

# Alternative Health

New York's ADAP expands into vitamins

April 1, 1994 By Robert Lederer

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Amidst growing scientific evidence and community experience showing the importance of nutrition in HIV treatment, New York City AIDS activists have won a modest victory in the battle for financial access to vitamins and minerals. Once again, people living with HIV/AIDS played the crucial role. The controversy concerned the state-run AIDS Drug Assistance Program (ADAP).

New York's ADAP, the broadest of 50 state programs, uses federal Ryan White Care Act funds to provide free medicines (64 FDA-approved drugs), primary health care and home care to people with HIV who are under- or uninsured but not poor enough for Medicaid. For example, single people earning below \$44,000 are eligible. Now, after the battle, some nutritional products and services are available as well.

Since early in the AIDS crisis, thousands of PWAs and dozens of their open-minded physicians learning from experience in their battles with cancer, have experimented with healthier diets and a range of nutritional supplements and natural remedies. Many have reported specific symptom improvements, reduced opportunistic infections and improved quality of life. But affordability has always limited access and thus potential life-extension.

Mark Milano, a New York City man, first diagnosed with pre-AIDS symptoms back in 1981, forged what he now calls a "somewhat haphazard" treatment package combining experimental drugs and nutrients.

Furthering the education that Milano and other HIV positive people have been receiving is a growing array of studies on nutritional therapy presented in medical journals and at three international AIDS conferences. In 1992, the University of Miami Medical School researchers reported that specific nutritional deficiencies begin early in HIV infection and are a major cause of disease progression. They -- and investigators from Harvard University -- found that correcting these deficiencies often resulted in T4-cell increases and stabilization of immune function.

Vitamins and Minerals  
Covered By New York  
ADAP

Multiple Vitamin/ Mineral Tablet
Beta-Carotene
Vitamin B-6
Vitamin B-12 (Sublingual)
Vitamin B-12 (Intramuscular)
Vitamin C
Folate
Folinic Acid
Iron
Lactaid
Magnesium Glutamate
Selenium
Zinc

This mounting evidence, combined with increased demands by HIV positive people, led New York ADAP last year to plan to add nutritional supplements and counseling to their coverage list -- the first, and only, state in the country to do so.

“After the Concorde study (showing no survival benefit to early intervention with AZT), we knew the PWA community was looking for other options,” says ADAP Director, Larry Cross. “They wanted access to nutrition, and we heard their voices.”

After the proposal was reviewed by physicians in and out of government, the AIDS Institute recommended sharply cutting the list, claiming inadequate evidence -- evidence they never asked for from the Working Group. Milano felt frustrated. “I thought the Working Group’s efforts needed more in-depth consideration.” An HIV positive ADAP administrator and AIDS activist, Darren Britton, openly supported Milano, strongly criticizing the “end-run around carefully considered proposals of experienced nutritionists.”

At the clinical subcommittee meeting, Milano arrived with Darren Britton, Fred Bingham of DAAIR and two other activists. What followed, a participant says, was an intense debate over whether the Working Group’s proposal amounted to “therapeutic” or “replacement” nutrition and whether any evidence supported the latter. Eventually, most of the items cut, including several antioxidants, were restored, though vitamin C was approved at only one gram a day. In the end, a list of 13 supplements was unanimously approved [see box].

Clearly activist pressure influenced the outcome. ACT UP member Mark Hannay explained the community’s widespread usage of and demand for nutritional products, and NIH community adviser Carola Burroughs discussed a proposed clinical trial of vitamin C and Beta Carotene for AIDS.

Last October, ADAP officially added the 13 supplements, in addition to the weight-gain products and nutritional services, to its list of items covered with a doctor's prescription. Two weeks later, a Manhattan pharmacy posted a sign, "Ask about new ADAP vitamins and minerals available."

"The community got together to fight for as broad an expansion as possible and everyone benefited, but more coverage is needed," says Bingham. Community advocates are continuing that fight to expand th treatments covered by New York ADAP.

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