- Factors that characterize and account for disparities experienced by AYA cancer patients must be identified.

Create the tools to study the AYA cancer problem that will:

- Create a prospective and central database on all AYA cancer patients.
- Increase the number of annotated AYA tumor, normal tissue and other bio-specimens.
- Expand the number of clinical trials appropriate for and available to AYAs is essential.

TREATMENT AND CLINICAL CARE

Provide education, training and communication to improve awareness, prevention, access and quality cancer care for AYAs. These might include:

- Expand education, training, and communication activities to raise awareness and recognition of the AYA population at both the public and professional levels.
- Disseminate current information on cancer in young adults to primary care physicians and health care providers.

Ensure excellence in service delivery across the cancer control continuum (i.e. prevention, screening, diagnosis, treatment, survivorship, and end of life).

- New AYA-specific clinical programs should be developed based on current knowledge and modeled after successful existing programs using a patient centered model.
- Establish standards of care and evidence based best practices for AYA cancer patients.

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

Generosa Grana, M.D.
Director, The Cooper Cancer Institute at Cooper University Hospital

Chemotherapy, radiation therapy and even hormonal therapy, have long-term effects that need to be considered when dealing with young adults with cancer. Effects of cancer treatment can be seen in 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. Major long term effects that must be considered in AYAs with a history of cancer include:

Fertility Issues in Young Adults with Cancer

For young patients, the effect of systemic therapy on their fertility remains one of the most critical issues. Planning for fertility preservation at the time of diagnosis and treatment including infertility prevention and sperm/egg cryopreservation should all be considered. Data suggest that outcomes of pregnancy in cancer survivors are excellent and that there are no

increased birth defects or genetic diseases in offspring conceived after cytotoxic chemotherapy when such steps are taken in advance. Patient and provider education remains an essential need.

Risk of Disease Recurrence

The risk of disease recurrence depends on the particular disease, the tumor staging and its pathology. Breast cancer has a preponderance for metastasis to bone, liver and lung while colon cancer has preponderance to liver. Five year disease-free survival is a very important end point for some cancers but it carries less significance for others, e.g. breast cancer. 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 identifying appropriate management after primary treatment and implementing screening strategies.

Surveillance

Currently the tools available for surveillance for disease recurrence tend to be limited. Tumor markers have been validated in certain diseases such as colon cancer (CA27), ovarian cancer (CA125) and prostate cancer (PSA). Ongoing research continues on others. Surveillance recommendations may depend on the specific cancer. For example, aggressive screening for

breast cancer has not demonstrated an impact on survival while colorectal cancer has established NCCN guidelines involving scans and biomarkers for follow-up.

Risk Modification

Adjuvant therapy such as chemotherapy, hormone therapy and the use of chemopreventive agents (such as Tamoxifen for breast cancer) may be valuable in managing risk of recurrence. Data on lifestyle modifications that might change risk are less clear. For example, two recent studies showed conflicting results for breast cancer recurrence when changes to diet and exercise were used.

Risk of Associated Malignancies

Second malignancies in cancer survivors may be due to treatment (carcinogenicity of the individual treatment modality varies), association (shared environmental exposures), hereditary syndromes, or the aging process itself. Secondary malignancies have a significant impact on the health of the cancer survivor population and usually 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 also varies with the agent used, the duration of

exposure, and the age during exposure. For example, the 30 year cumulative risk of a second occurrence for men and women diagnosed with Hodgkin's Lymphoma at 30 years of age were 18% and 26% respectively in a recent article in *The Journal of Clinical Oncology* by Hodgson et al. This compares to the risk of similar individuals in the population whose risk would be 7% and 9% respectively. Women with hereditary breast and ovarian cancer syndromes have approximately a 60% risk of developing a new primary contra lateral breast cancer as well as a 20-40% risk of developing a primary ovarian cancer.

Impact of the Disease on Family

Cancer is a family issue. In certain cancers, first degree relatives have an increased risk of the disease themselves. Families with multiple cases of cancer or young age onset may have a hereditary syndrome and face much higher risks. Such syndromes have been identified in breast, ovarian, colorectal, kidney and a variety of other cancers. In some instances, genetic testing is commercially available and can be used to guide the management of at-risk individuals including individualized screening guidelines, prophylactic surgery, or chemo preventive agents such as tamoxifen.

Dealing with the Psychosocial Issues as Young Adults with Cancer

Kathleen Neville, Ph.D., R.N.
Professor of Nursing
Kean University

Adolescence and young adulthood are two unique developmental time periods during the lifespan; 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. For adolescents and young adults, life involves new roles, significant stress and changing self-perceptions. Cancer may impose additional stress and complexities to these changes resulting in many psychosocial and behavioral

problems unique to the adolescent and young adults including:

Interpersonal Relationships

Interpersonal issues pertain to relationships with family, peers, significant others and health professionals during the cancer experience. The increased need for, and changes in, social networks and support systems as a result of cancer, the development of protective communication between parents, the experience of isolation, and loss as a result of lengthy periods away from school, work, or social events are extremely

important concerns for this age group.

Emotional

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 one self back into their previous school, work and home life while feeling different, often poses difficulties.

Intellectual

A need for increased education and knowledge pertaining to disease, treatment, and long term effects is important. Sensitivity in relaying information based on cognitive ability and age in a culturally competent and compassionate manner is essential to improving health care delivery to this age group.

Practical

The challenges of peer pressure including the use of alcohol, tobacco and drugs may influence adherence to treatment.

Financial issues such as being uninsured, launching new careers and housing/child care responsibilities pose very practical, but real issues that warrant the provision of services to aid AYAs in their cancer experience.

Existential/spiritual issues

Individuals with cancer must learn to live with uncertainty and while this may be viewed as negative, many AYA survivors have indicated that such uncertainty results in an increased appreciation of life, meaning, purpose and resilience. In terms of religious perspectives, many AYAs report an increase in faith and belief, while others indicate that cancer challenges their religious beliefs.

In summary, the need for increased psychosocial research and services specific to the adolescent and young adult with cancer is a critical concern for this group. 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.

Barriers to Supportive Needs and Services

Julie E. Larson, LMSW
Young Adult Services Program
Coordinator
CancerCare, New York City

Young adults are uninsured or underinsured more than any other age group leading 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 *Closing the Gaps* Report, 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 AYAs with cancer.

Patient Navigator Programs

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 of and allows for a safe space to express questions and concerns. Imperative to the value of professional support for AYAs 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

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 in the *Closing the Gaps Report*, 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 report by writing, *Closing the Gap: A Strategic Plan*.

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

Survivorship Issues for Young Adults with Cancer

Regina 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. And while cancer survival rates among young adults have lagged, most young adults with cancer will be long term survivors. As previously mentioned, 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. Psychosocial concerns, 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?

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

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 intra-disciplinary and must involve oncology-specific as well as primary care providers.

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.

Identifying the Unmet Needs of Young Adults with Cancer: Dialogue Summary

Barbara Rabinowitz, Ph.D., R.N., Moderator

Director of Cancer Services
Meridian Health System
Member, New Jersey Commission on
Cancer Research

Dr. Barbara Rabinowitz led two interactive sessions among audience members to identify some of the major unmet needs of young adults with cancer so that New Jersey could begin to set an agenda for action and help lay the groundwork for a strategic approach at a state level. Issues were discussed by major categories including surveillance and data, research, treatment and access to quality care, long-term effects and survivorship, psychosocial and supportive services so that all who collaborated on this endeavor, as well as the breadth of constituents involved in cancer care throughout New Jersey, might lend their expertise and resources in a collaborative effort to address these critical points.

Surveillance and Data

- New methods to assure the quality and validity of data are needed to permit comparisons among different populations and geographic areas.
- Database linkages are needed for better quality of care and outcome studies.
- New data fields are necessary to better identify and address gaps in

care and other outcome-driven needs.

- Evaluating the use of drugs, alternative modalities or other non-traditional approaches common among young adults with cancer is important.
- New strategies for long term tracking of this inherently mobile population are important.
- New ways of using the New Jersey SEER Registry should be explored.
- Innovative communication networks that capture long term survival information on younger patients need to be developed.

Research

- Wider availability of bio-specimens, bio-informatics and molecular/genetic profiling are needed to reduce the gaps in care for young adults with cancer.
- More research on the best clinical pathways for young adults with cancer to establish evidence-based medicine and standards of care must be promoted.
- Increased research on long term effects and survivorship is required.
- Expanded research on the unique psychosocial needs of young adults with cancer should be promoted.
- More cancer clinical trials and new recruitment strategies for young adults with cancer should be developed and made available.

Treatment and Access to Quality Care

- New models are needed for the coordination of treatment among disciplines and improved collaboration among providers (e.g. survivor's clinics).
- Standards of Care and Best Practices for young adults treated in the adult oncology system should be developed and advanced.
- *Young Adults Cancer Clinics/Centers* that focus on the treatment of young adults with cancer should be supported.
- More attention to symptom management and quality of life at initial and post treatment stages are required.
- Expanded professional education on cancer in young adults should be initiated.

Long Term Effects and Survivorship

- A seamless system to address the unique psychosocial and quality of life needs of young adults with cancer from diagnosis to end of life is essential.
- New approaches assist in the transition between pediatric oncology care and the primary care settings are needed.
- Public education to overcome misperceptions concerning cancer in young adults and survivorship issues are needed.
- Special tools should be developed to help young adults with cancer coordinate their care throughout the continuum, treatment diaries.

- Professional education for primary care providers on co-morbidities, symptoms after cancer treatments and long term effects is needed.
- New resources and marketing approaches are necessary to reach young adults with cancer.
- Innovative communication networks are needed to find young adults with cancer over the long term.

Psychosocial and Supportive Services

- Improved communication about services for patients, their families and friends throughout the health care system must be provided.
- An ongoing dialogue with young adults with cancer on the types of services needed and the best venues for providing those services should be launched.
- A system for young adults with cancer to find the resources and supportive services that they need in a format that they are comfortable with is required.
- Better strategies to deal with the gap in insurance coverage and the financial needs of young people just starting out as independent and then dealing with cancer are essential.
- New mechanisms for long term survivors of young adult cancer to tell their stories and reach their peers would be helpful.
- Advocacy campaigns should be developed to address the many unmet needs of this special group of cancer patients.

In closing, Dr. Rabinowitz thanked the sponsors, partners and audience for sharing their time, energy and passion during the afternoon and congratulated them on a positive beginning. She noted, however, that the urgent needs that were identified during the course of the program would require a “roll up your

sleeves” commitment by all who contributed to the success of this day. She charged the participants with mobilizing and organizing their talents, skills and determination to accept responsibility for developing each area of need into workable action agendas in the coming months.

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