The Vision Thing

At New York City's PWA Health Group, the bottom line ousts a top activist

November 1, 1998 By Dave Gilden

The news last summer that Sally Cooper was forced out as director of New York City's PWA Health Group came as a shock to many activists and clients. During her five-year tenure, the Health Group served as an independent, courageous voice in the debates over drug development and treatment strategy. "Cooper's work has been a real asset to the community in gaining access to treatments," says John James, editor of AIDS Treatment News. "When I had questions about a drug, she was an important source."

Cooper, who declined to be interviewed because of legal considerations, was asked by the board in June to hand in her resignation. In making this sudden move, the board allegedly cited her management style as well as questions about the group's survival at a time when new treatments have altered many organizations' missions. A majority of community reps and doctors on the board apparently favored an organizational shift to a more traditional, business-based structure.

Launched in 1987 as the nation's first "AIDS buyers club," the Health Group has specialized in selling unapproved AIDS drugs, many "smuggled in" from abroad. Treatment activism was always inherent, but under Cooper, the Health Group gained new prominence in the movement to speed HIV drug access. One major battle occurred over a compassionate-use program for thalidomide. Against FDA opposition, Cooper went so far as to import and sell the compound, an anti-inflammatory that can reverse AIDS-related wasting, when the agency declined to press for preapproval distribution because of fears of the drug's side effects.

Led by Cooper, the Health Group also took a firm stand during this year's debacle over Cryptaz (NTZ), which it imported from Mexico as a therapy for cryptosporidiosis, a fearsome, untreatable intestinal infection. When Unimed Pharmaceuticals requested FDA permission last spring to market the drug, AIDS groups nationwide backed the application. The Health Group alone held out, circulating a letter denouncing Unimed's miserly testing program and unconvincing data. Cooper and Health Group deputy director James Learned had had more firsthand experience with Cryptaz than anyone else in the community, yet they were widely criticized by other activists for committing the "mortal sin" of working against the approval of a desperately needed drug. Only after an FDA advisory committee voted against Cryptaz did the community accept that the compound was too poorly researched to bring to market. Treatment activists then resisted company pressure to fight on at the FDA and instead insisted that a compassionate-use program

continue pending further trials.

With the advent of highly potent anti-HIV combinations, the Health Group business end is suffering from lack of clear goals, sales and customers are down sharply, and the range of meds offered is limited. The group has expanded its treatment-education component—including a women's meds project, pediatric and drug-naive support groups, one-on-one counseling and outside workshops to train other agencies' staffs—and certainly these programs need the best management and funding as possible.

Such considerations apparently led the board to demand a more conventional ED with an administrative background. "Visionaries are fine to start with, but a manager has to take over to keep the organization functioning" seems to be the rationale, though board members have refused to speak publicly.

Yet it doesn't have to be either/or. The San Francisco advocacy group Project Inform resolved a financial crisis—and kept its vision intact—five years ago by naming guiding light Martin Delaney "founding director" while hiring a day-to-day executive director.

The Health Group's Learned laments Cooper's departure but insists that "the end result is, the organization will continue to serve people well and with integrity." As the acting executive director, Lillie Mikesell, puts together structural and fund-raising proposals, the question is not how well the clients are served in the immediate future. Arguably, they may well be served better by more efficient leadership. The real problem lies in the loss of one more independent voice that strengthened treatment activism by challenging its common assumptions.

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