

# San Francisco Chronicle

## For San Francisco's AIDS network, survival and evolution

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Photo: Liz Hafalia, The Chronicle

Wilshia Seeley (left) and San Francisco campaign monitors Dustin Finkle (right) and Sshamita Jayakumar (middle right) prep carrots in the kitchen of Project Open Hand on Friday, June 24, 2016, in San Francisco, Calif.

In the founding days of Project Open Hand, a nonprofit agency that grew out of the AIDS epidemic, volunteers would make and deliver meals for clients: young men who were barely able to get out of bed, much less shop for food or cook their own dinners. Young men who were dying.

They'd be given steaming plates of high-carb, high-protein, high-calorie comfort foods like pastas and casseroles to combat malnutrition and weight loss from the wasting condition that marked their illness.

But 35 years later, the menu has changed — it's skinless chicken breasts and steamed vegetables now — along with the clients. They have diabetes and heart disease in addition to HIV. They're 55, not 25. And they're going to live.

"Our guys are complex now," said Mark Ryle, chief executive of Project Open Hand. "And we're a more sophisticated organization."

Project Open Hand is part of a vast web of nonprofit services for San Francisco residents with AIDS or HIV that formed alongside the epidemic and is now in the midst of an evolution. The landscape of the disease has shifted so dramatically in the past 15 years that each agency's leaders must figure out what role, if any, they play in the arena of HIV support.

About 16,000 people are living with HIV in San Francisco, and for many, their health and well-being depend on the survival of these agencies. But the population and its needs have changed. A disease that once was largely considered a death sentence is now a chronic and treatable condition. People with HIV are older — in San Francisco, more than half are at least 50 — and they need financial help, mental health services and care for medical issues beyond HIV.

Meanwhile, funds for HIV and AIDS are drying up. In San Francisco, federal funding has been cut in half since the peak years in the 1990s, to less than \$20 million annually. The city has always supplemented that federal money, but the drop is still concerning. And many agencies report that they're losing donors to more urgent or popular charitable causes.

In response, some nonprofits have disappeared. Many have expanded services to better match the changing needs of their HIV clients or to reach new groups — patients with cancer, heart disease or diabetes, for example. Some nonprofits are merging to conserve resources.

“The AIDS epidemic is changing. And we should be changing with it,” said Barbara Garcia, head of San Francisco’s Department of Public Health, which funds roughly 100 HIV/AIDS nonprofits. Those changes, she said, aren’t always easy, and may mean some agencies need to shut down.

A form of “organizational Darwinism” is under way, said Craig Miller, the founder of AIDS Walk, which raises money for HIV groups. “The process isn’t necessarily any prettier than it is in the animal kingdom, but it’s necessary,” he said.



Photo: Liz Hefalia, The Chronicle



Basil as well as other herbs grown in hydroponic systems at Project Open Hand are used in their meals on Friday, June 24, 2016, in San Francisco, Calif.

## 'Double-edged sword'

Last week, Positive Resource Center — one of San Francisco's oldest AIDS agencies, which provides benefits and employment counseling to people with HIV — announced plans to merge with Baker Places and AIDS Emergency Fund. Baker Places is a 52-year-old agency that provides housing and treatment services for people with substance abuse and mental health issues, and AIDS Emergency Fund offers grants of up to \$1,000 for people with HIV.

Leaders of the agencies said the merger will give clients better access to long-term care, while keeping the nonprofits solvent.

"Many organizations are asking themselves, 'How am I going to survive on just HIV?'" said Brett Andrews, executive director of Positive Resource Center. "It's almost a double-edged sword. We are excited people are living longer, but we may have lost the political will to keep these organizations going."

Sandra Nathan was hired as executive director of AIDS Emergency Fund last year specifically to help the agency plot a path for survival. Its client base has fallen dramatically since the peak years of the epidemic in the mid-1990s, from roughly 3,000 to 1,700 last year.

But it's tough to let go of an agency so deeply rooted in the response to the crisis. The AIDS Emergency Fund was built by men in the gay community, and their friends and families, who raised money for emergency grants to help AIDS patients pay phone bills, rent, groceries and other expenses that could throw an already chaotic life into financial ruin.



Photo: Liz Hafalia, The Chronicle

Volunteer shoppers Greg Karabeinikoff (left) and Richard Melnick get listed items for clients at the grocery center at Project Open Hand on Friday, June 24, 2016, in San Francisco, Calif.

"We've always occupied a unique niche," Nathan said. "The best we can do now is to combine our programs with a larger nonprofit organization."

The shift in services at HIV agencies started not long after the first antiretroviral drugs to treat the virus arrived in the late 1990s. But it's been a prolonged shakeup, and one that continues to rattle the city's nonprofit infrastructure, often referred to as the "San Francisco model."

In recent years, as HIV service providers have become more aware of the needs of aging, long-term survivors, many of whom never expected to live this long. Groups like Shanti Project, which provides peer support, have expanded their services.

Two years ago, Shanti incorporated a program called Honoring Our Experience, which holds weekend retreats and dances for survivors. In November, Shanti merged with a group called PAWS — for Pets Are Wonderful Support — that opened in the mid-1980s and seemed like a good fit for Shanti's older clients, many of whom rely on pets to fend off isolation.

"We actually went from Shanti helping people die well to Shanti helping people live well," said Executive Director Kaushik Roy.



Photo: Liz Hafalia, The Chronicle

David Wamecke (right) pets Rocco (middle) as they wait for food at the grocery center and kitchen at Project Open Hand on Friday, June 24, 2016, in San Francisco, Calif. Owner of Rocco (left) accepts photo but does not want to be identified.

Even more fundamental was the decision to take on clients who did not have HIV. Shanti started a program for people with breast cancer in 2001, and later expanded it to women with all kinds of cancer. Two years ago, the agency added a program for people with hepatitis C. Now, only about two-thirds of Shanti's clients have HIV.

Roy and other nonprofit leaders said that even as they've reached out to non-HIV clients, they remain HIV-centered. But the shifts in services can be difficult — for clients, volunteers and the community at large. Long-term survivors complain of feeling left behind as agencies move on to other types of clients.

The San Francisco AIDS Foundation, the city's largest and oldest HIV-focused agency, took criticism for merging with the Magnet health clinic in the Castro eight years ago and Stop AIDS Project in 2012.

But perhaps the most emotional transition in the foundation's history was a much smaller one, said James Loduca, senior vice president. One of the foundation's first services was a phone hotline, which famously started ringing immediately after it was installed in a small Castro Street office in 1982. By 2009, the hotline, which offered advice and support for people with HIV, had become all but irrelevant; no one called for information they could get so easily online.

"The amount of resources that were being poured into keeping it functional versus the sharp decline in calls, of course we couldn't keep it," Loduca said. "But it brought on some soul-searching, especially for board members who were some of the first volunteers at the hotline."



Photo: Liz Hafalia, The Chronicle

Dispatcher James Vilchez (left) and driver Otto Baltodano (right) unload the truck used to send meals to the elderly from Project Open Hand on Friday, June 24, 2016, in San Francisco, Calif.

### **'Breaking up the family'**

When Project Open Hand started offering meals to people with conditions besides HIV a year ago, some of its older HIV clients objected, said Ryle, the chief executive. They told him that they wouldn't feel comfortable with so many unfamiliar faces around. Even some volunteers had reservations. One morning, Ryle was in the kitchen watching workers prepare the day's meals when a longtime volunteer took him to task.

"You know, you're breaking up the family," Ryle recalled her saying. "You're bringing in people who aren't part of us."

But even as she griped, she never stopped chopping carrots. "Maybe it was for someone with diabetes instead of HIV," Ryle said. "Maybe she wasn't happy about that. But she knew it was important work."

<http://www.sfchronicle.com/health/article/For-San-Francisco-s-AIDS-network-survival-and-8325339.php>