



State Society on Aging of New York

SSA BULLETIN

WINTER 2009

Letter from the 2009 SSA President, Thomas V. Caprio: Focus on Caregivers

I am honored to be the President for the State Society on Aging (SSA) of New York for 2009. As a geriatrician and physician faculty member with the University of Rochester, I understand the importance of interdisciplinary education, workforce training, and the provision of needed services to support older adults. I am pleased to undertake this leadership role with SSA, as the organization continues to grow and move forward in a variety of areas thanks to the dedication and support of its membership.

I do not have to remind anyone of the challenges that face our State with the financial crisis and proposed budget cuts. Some serious choices have been proposed in order to protect core programs and services for our communities, but this also means there will be an inevitable trade-off as other services and agencies will face substantial budget cuts or be forced to close entirely. At the same time, we look forward with great anticipation at the federal level to the new President's administration and a round of stimulus packages which includes new state funding, however even with an infusion of new financial assistance there is likely to be significant changes upon the

landscape of services and legislative priorities that will continue to impact the lives of older adults across New York State.

In the face of these challenges, I see a significant opportunity for SSA to continue our work and to highlight our significant role in project development and education across the State. For example, the partnership of SSA and the New York State Office for the Aging (NYSOFA) that resulted in the project "Working with Older Adults: Charting the Future of Workforce Training and Education in New York," is more critical than ever as health care may see a significant increase in both entry level workers seeking jobs and the retraining of an established workforce to meet the health and social service needs of the elderly. It is through this work that SSA has been able to create a roadmap of priority areas for workforce recruitment and training which was obtained from statewide "listening sessions" including the NYSOFA leadership. Another example is the work of the SSA Social Policy Committee through the development of Town Hall Meetings and policy briefs that continue to highlight areas such as poverty, transportation, substance abuse and addiction. These are all critical areas to consider as the pressures of the financial crisis impact the most vulnerable older adults across the State.

Each SSA President has the opportunity to propose a theme for the year and the annual conference. For 2009, I have proposed the theme to be a focus on caregivers. The vast majority of services provided to the vulnerable elderly are through formal and informal caregivers in homes and facilities. The discussion of caregiver support is underscored with the current financial crisis, as budget cuts will inevitably cause a shift towards unpaid or family caregivers in an attempt to fill in the gaps of services. This gives us a significant opportunity to examine our training, support, and advocacy on behalf of caregivers. Stay tuned as the SSA programs and events unfold for 2009 and I hope that many of you will be able to join us for the **SSA 37th Annual Conference** to be held at the Hyatt Regency, Rochester, New York during **October 15 – October 17, 2009** as we further explore this focus on caregiving. I look forward with great anticipation to another exciting and productive year!



**SSANY 2009 President,
Thomas V. Caprio, MD**

MEMBERS IN THE SPOTLIGHT

Forum explores aging with HIV-AIDS

By
Meg Haskell

As the general population in Maine gets older, so do Mainers living with HIV-AIDS. Because new cases are holding fairly steady at about 50 a year, and because people infected with the Human Immunodeficiency Virus are living longer thanks to new drug treatments, about three-quarters of the roughly 1,220 infected Mainers are more than 40 years old. About a third older than 50.

Jean Lavigne of Orono contracted HIV in 1985 from her husband, who was a hemophiliac, when she was 27. Her infant son was also infected. "I was told to get my affairs in order, because I would probably die in two years," she recalled, speaking at a University of Maine conference on Friday. Lavigne's husband died with Acquired Immune Deficiency Syndrome (AIDS) in 1990 – followed by his brother, his brother's wife and their 1-year-old child – but she and her son, who is completing his college education, are testimony to medical progress in managing the virus.

Maine's HIV-AIDS numbers are relatively small, but they correspond to national trends, according to **Mark Brennan**, senior researcher at the AIDS Community Research Initiative of American, which is based in New York City. **Brennan** was the first keynote speaker Friday at "A Graying Epidemic: HIV/AIDS and Older Adults," a half-day conference hosted by the University of Maine Center in Aging and the

University of Maine School of Social Work.

The outbreak of HIV first was recognized in the early 1980's, primarily as a sexually transmitted disease among young gay men. The virus is also spread through unprotected heterosexual contact, sharing needles during intravenous drug use, and from mother to child during pregnancy and in breast milk. Before 1985, blood transfusions were another frequent source of infection.

In 1995, the number of Americans older than 50 with AIDS – the lethal late stage of HIV in which individuals lose the ability to ward off even common infections – was only about 20,000, **Brennan** told conference participants. By 2005, the number had ballooned to more than 120,000 Americans. That's actually good news, a reflection of advances in medicine that have changed an HIV diagnosis from a death sentence to a chronic health care challenge, he said. But on the far end of that challenge lies old age and its attendant problems, many of which are compounded by a diagnosis of HIV-AIDS.

“What will happen as they continue to age? Who will take care of them? **Brennan** asked his audience, most of whom were social workers or other professionals. “When we ask people, ‘Who’s going to take care of you,’ they say, ‘my friends will.’ But more than half of their friends are infected, too. And the long-term care environment is really not prepared to deal with this. It’s going to be a real problem.”

The HIV-AIDS population resists easy characterization, Brennan said. But a recent study conducted by his organization found that many

affected individuals suffer from social isolation and loneliness, especially as they get older. Depression is a common complaint, and medical studies show that a diagnosis of HIV-AIDS predicts the relatively early onset of age-related conditions such as arthritis, high blood pressure, diabetes and cardiac conditions. A high percentage of affected individuals currently use tobacco, alcohol and other drugs, and an even percentage are in recovery from those habits but may still suffer from their long-term ill effects.

After Brennan’s presentation, a four-person regional panel shared personal reflections on the HIV-AIDS outbreak in the United States.

“I hope to be around for a while,” said Ron King; an HIV-positive artist, farmer and retired AIDS program coordinator from Penobscot. King said social stigma against homosexuality remains a primary barrier to people getting tested and treated early in their infection. A diagnosis of HIV “potentially doubles the discrimination” already associated with old age in this country he said.

AIDS activist Lavigne said that while she is grateful for the medical progress that has allowed her to live into her fifth decade, it has been “a roller coaster.” Medications that have been effective in managing the virus have caused serious complications for many people, she noted, ranging from chronic diarrhea to heart problems. She recently suffered a heart attack, she said, while waiting for “the next big thing” from pharmaceutical researchers.

Lavigne discussed how the health care system has changed over time in its response to the virus. For example, when her 1-year-old nephew died at Children’s hospital in Boston, the family

could not find a funeral home in their home state of New Hampshire that would handle his body. That situation wouldn't happen now, she said. Wayne Moore, a social worker at The Arcadia Hospital, drew laughs when he said he "grew up in a typical small-town Maine family, with three daughters and three gay sons." His older brother died of AIDS in 2000, he said, and was nursed through his final ravages of his illness by their widowed mother. "It's not something any parent expects to be doing," Moore said. His twin brother also is infected, he said.

Latona Torrey, a social worker with Regional Medical Center at Lubec and a former ranger at Baxter State Park, said the HIV-AIDS epidemic sparked at least two new trends: men providing intensive care, intimate, end-of-life care for their dying friends or partners and – as treatment has improved – the development of valuable, long-term relationships between infected individuals and their physicians.

SSA Member Dr. Vicki Rackner Speaks Out

Sometimes I wonder if I made the right professional choice. A surgeon leaving the operating room to help patients and family caregivers and health care providers work together more effectively? To set down the scalpel and pick up my pen and microphone to help patients and their loved ones find their own voices? To extend the reach to communities rather than individuals who want to achieve better health outcomes, stretch health care dollars and feel cared about as they seek medical care?

Every day brings a story that convinces me that I'm on the right track. Yesterday I delivered a keynote address

and several afternoon sessions to a group of caregivers (family caregivers, paid caregivers and hospice volunteers) in a rural community. The otherwise reserved and polite audience erupted into a maelstrom of anger during my afternoon Q&A session as they told story after story about sub-standard medical care. Several had aging parents who were fired after they made efforts to advocate for themselves; when they tried to transfer their care they discovered that only one doctor in town takes new Medicare patients. Patients with state-funded insurance were excluded if their medical problems were too complex or their care involved the management of chronic pain. A hospice nurse told me privately that several on-call doctors are well known for their unwillingness to increase the morphine drip on dying patients. This could be one isolated rural community with bad luck; however, they could be the picture of what's to come as increasing numbers of doctors are unwilling to accept the lower compensation and increased administrative requirements for Medicare patients.

Of course I must speak and write and consult about empowering patients and their caregivers. Of course I continue to support the family's trusted inner circle like members of your organization. Making specific suggestions about what to say and do to improve the health of the doctor-patient relationship is as rewarding as curing a patient of appendicitis.

Vicki Rackner MD, founder of The Caregiver Club, works with caregivers who want to avoid burn-out, speak up with the doctors and stretch health care dollars. She can be reached at Rackner@MedicalBridges.com or 425 451-3777

***SSA Town Hall Meeting: Serving
Older New Yorkers with the
Challenge of Addictions***

By
EJ Santos, MD; Ann Brownhill
Gubernick, LMSW; and Thomas Caprio,
MD

Substance and gambling addictions among older New Yorkers are a hidden epidemic and reflect the national trends of increasing in prevalence. Not only is alcoholism increasing among the diverse population of older adults, but the misuse and mixing of prescriptions and over-the-counter medications are also rising. All can have far-reaching consequences for health care, social services, communities, and families across New York State. An open discussion of these growing challenges was the focus of the SSA Town Hall Meeting held on October 23, 2008 during the SSA Annual Conference held in Saratoga Springs. Entitled "Getting Renewed Life: The Interface of Treatment and Legislation to Help Older New Yorkers with Substance Misuse, Abuse and Addiction", the Town Hall Meeting brought together statewide SSA members, legislators, advocates, and service providers and highlighted the 2005 Geriatric Mental Health Act that included the integration of mental health and aging services with alcohol, drug, health and other support services and created an interagency mental health planning council with representation from OASAS. The session was moderated by **Dr. EJ Santos**, a geriatric psychiatrist from the University of Rochester and the incoming Co-Chair of the SSA Social Policy committee. Panelists included **Ann Marie Cook**, President and CEO of Lifespan in

Rochester, who discussed her agency's model Geriatric Addiction Program, which has seen continued growth in needed services and has demonstrated positive outcomes in assisting clients. **Patricia Zuber-Wilson**, Director of Government Affairs & Interagency Collaboration for the New York State Office of Alcoholism and Substance Abuse Services (OASAS), outlined many of the statewide issues that impact New York's elderly living with alcohol, substance, or gambling addictions and the challenges to receiving appropriate services. **John Cochran**, Assistant Director for Intergovernmental Affairs and Strategic Planning for New York State Office for the Aging (NYSOFA), discussed the unique collaboration between aging services and OASAS. **Edward Woda**, Legislative Coordinator for Assemblyman Jeffery Dinowitz, Chair of the Assembly Committee on Aging, highlighted many of the legislative priorities regarding older adults with addictions. In addition to panel presentations, participants had the opportunity to develop a dialogue with the panelists.

Robert Higgins of OASAS and **Michael Friedman** of the Geriatric Mental Health Alliance (GMHA) and recipient of the SSA Presidential Award were among those who exchanged information with the panelists and fostered a lively and informative dialogue that underscored the current gaps existing in needed services and the professional skills needed to address gambling, alcoholism and substance-related issues with older adults. Only a fraction of those older adults who would benefit from professional help, are being identified, assessed and referred to appropriate services. Older adults often do recognize they are in need of

assistance, and when they do seek help, find it increasingly difficult to access services often designed for a younger clientele.

Sponsored by the SSA Social Policy Committee, the purpose of the 2008 Town Hall was to raise awareness, highlight problems and identify the barriers and resources needed for community-based services; treatment and medical services; and develop a dialogue among participants and panelists about possible solutions. The Social Policy Committee will follow-up by developing a policy statement that will underscore continued advocacy.

Pictures from the 2008 Conference



At the Luncheon on **Workforce, Education, & Training**



The Student Participation Award went to **Ithaca College**



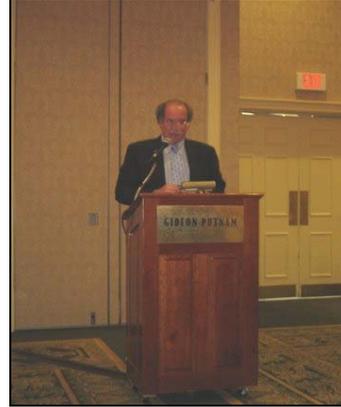
Dr. Thomas Caprio presents on the Impact of Support Services in New York



Dr. Larry Honig from Columbia Presbyterian talks about Alzheimer's Disease



Deborah Heiser, PhD participates in a session on technology and the elderly



Keynote speaker **Robert Blancato**

A SPECIAL THANKS GOES OUT TO OUR 2008 PROGRAM CHAIR, **JANNA HEYMAN**. THANK YOU FOR ALL YOUR HARD WORK AND DEDICATION ON A SUCCESSFUL CONFERENCE.

SAVE THE DATE

**Thursday, October 15 –
Saturday, October 17, 2009**

Hyatt Regency Rochester
Rochester, New York

37th Annual Conference
State Society on Aging of New York
State



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We look forward to hearing from you!!



Meredith Morris
Publications Committee