Cultivating the Seeds of Political Action in Our Communities

[Editors Note: New York Citizens AIDS Network (New York CAN!) is GMHC's grassroots advocacy effort. This volunteer-driven project can be reached by phone (212) 367-1231 or via e-mail at nycan@gmhc.org. The following is reprinted by permission from THE VOLUNTEER, *July/August 1997, p. 4.]*

by Andy Stern

The New York Citizens AIDS Network! (New York CAN!) was launched in the fall of 1994 to provide an outlet for New Yorkers everywhere to hone the advocacy skills necessary to effect positive political action on behalf of people with HIV/AIDS. Michael T. Isbell, GMHC's Associate Executive Director and one of the architects of New York CAN!, summarizes the driving motivation behind GMHC's sister advocacy group: "It is our conviction that people living with HIV/AIDS and their caregivers not only can but must speak for themselves, tell their own stories, and communicate their specific needs directly to their elected officials. Only through political awareness and the exercise of our collective voices can we achieve meaningful legislative change for people with HIV and AIDS."

Isbell recalls the group's early years. "Our community organizing unit spent much of its first two years on the recruitment and basic advocacy training of GMHC clients, volunteers and staff. As our ranks expanded and our voice strengthened, the network began to take on a life of its own, extending far beyond the walls of GMHC and reaching out to communities throughout New York City and beyond."

At this point in New York CAN!'s journey, more than half of the group's time is spent working in coalition with other organizations, conducting advocacy trainings throughout New York State, and providing technical assistance to other community-based organizations (CBOs). "We are proud of the more than 1,500 New York CAN! advocates who write letters, make phone calls, register people to vote, and meet with elected officials," says Ed Galloway, New York CAN! coordinator. "But we are just as proud of the partnerships we have developed with other organizations throughout the state and across the country."

Over the last two and a half years, New York CAN! has conducted trainings in all five boroughs of New York City, working with such diverse groups such as the Staten Island HIV CARE Network and the HIV Parents Education Network (HAPEN) in Staten Island; East New York/Brownsville HIV CARE Network in Brooklyn; South Bronx HIV CARE Network in the Bronx; and Steinway Family and Children Services in Queens, among many others. Outside of the city, New York CAN! has traveled to the Mid-Hudson Valley HIV CARE Network and AIDS-Related Community Services (ARCS). In addition to this kind of community outreach, New York CAN! always provides a substantial number of PWA scholarships for people wishing to attend its annual advocacy skills-building conference. This year, for example, well over fifty percent of conference participants from all parts of New York City attended the two-day conference at no cost.

Coalition work and partnership is where all real change must occur.

While many agency representatives and consumers have decided to join the New York CAN! network, many others have chosen to take the tools and information they have acquired to develop and further their own advocacy agendas and projects.

"We think of New York CAN! as a resource to the AIDS community, one place among many where people can access information and develop their advocacy skills," says Galloway. "One of the most exciting elements of our outreach efforts is observing those people who spend the day with us, then depart and are not heard from for a while, but whose actions later attest to the success of our efforts — we plant seeds, help them take root, and then hear back about the fantastic work being done by our fellow advocates."

Last February, New York CAN! took a major leap forward, traveling to the Albany region for an all-day advocacy training in collaboration with the Northeastern New York HIV CARE Network and the New York AIDS Coalition (NYAC), which has a long-standing record of building consensus and coalition among AIDS organizations fighting for the needs of people living with AIDS. According to Amy Herman, Executive Director of NYAC, "Politicians need to hear from individual consumers as well as AIDS service organizations, working hand-in-hand to create the groundswell we often need to effect significant change. The training in Albany presented a valuable opportunity to reach people who live in strategically critical areas of the state."

As a direct result of the Albany training, two constituents of Congressman Gerald Solomon's district (important because Solomon chairs the Rules Committee for the House of Representatives) attended AIDSWatch '97 and met in Washington with the Representative's aide on health issues. It was the first time constituents met face-to-face with an official from Solomon's office in the 7-year history of the national lobbying event. "Our visits confirmed for me how important it was for us to be telling our elected officials about our issues," says Lenny Hoffman, one of the constituents who first came in contact with New York CAN! during the Albany training. "It was clear to me that they were uninformed about exactly what the personal issues were

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Organ and Tissue…

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Aftercare: Special Attention for Grieving Families

Our commitment to these brave families does not end when the consent form has been signed. An Aftercare Program has been established to follow families through the difficult first year after the death of a loved one. If a family elects to do so, they can continue a relationship with our organization beyond the first year. Donor families receive correspondence, newsletters and are invited to an annual Donor Family Luncheon and other special events. Family counselors are available to provide families with resources.

Those of us who chose health care as a career probably did so to help people and touch lives directly. No where is this mission better fulfilled than in the life-saving act of organ and tissue donation and transplantation.

If you have any questions or would like to schedule an educational workshop, contact The Donor Network at 212-870-2240. To refer a potential donor, call 1-800-GIFT-4-NY, 24 hours a day.

Denise Payne, M.P.A., R.N., is the Executive Director of the New York Organ Donor Network, a federally-designated, state-certified nonprofit organization responsible for coordinating all organ and tissue donation activities throughout the five boroughs of New York City and several New York State Counties.

New York CAN!

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that confronted PWAs every day." In the fall, New York CAN! will hold trainings with NYAC in both Rochester and Buffalo, furthering its objectives to recruit for the network, share ideas with the community, plan strategy with local AIDS organizations, and provide technical assistance and support where needed. In addition, New York CAN! organizers will be meeting with their counterparts from AIDS organizations all across the country to develop a national grassroots strategy for the year ahead.

"Coalition work and partnership is where all real change must occur" says Galloway. "As we say in our New York CAN! brochure, GMHC is proud of its leadership on AIDS advocacy. Now more than ever, it is clear that neither GMHC nor any other organization can wage this fight alone."

Andrew Stern is a community organizer in the Public Policy Department at Gay Men's Health Crisis and a coordinator of the New York Citizens AIDS Network (New York CAN!). He served two terms as a Democratic Committeeman in Nassau County and served on CUNY Hunter College's Presidential Task Force on AIDS. He is a founding member of Peacesmith House*, a grassroots organization which works for environmental and liberal political causes.*

New PAP Technology…

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those should be treated." A note from Planned Parenthood said "in a worse case scenario, it takes 2-3 years for a normal pap to progress to invasive cancer so that if every woman had a pap every 1-2 years, the abnormal cells would get picked up on pap before becoming cancerous." They argue PAPNET is not as good as a traditional pap picking up low-grade lesions. To obtain new Pap test coverage from doctors and insurers, women must request it — not fair to those unaware, plus some insurers deny coverage. It should be noted that PAPNET is used in about 25 other countries, often for primary screening, which since July 30 is also being sought in the US. The need for setting some national insurance standards and further review of still overly restrictive FDA requirements are topics health advocates should pursue, especially for preventive care.

Women have got to learn to be more mutually supportive in areas of mutual need.

What is perhaps the most alarming is that many women are reluctant to confront their doctors or insurance companies about any health issue, even when presented with well-documented information. PAPNET, for example, is endorsed by the American Women's Medical Association. Carol Armenti won a lawsuit based on re-screenings of her earlier misread Paps which clearly showed precancerous "slow growing" cells, accelerated by pregnancy. As a result of her cervical cancer, Carol had a miscarriage, a radical hysterectomy, and chemotherapy. She has established a support and educational group for women who have (had) cervical cancer. She is in the process of also creating a national educational program at the high school level to help young women become more knowledgeable and assertive about their health.

Women have got to learn to be more mutually supportive in areas of mutual need. I am hoping this issue of ensuring that the best new Pap technology becomes a "standard of care" will act as a catalyst to unite women for their own health advocacy and other common causes. If you think reducing the false negatives in Pap smear tests is unimportant, ask yourself, "Are you volunteering yourself or a loved one to be in the missed % when it could mean life itself or ability to have children?"

P.S. July 18, 1997, I wrote an expanded version of this article and sent it along with documentation to numerous women's organizations and magazines, some newspapers, Planned Parenthood, many major HMOs, and several particular individuals. Additions are ongoing. Anyone who would like a list of the recipients and/or a full copy of the report for themselves or others, please contact me at 10 Manitou Road, Westport, CT 06880. Tel. 203-454-3193, (1783-fax). Those interested in making donations to Carol Armenti's nonprofit support/educational organization may send it to the Center for Cervical Health, PO Box 1209, Toms River, NJ 08753 or call 908-255-1132 for further details.

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