

Harlem's Holistic AIDS Alternative

Members of the Standup Harlem community combat illness, homelessness, and addiction with prayer, meditation, alternative medicine—and love.

BY STEPHANIE GOLDEN

A gentle shower of tiny yellow-green flowers, detached by the wind from the trees growing by the fence, is falling over five of us as we sit around a card table in the peaceful backyard of a Manhattan brownstone on a June afternoon. The flowers catch in everyone's hair, float in my glass of red juice, lodge in the pages of my notebook.

"Can you believe this is Central Harlem?" asks Louis Jones, looking around at the green yards backing onto each other up and down the block. But it's not just nature that has created an oasis here. It's also Jones and his fellow members of the Standup Harlem community, a residence for HIV-positive, formerly homeless people, many of them recovering from drug and alcohol addiction. Black, white, and Latino, straight and gay, female and male, they have made a commitment, based on spiritual principles, to "survive living with HIV in loving support of each other," as their mission statement puts it, and to "empower those living with the virus within our communities."

"I was homeless and addicted," recounts Lenny Wilbourne, a 45-year-old unemployed construction worker. "I came to Standup not aware that I was HIV positive, though I knew others I hung out with were. I felt it couldn't happen to me." He stayed a while, then "went back out there on those streets, got beat up a little bit more. I wasn't tired yet of abusing myself." But "by the grace of God, I wound up back at Standup. When I found out what this disease was about, I realized we're just everyday people, trying to make something good out of what a lot of people seem to think is really bad. And I felt a part of what was going on, which I hadn't felt in a long, long time."

Of the current 11 residents, most of them people of color, nine are HIV posi-



tive or have been diagnosed with full-blown AIDS. But in contrast with the aura of catastrophic illness and intensive medical treatment that often surrounds AIDS, the three men at the table radiate well-being.

"I'm not on any medications now," says Willie Reyes, a 35-year-old gay man who was formerly a commercial artist and photographer. He was diagnosed with AIDS after being hospitalized with two opportunistic infections. "When people think of full-blown AIDS, they think 'one foot in the grave.' But it's really just a diagnosis. I don't feel any different than I did when I was asymptomatic. I believe that my attitude is the most important thing. I keep a positive frame of mind and stay as stress-free as possible."

"Optimum health for us would be wholeness," adds Jones. In his red sweatpants and T-shirt reading "AIDS, Medicine, and Miracles: Resources for Renewal," the muscular 32-year-old seems the very model of health. "What we do spiritually, physically, emotionally, and socially makes up a whole regimen to maintain health. Wholeness is appro-

priate for us because of our having experienced brokenness."

Standup grew out of Jones's experience at Emmaus House, a Harlem community for the homeless that is part of a worldwide movement founded by a French priest after World War II. In April 1989, after 15 years of alternating between heroin addiction, incarceration, failed detoxification/rehabilitation programs, and homelessness, Jones came out of detox once again, facing a future just like his past—except that this time he discovered Emmaus. "I found people I could identify with, empowerment, shared leadership," he explains. "I came in on the soup line. Soon I was running the soup line. There wasn't someone doing for me, I was doing with. I wasn't a client—that was critical."

Emmaus provided a safe place for Jones to begin his spiritual transformation. "I realized it was change or die," he says. He began practicing the meditation techniques and prayer he had learned at Narcotics Anonymous. Realizing he couldn't face his pain alone, he let other people into his life; it was through these

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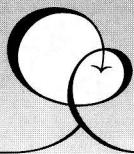


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relationships, he says, that God became real to him.

One person he met at Emmaus was Paula Palmateer, a volunteer from Colorado. "Two people, both on a search—me a Harlemites, formerly homeless, intravenous drug user, Paula an affluent, upper-middle-class white woman—found a consciousness that connected us and gave us a sense of purpose. We felt a call to build community."

"We live in community to serve others," says Standup founder Louis Jones. "We try to epitomize the experience of empathy, acceptance, belongingness, unconditional love, which is the essence of community for us."

Meanwhile, Emmaus members were dying. Memorial services were held, but nobody talked about *why* people died. AIDS was still shrouded in collective denial; community members were simply too frightened to look at the issue directly.

"What the deaths brought up for me was my own diagnosis," Jones remembers. Diagnosed HIV positive in 1986, he had been trying to ignore his condition despite a severe illness in 1987. Finally, at a December, 1990 memorial service, Jones stood up and disclosed that he was HIV positive. "I was brought to do it by the death of people I loved, the ignorance and fear of people I also loved, and my own need to not die from, but to live with HIV."

His action helped others "stand up," and he began running a support group for other HIV-positive Emmaus members—secretly, because of the stigma still pervasive there. He also began doing AIDS education in the community, as well as political actions with groups like ACT UP.

Eventually, with Palmateer's help, Jones borrowed an unoccupied building Emmaus owned in central Harlem, set up offices to provide information and referrals, and began holding support meetings for various groups of people who were HIV positive or had AIDS—women and their children, addicts in recovery—and for people in relationship with someone

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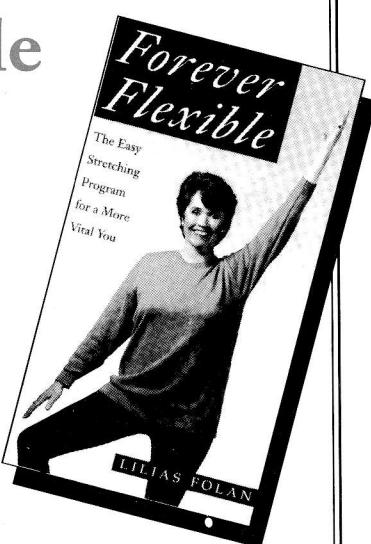
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with AIDS. When, in June 1991, a group member was in need of a place to stay, Standup suddenly became a residential community, based upon the spiritual principles that Jones had cultivated at Emmaus.

People discovered Standup by word of mouth—on the street, in prisons, at political actions—and through Jones's occasional radio appearances. The community quickly grew to about 20 residents, although the number fluctuates constantly. Some people stay overnight or just stop by for an occasional meal; others remain there a few days or for several weeks; and a few choose to become long-term residents.

Eventually Standup incorporated and obtained its tax-exempt status. They found a building for sale 10 blocks uptown, and by February, 1992, they had scraped together enough money for a down payment. Now they're living in the old building while working on renovating and paying for the new one. They've raised money through appeal letters, raffles, and a share in the proceeds of a play, and they've received in-kind donations from other AIDS organizations, churches, individuals, and community groups, as well as some small grants. Some members on public assistance contribute the rent portion of their checks, although this donation is not required. "Goods, money, and people helped us get by day by day, to pay the electric bill, the oil bill, though sometimes we'd be cold," Jones recalls. "We had cold showers, cold cereal—warm hearts." Since none of their income sources is reliable, Standup is seeking government money targeted to help the homeless and people with AIDS.

Standup's basic principles of communal living, shared leadership, empowerment, social change, and personal transformation are given expression in the four aspects of their daily practice: spirituality, support, service, and social action. "We are one family of many faiths," Jones explains. Current members are Muslim, Christian, or follow "a god of their own understanding." Every morning they all gather for prayer, meditation, and "worship sharing" in the form of poetry, readings from sacred books, or sharing from within. "We also get to share our pain," adds Wilbourne. "To be able to share your pain with people who understand really helps. It's not sympathy but empathy that lets you know you're not alone, that it's not the

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Many of Standup's spiritual practices, including yoga, meditation, and chanting, were learned from the Serulanda Spiritual Planetary Community, a worldwide non-sectarian clan founded in 1975 by Bambi Baaba (J. K. Mugonza) and headquartered in Uganda. The American Serulanda community in Harlem offers support groups, spiritual discourses, and alternative treatments including African healing traditions. Indeed, at Standup, the medical and spiritual regimens overlap.

Medically, says Jones, "we're open to anything and everything." Some members follow the standard prophylaxis against AIDS, taking drugs like AZT. Others choose alternative treatments: For example, when Jones's T-cell count (indicating the number of virus-fighting white cells in the blood) goes down, instead of AZT he takes hypericin, a natural antiviral agent extracted from the herb St. John's Wort. Right now, though, he's not taking anything.

"Our real regimen is visualization, affirmation, massage, nutrition, acupuncture, conscious breathing, meditation, and exercise," Jones continues, "things we can do for ourselves and at the same time with each other." And, Wilbourne chimes in, "Belief: believing that the disease is not always fatal."

Support arises from community: working and meeting together, as well as eating communal meals on the three small kitchen tables pushed together to form one large one. Support is also provided "one on one," with each new entrant seen regularly by an "elder brother or sister." And help comes from outside Standup—in the form of 12-step programs, HIV support groups run by other AIDS organizations, or hatha yoga at the Integral Yoga Institute downtown—to help people create networks of support independent of Standup.

As for service, "We live in community to serve others," says Jones. "We try to epitomize the experience of empathy, acceptance, belonging, unconditional love, which is the essence of community for us." Service ranges from the offer of hospitality—a 24-hour welcome including food, clothing, showers, and "an atmosphere of relaxation, sometimes a hug"—to formal case management.

In particular, Standup provides what they call "identification," a mutual experience in which the helper and the person being helped can identify with each other. "I just did an intake for two gen-

tlemen from the Veterans Administration hospital," explains Reyes, Standup's case manager. "Both are addicts seeking recovery, and one just found out he was HIV positive. No one understood their needs at the hospital, but finding someone here who has experienced the same type of circumstance, they automatically felt more at home."

Case management involves assessing people's individual needs and providing referrals to detox, rehabilitation, acupuncture, or other special treatments,

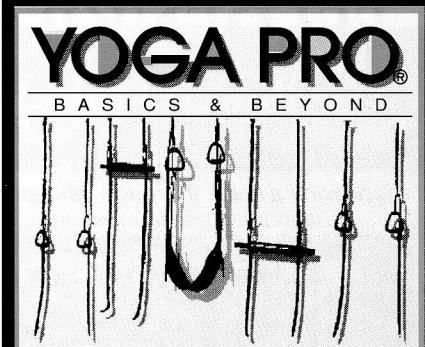
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as well as helping people get entitlements such as federal disability pensions, Medicaid, and state welfare. Despite its lack of professional accreditation, Standup has successfully learned to function as an advocate with the social service system, applying pressure to get immediate action for people with AIDS who need to obtain medication.

Out of advocacy grows social action. "AIDS has a political face," Jones affirms. "We say, 'AIDS is colored.'" Long-standing issues in the Harlem community are magnified by the epidemic: unemployment, lack of affordable housing, and inadequate health care and social services. Standup sees these, along with stress and poverty, as factors in the spread and progression of AIDS. "In fact, people of color primarily die not from AIDS but from these other factors—and a lack of honest prevention education," Jones adds.

The official focus on certain groups said to be at risk—gays, intravenous drug users, and prostitutes—misinforms people not in these groups and leads to false confidence and carelessness, he says. Misinformation also promotes myths generating fear that further marginalizes people with AIDS.

"If you say you're HIV positive, people start moving the food around, washing plates right after you've eaten out of them, because they're still afraid of being



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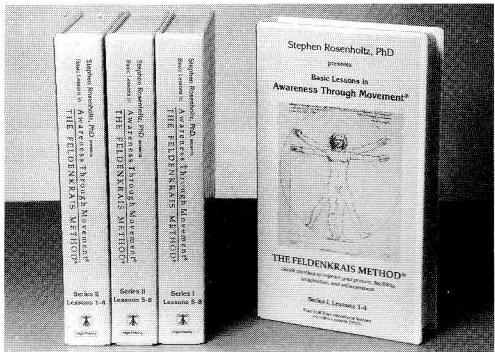
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infected—even after 11 or 12 years of AIDS being so widespread,” says Maria Olds, who has come outside to take a place at the table. Olds herself is not HIV positive, but she has lost many friends and family members to AIDS. A recovering alcohol and heroin addict, she doesn’t live at Standup but visits regularly to help residents and people from the neighboring community with recovery from addiction, as they create structure in their lives and learn “to deal with the real world.”

“I push to them that community love. Addicts need to feel loved,” she says. Smiling broadly amid the drifting tree flowers, Maria emanates the rock-solid energy of someone whose “bottom got so deep” she was finally ready to change. “What it takes,” Reyes elaborates, “is a combination of getting to that bottom and getting that support.”

Going inside, I get a tour of the house, through the kitchen where red-haired resident Michael English is busy chopping onions for dinner, and on upstairs, through dormitories with bunk beds, an office, and a green-carpeted recreation room where a poster on the wall reads, “114,000 AIDS Deaths: It’s Time for a National Plan.”

Sitting in an easy chair in the recreation room is Pamela Thomas, who has just come back to Standup after six days in detox. Today she had her first acupuncture session “to take away the anxiety and the urge. It really calms you down,” she says. Thomas’s husband died of AIDS, and she found she was HIV positive herself while she was in jail on a drug charge. She began using drugs again when she got out but “felt so bad” she went to the Department of Health, where a counselor told her about Standup. “I need to be around positive-thinking people,” she says, “stand on my own two feet with Standup’s help, get a job and have a normal life. But I need to be sure of myself before I get an apartment on my own. I don’t want to get back on drugs.”

Jones and Reyes walk me uptown to their new building, a four-story brownstone on a quiet block whose trees are releasing a sweet scent into the air. Standup intends to restore this house, with its gorgeously detailed woodwork, to its original condition. So far only the ground floor is usable: a meeting room with bare brick walls, a marble fireplace, blue plastic chairs, and long gray couch-

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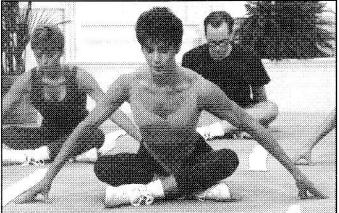
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es. "We cleared out the garbage," Jones recounts, "and held meetings by candlelight before we got electricity." Currently it's a meeting place for Alcoholics Anonymous, Narcotics Anonymous, Positives Anonymous, and support groups for gays, lesbians, and women, all open to the public.

Eventually this floor will be used for crisis management, needs assessment, and hospitality. Upstairs will be communal living space for 30 people, child care, and offices. The overgrown garden in the back will be cleaned out and fixed up too. "It'll be a lot of hard work," Reyes remarks, "but it's ours. We'll take our time—it's home."

"The communal process is the way for people to reintegrate themselves in the larger community," declares Jones in conclusion. "I've chosen on this plane to live out my days in community, as opposed to in an apartment, which for those of us living with AIDS is isolation—which is death." The healing power of community, he says, brings about transformation.

"A lot of people who have been institutionalized in shelters for years come here and wear their coats to breakfast, carry their bags to the bathroom and to bed," Reyes says. "Weeks later you see them leave the bags in their room, and you slowly see them take off their coats and reach out and hug people. To see someone come out of that shell and know that you're part of it is very fulfilling. I think that's what keeps us all here. How good that feels, to know you've touched someone!"

Later, at home, scraping the tree flowers off the bottom of my tape recorder, shaking them out of my handbag, peeling them off my notes, I find I can't throw them all away. I keep a pile on my desk, an emblem of the flowering that is Standup. □

*Stephanie Golden is a freelance writer based in Brooklyn, New York. Her latest book on homeless women, *The Women Outside: Meanings and Myths of Homelessness*, was published last year by the University of California Press.*

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