

# The Chronicle

*A publication of the New York State Cancer Consortium*

New York State



Cancer Consortium

## New York State Comprehensive Cancer Control Plan Revision Update

In June, a first, very early draft of the New York State Comprehensive Cancer Control Plan, 2011-1016, was made available to members of the Consortium for review. Individuals requesting a copy received the document along with a review tool to help guide the process and provide feedback in a systematic manner. Comments are being incorporated into the next draft.

Over the course of the next month, the next draft of the Plan will again be made available to Consortium members for comments and feedback. Members will receive notification of availability of this next draft via e-mail. In addition, there will be a public comment period later this fall. Please be on the lookout over the next few weeks for the opportunity to provide feedback and lend your voice to these efforts.

*Dear Consortium Members, As part of our on-going efforts to communicate the work being done to implement the Comprehensive Cancer Control Plan, the Chronicle will be highlighting one topic area of interest in each edition. This edition has a focus on Palliative Care.*

### In Focus:

## Hospice and Palliative Care Legislative Update

One of the proposed goals of the 2011 – 2016 New York State Comprehensive Cancer Control Plan currently in development is that New Yorkers will have evidenced-based, patient-centered palliative care services, and 2011 is shaping up to be a banner year for hospice and palliative care. At the very end of 2010 (December 22), the Task Force on Life & the Law issued their report to the Legislature recommending that the Family Health Care Decisions Act (FHCA) be amended to include decisions regarding hospice care. In January – February 2011 the newly formed Medicaid Redesign Team (MRT) did yeoman’s work and delivered to the legislature a series of 79 recommendations—including

two (MRT # 109 and MRT # 209) to facilitate access to palliative care and expand hospice. The MRT’s recommendations were accepted by the legislature, and many were included in the 2011 New York State Budget, passed on April 1, 2011. Before recessing in late June, the legislature passed two landmark bills for hospice and palliative care—A. 7343A/S.5259A and A. 7650A/S.5554.

### Medicaid Redesign

On January 5, 2011, Governor Cuomo issued an Executive Order aimed at redesigning New York’s Medicaid program. The order called for the creation of a Medicaid Redesign Team (MRT) to discover ways to save money

and improve quality within the Medicaid program for the 2011-2012 state budget. The MRT was also tasked with engaging stakeholders, Medicaid beneficiaries and citizens. In less than two months, the MRT gleaned over 4,000 ideas, held five public hearings, and developed a package of 79 proposals that were subsequently accepted by the Governor and the Legislature. The proposals achieved the Governor’s Medicaid budget target of \$2.2 billion (state share) savings in the first year. The savings were achieved without any cuts to eligibility or elimination of any “options benefits.”

Of particular interest to con-

*(Continued on page 2)*

### Inside this issue:

News You Can Use Now	2
NYSCC Steering Committee: Welcome Gary Mervis	3
Member Profile: Joan Dachter, PhD	3
Ovarian Cancer Awareness Month, September 2011	4
Upcoming Cancer Awareness Months	5

## Palliative Care, Cont. from Page 1

(Continued from page 1)

sumers in need of palliative care and hospice, as well as hospice and palliative care providers are:

### Medicaid Redesign Team Proposal #109

MRT Proposal #109 to facilitate access to palliative care was enacted in the NYS budget bill. The statute (Public Health Law 2997-d) requires hospitals, nursing homes, home care, and some assisted living residences to provide patients with advanced life limiting conditions and illnesses with access to information and counseling regarding palliative care, including hospice, and pain management options appropriate for the patient. Facilities are also required to facilitate access to appropriate palliative care and pain management consultations and services including referrals consistent with patient needs and preferences. In instances where patients lack capacity to make medical decisions, facilities are required to provide access to such information and counseling to persons legally authorized to make medical decisions on behalf of such patients.

### Medicaid Redesign Team Proposal #209

MRT Proposal #209 expands access to the hospice benefit through three mechanisms:

- Changing the definition of terminal illness for Medicaid-qualified hospice program patients from six to twelve months (see A.7650A/S.5554 below).
- Incorporating hospice into Accountable Care Organizations (ACOs) and medical home projects.
- Providing concurrent care (curative treatment and hospice care) to adults. This proposal requires an amendment to the Federal Social Security Act or a Medicaid Waiver.

### **2011 Legislative Session**

#### A.7343A/S.5259A – Surrogate Decision Making Improvement Act for Hospice

Passed by the Assembly and the Senate, A.7343A/S.5259A amends the Family Health Care Decisions Act (FHCDA) to include decisions regarding hospice care. Currently, the FHCDA applies only to surrogate decisions made in facilities—hospitals or nursing homes. The new legislation allows surrogates to make decisions regarding hospice care, including the decision to elect hospice and consent to the hospice plan of care, regardless of where the decision is made and the hospice care is provided. This amendment to the FHCDA is consistent with the recommendation of the Task Force on Life and the Law, submitted to the Legislature in December 2010. The bill was delivered to the Governor for signature on July 8, 2011.

#### A.7650A/S. 5554 – Definition of Terminal

#### Prognosis and Employment of/ Contracting with Physicians for the Provision of Palliative Care

Passed by the Assembly and the Senate, A.7650A/S.5554 is consistent with the Medicaid Redesign Team's recommendations to expand hospice (MRT #209) and facilitate access to palliative care (MRT #109). The bill implements the recommendation to change the definition of terminal prognosis from six months to 12 months. The legislation also provides the flexibility needed to allow more hospices to directly implement palliative care programs under their Article 40 licensure. Both provisions will provide greater access to quality hospice and palliative care.

#### A.4899A/S4830A – Model advance care planning forms provided to individuals applying for Medicaid

This bill, passed in the Assembly and the Senate, requires that individuals applying for medical assistance be provided with a model health care proxy form, except where doing so would impede the immediate provision of health care services.

**These legislative successes support the New York State Cancer Consortium's recognition that the pain control, symptom management, psycho-social support and caregiver support that are part of palliative care are vital to improving the quality of life for patients and families impacted by a cancer diagnosis.**

## News You Can Use Now

### **NYLearnsPH**

The NYLearnsPH learning management system (LMS) is a free, online tool to help meet workforce development goals of public health in New York State. The system enables listing, promoting, delivery, and tracking of essential training at low or no cost to anyone working in public health or with an interest in the many topics in this field.

This web-based system provides users with access to more than 500 trainings offered by experts in a variety of content areas from across the nation, providing 'one-stop shopping.' Many of the courses offer continuing education credits for a variety of professions, making it helpful in maintaining accreditation.

To learn more about this powerful resource, or to sign up and begin using it, please visit the NYLearnsPH website at: [www.NYLearnsPH.com](http://www.NYLearnsPH.com)

(Continued on page 3)

## NYSCC Steering Committee: Welcome Gary Mervis

The Consortium is pleased to welcome Gary Mervis to the Steering Committee.

Gary Mervis is the Chairman and Founder of Camp Good Days and Special Times, which he founded in Rochester, New York in 1979, following the diagnosis of his youngest daughter, Teddi, with a malignant brain tumor. What was started to provide a residential camping experience for Teddi and 62 other children with cancer has grown to become one of the largest organizations of its kind in the country. Many of the programs and services started at Camp Good Days have been used as models for childhood cancer treatment centers and organizations all across the world. Over the years Camp Good Days has served more than 43,000 campers from 22 states and 26 foreign countries.

Today, under Mr. Mervis' direction and leadership, Camp Good Days provides residential camping experiences and year-round recreational and support activities for children, adults and families whose lives have been touched by cancer and other life threatening challenges. Most recently, Camp Good Days launched CANCER MISSION 2020...THE END OF CANCER BY THE END OF THE DECADE, a movement to build awareness and create a call to action, to ensure collaboration and coordination between public and private sectors in cancer research, paving the way for a comprehensive, cohesive, and collaborative way to find the elusive answers in the war on cancer.

A lifelong resident of Monroe County, New York, Gary Mervis is recognized throughout the community for his many accomplishments, both personally and professionally. A product of the State University systems of New York and New Jersey, Gary holds a Bachelors Degree in Recreation Administration and a Masters Degree in Urban Sociology. In 2005, he was awarded an Honorary Doctor of Laws Degree from St. John Fisher College. In his spare time, Mr. Mervis also serves as an Assistant Football Coach with the St. John Fisher College Cardinals as well as the Huddle Coach for the FCA (Fellowship of Christian Athletes) Huddle at Fisher and in 2007, he was inducted into the St. John Fisher College's Athletic Hall of Fame. Gary married Wendy Bleier on June 10, 1995 and they currently reside in Pittsford, New York.

## Member Profile: Focus on Joan Dacher, PhD

Since 2009, Joan Dacher has chaired the Palliative Care Committee, providing leadership and guidance to committee members, ensuring that they identify and implement activities that help the Consortium to best understand palliative care services across the state. Most recently, Joan led the committee through the process of developing recommended goals, objectives and measures for the palliative care section of the Cancer Control Plan. Joan's experience, skills and dedication make her a valuable asset to the Consortium and demonstrate her capacity to lead this committee.

Joan joined the faculty of The Sage Colleges in 1995 as an Associate Professor and in 2006 became the Founding Director of the Doctorate of Nursing Sciences program. Since 2006, she has also been involved with the Arc of Rensselaer County, and is a consultant with New York State ARC, where she addresses health and wellness issues by creating models to address the needs of individuals with developmental and intellectual disabilities. She began working on palliative care issues in 1985 through her work as a Gerontological Nurse Practitioner, where she was able to realize her interest working with vulnerable populations through early work with people with Alzheimer's disease and other types of dementia. What she saw when working with the elderly was that the patients were not being included in the conversations regarding their care; families made the decisions regarding end-of-life and palliative care and death was taking place in the hospital.

Dr. Dacher works to educate people that palliative care is not just about end of life, but about people living well in the face of multiple chronic diseases. This is particularly important when working with individuals with developmental and intellectual disabilities because they are often underserved, particularly as they age, and may have unique needs to address that fall within the realm of palliative care. In her role as an educator, Dr. Dacher teaches nurses to take a multi-faceted approach to fully understand the health issues they are trying to address and to create change that leads to healing and staying well. The key is using the evidence base and applying this knowledge to practice.

When asked what she considered the emerging issues in palliative care, Joan indicated that she felt access and availability of informa-

## News You Can Use Now, Cont. from Page 2

(Continued from page 2)

**Tools for Healthy Tribes**  
[Tools for Healthy Tribes](#) was created through a partnership between the American Indian Healthy Eating Project of the University of North Carolina and seven tribal nations. While it is recognized that there are distinct differences between Tribes, an effort was made to for this resource to be broad-based and provide strategies that can reduce American Indian health disparities nationwide. Using community-based participatory research, tribal leaders and members provided insight into their local food environment and the potential for community changes around healthy eating. The toolkit aims to provide tools and technical assistance to strengthen the

capacity of tribal leaders to develop, implement, and evaluate community change around healthy eating and active living and to disseminate lessons learned to foster the translation of culturally appropriate, tribally led strategies.

Here is the direct link you can click on or type into your internet browser: <http://americanindianhealthyeating.unc.edu/>

### Decline in NYS Youth Smoking Fuels Drop in Adult Smoking

In July 2011, the NYS Department of Health (NYSDOH) issued a report entitled *Youth Prevention and Adult Smoking in New York* that focuses on the relationship between youth smoking prevention efforts and adult smoking. The report indicates

that 35% of the reduction in adult smoking in New York is attributable to youth smoking prevention efforts such as decreasing youth exposure to retail tobacco product marketing and promotion and increasing the number of schools, colleges and universities that have comprehensive tobacco-free policies.

For more information on this report please see the related press release at: [http://www.health.state.ny.us/press/releases/2011/2011-07-01\\_tobacco\\_smoking\\_declines\\_in\\_youths.htm](http://www.health.state.ny.us/press/releases/2011/2011-07-01_tobacco_smoking_declines_in_youths.htm).

The full report can be downloaded at: [http://www.health.ny.gov/prevention/tobacco\\_control/docs/2011-03-11\\_ny\\_state\\_brief\\_report\\_prevention.pdf](http://www.health.ny.gov/prevention/tobacco_control/docs/2011-03-11_ny_state_brief_report_prevention.pdf).

## Joan Dacher, Cont. from page 3

(Continued from page 3)

tion were critical in order to enable people to understand the difference between hospice and palliative care and the availability of community-based hospice. In addition, it is critical to address the policies that make it difficult for physicians to provide palliative care and pain management in order for people to have better access to the best standard of care. She notes that the Palliative Care Committee revisions recommended for the revised Comprehensive Cancer Control Plan for 2011-2016, although still in draft form, appropriately capture the critical policy issues facing palliative care and that the Plan can become a model for addressing these issues.

Summing up her philosophy, Joan immediately states her favorite phrase from The Talmud, "It is not upon you to finish the work, but you are not free to ignore it." This seems particularly relevant as we recognize the changes in the field of cancer control which have occurred since the original Plan was released in 2003, and look to the future and what still needs to be done.

## Ovarian Cancer Awareness Month, September 2011

September is Ovarian Cancer Awareness Month. Organizations around New York State and the country are working to bring awareness to the public and providers about the signs and symptoms, risk factors, screening and diagnostic issues, and treatment options associated with ovarian cancer. More than 1,500 women were diagnosed with ovarian cancer in New York State in 2008 and nearly 1,000 New York women died of the disease in that same year. Ovarian cancer is the fifth leading cause of cancer deaths among women in New York State; among cancers of the female reproductive system, it has the highest mortality rate.

### Not a "Silent Killer"

Ovarian cancer used to be known as the silent killer; the general wisdom was that symptoms did not appear early enough to detect and treat the disease successfully. *We now know that a majority of women do have symptoms even in the early stages of the disease, and that awareness of these symptoms, and earlier detection of ovarian cancer, can improve outcomes and save lives.* Providers who work with women in various contexts can help recognize the signs, symptoms and risk factors for ovarian cancer and can help ensure that women are referred for appropriate and timely evaluation and treatment. They can also help to spread awareness about ovarian cancer to colleagues and patients.

### Signs, Symptoms and Treatment

Signs and symptoms of ovarian cancer can mimic gastrointestinal problems. They include: bloating; pelvic or abdominal pain; difficulty eating or feeling full quickly; and urinary symptoms (urgency or frequency). A

woman who has these symptoms almost daily for more than a few weeks should see a health care provider - preferably a gynecologist. The best outcomes for women who have been diagnosed with ovarian cancer are associated with treatment by gynecologic oncologists, who are specially trained to treat cancers of the female reproductive system. A gynecologic-oncologist can be located using the "Find a Doctor" tool on the Foundation for Women's Cancer website: <http://www.wcn.org/findadoctor/>.

### Risk Factors and Genetics

Risk factors for ovarian cancer include age (the average age at diagnosis is 63 and more than 88% of cases are diagnosed at age 45 or older) and never having been pregnant. Some women are at higher risk for ovarian cancer due to genetic factors. Early onset of breast cancer or multiple relatives with related cancers may signal a higher risk. Women concerned about whether their personal and/or family history indicates an increased risk can meet with a genetic counselor to discuss their risk and available preventive strategies. To locate a genetic counselor, call **1-866-442-2262** or visit <http://www.nsgc.org/FindaGC/tabid/64/Default.aspx>

### How Can the Ovarian Cancer Program Help?

The New York State Department of Health Ovarian Cancer Program works to increase awareness of ovarian cancer among the public and providers and to promote the message that signs and symptoms of ovarian cancer can be detected even in early stages of the disease. The program has resources to help providers and members of the public understand risk factors, signs and symptoms, screening and diagnostic issues

and treatment. The program's website offers resources including fact sheets for providers, and contact information for national, state and local resources. For more information about ovarian cancer or about the program, please visit our website, <http://www.health.ny.gov/diseases/cancer/ovarian/index.htm>, or contact Maria Ayoob, Program Coordinator, at [mya01@health.state.ny.us](mailto:mya01@health.state.ny.us).

1. New York State Cancer Registry. (2011). *Cancer Incidence and Mortality for all Sites of Cancer, New York State, 2004-2008*. Available at: <http://www.health.ny.gov/statistics/cancer/registry/table1/tb1nys.htm>
2. Ibid.
3. National Cancer Institute, Surveillance and Epidemiology End Results Program (SEER). (2011). *SEER Stat Fact Sheets: Ovary*. Available at: <http://seer.cancer.gov/statfacts/html/ovary.html>

\*\*\*

New York State



Cancer Consortium

**Working Together  
Reducing Cancer  
Saving Lives**

1120 S. Goodman Street  
Rochester, NY 14620

T: 585.224.4915  
F: 585-585-473-6869  
E: [nyscccp@cancer.org](mailto:nyscccp@cancer.org)

[www.nyscancerconsortium.org](http://www.nyscancerconsortium.org)

*The New York State Cancer Consortium is the network of organizations and individuals who have come together to implement the New York State Comprehensive Cancer Control Plan.*

*Our mission is to reduce the human and economic burden of cancer in New York State.*

*Our vision is that people concerned about cancer will work collaboratively to implement the New York State Comprehensive Cancer Control Plan, while respecting and embracing the cultural, demographic and geographic diversity within New York State.*

## Upcoming Cancer Awareness Months

Over the course of the next few months, multiple cancer awareness month activities will be underway. If your organization has events related to any of these upcoming months, please be sure to send them to the Consortium webmaster for inclusion in the Consortium's online calendar. Consortium members are encouraged to reach out to other member organizations to partner on activities and to share information about each other's resources. Below are several of the awareness months, where possible, including websites providing more information:

### SEPTEMBER

#### Childhood Cancer Awareness Month

Curesearch for Children's Cancer  
[www.curesearch.org](http://www.curesearch.org)  
Camp Good Days and Special Times  
[www.campgooddays.org](http://www.campgooddays.org)

#### Leukemia and Lymphoma Awareness Month

Leukemia and Lymphoma Society  
[www.lls.org](http://www.lls.org)

### Ovarian Cancer Awareness Month

Ovarian Cancer National Alliance  
[www.ovariancancer.org](http://www.ovariancancer.org)  
National Ovarian Cancer Coalition  
[www.ovarian.org](http://www.ovarian.org)  
NYSDOH Ovarian Cancer Program  
[www.health.state.ny.us/diseases/cancer/ovarian/index](http://www.health.state.ny.us/diseases/cancer/ovarian/index)

### Prostate Cancer Awareness Month

Us Too  
[www.ustoo.org](http://www.ustoo.org)  
New York State Prostate Cancer Coalition  
<http://newyorkprostate.com/>

### OCTOBER

#### National Breast Cancer Awareness Month

Susan G. Komen for the Cure  
[www.komen.org](http://www.komen.org)  
NYSDOH Cancer Services Program  
<http://www.health.ny.gov/diseases/cancer/services/>  
American Cancer Society  
[www.cancer.org](http://www.cancer.org)

### NOVEMBER

#### Lung Cancer Awareness Month

Lung Cancer Alliance  
[www.lungcanceralliance.org](http://www.lungcanceralliance.org)  
NYSDOH Center for Environmental Health  
<http://www.health.state.ny.us/environmental>  
NYSDOH Tobacco Control Program  
[http://www.health.state.ny.us/prevention/tobacco\\_control/](http://www.health.state.ny.us/prevention/tobacco_control/)  
New York State Smoker's Quitline  
<http://www.nysmokefree.com/>

**National Healthy Skin Month**  
American Academy of Dermatology  
[www.aad.org](http://www.aad.org)

NYSDOH Skin Cancer Program  
<http://www.health.state.ny.us/diseases/cancer/skin/>  
United States Environmental Protection Agency  
<http://www.epa.gov/sunwise/index.html>

#### National Hospice and Palliative Care Month

Hospice and Palliative Care Association of New York State  
[www.hpcanys.org](http://www.hpcanys.org)