Not Dead Yet

Protease-pummeled buyers clubs find new ways to serve PWAs

August 1, 1997 By Michael Onstott

Reports of the imminent death of AIDS buyers clubs are greatly exaggerated (with apologies to Mark Twain). True, the past year has seen masses of PWAs switch from eclectic treatment programs to protease-based cocktails. And yes, this has driven down sales that have helped sustain the nation's dozen-plus buyers clubs, some a decade old, which provide access to experimental and imported drugs and discount alternative treatments.

But now the nonprofit, often PWA-run clubs are reassessing and broadening their roles to meet the community's needs in new ways. Whether protease inhibitors work or fail long-term, buyers clubs will remain key sources of honest treatment information to help us maneuver through ever-changing standards of care.

Matt Sharp, director of the Healing Alternatives Foundation (HAF) in San Francisco, says, "HAF is committed to educating people about the entire spectrum of AIDS therapies and fighting for access to those therapies -- we're not just a glorified health-food store." Indeed, HAF's services include an extensive alternative-treatment library and a "Doctor's Report Card" -- a notebook with candid PWA reviews of Bay Area physicians. "It's going to take a real energized effort to find our new niche," Sharp says. Along with stepped-up fundraising, planned initiatives include educational health fairs, broader community outreach and expanded political advocacy.

Meanwhile, at the PWA Health Group (PWAHG) in New York City, director Sally Cooper says: "Currently, the medical system has a lot to offer. I'm not here to sell anything to anyone. But buyers clubs have always been about experimentation, em-powerment and survival." That includes feisty advocacy 0000(often jointly with HAF) to gain access to new drugs for such ills as wasting and dementia, and to fight pharmaceutical price-gouging. PWAHG also publishes valuable information packets, plus bimonthly newsletters in English and Spanish offering a detailed, sassy look at the practicalities and politics of treatment. In recent years, PWAHG has greatly boosted its revenue from private donations. Cooper thinks the club's continued success will depend on increased funding to provide emotional support services and unbiased information to "help people design individualized treatment strategies." For years it has offered the city's only intensive women's treatment support group and training sessions. Recently it launched a pediatric study group for parents and practitioners.

Last year, product sales at the New York City -- based buyers club DAAIR (Direct Alternative AIDS

Information Resources), which offers mainly nutrients and herbal extracts, plummeted 30 percent below 1995 levels. Today, after price cuts and expanded outreach, sales have doubled. Director Fred Bingham says, “DAAIR recently increased the number of alternative treatments we offer from 80 to 320. But it’s not just about options. Price equals access.” The club’s new membership packet and website include in-depth, scientifically documented nutrient recommendations, anti-HIV strategies and advice on countering drug side effects.

For years I’ve worked with various clubs as a consultant, treatment advocate and consumer. Simply put, buyers clubs have saved my life. While the Crixivan-based three-drug combo I started last year made my viral load undetectable, it failed to resolve the diarrhea and wasting that were slowly killing me. It took large daily doses of the amino acid glutamine to stop the endless toilet trips and reverse the unrelenting wasting. And I’ve only been able to detox my drug cocktail -- clogged liver by combining alpha-lipoic acid and silymarin (milk thistle). Many of us can afford products like these only because buyers clubs sell them so cheaply.

And these groups continue to wage many battles to keep treatments coming. Recently, buyers clubs across the country united and reversed the FDA’s wrongheaded effort to stop the importation from France of SPV-30, a nontoxic boxwood extract with antiretroviral qualities. Now the clubs have formed a political alliance to fight for access to and research on alternative treatments.

PWAs need this advocacy as we continue to experiment with combinations of conventional complementary therapies, and seek answers that diverge from medical dogma. So until there’s a cure, buyers clubs -- in one form or another -- will survive.

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