

BATTLE AGAINST HIV/AIDS

A Look Back at the First Decades of the Santa Clara County Experience

Ken Yeager

Supervisor, Santa Clara County





Ken Yeager has been a Santa Clara County Supervisor since 2006. In 1992, he became the County's first openly gay elected official when he won the first of two terms on the San Jose Evergreen Community College Board. He followed that with two terms on the San Jose City Council and then three on the Board of Supervisors.

He is the co-founder of BAYMEC, Silicon Valley's leading LGBTQ political advocacy group, and was the first chair of the Santa Clara County AIDS Task Force. Before running for office, Yeager taught at San Jose State University.

He received his doctorate and master's degrees from Stanford University and his undergraduate degree from San Jose State.

INTRODUCTION : 1

BATTLE AGAINST HIV/AIDS : 2

AFTERWORD : 35

ACKNOWLEDGMENTS : 40

INTRODUCTION

The LGBTQ community has made great strides toward civil rights and in the fight against HIV/AIDS. Today does not feel like it did in the 1980s and 90s. It's important to recognize that the decades prior to our recent advancements were ones of hardship and devastating loss of life.

Two years ago, I embarked on a mission to create a written record of some of the significant challenges the local LGBTQ community has faced. In this account, I focus on the period from the first public knowledge of AIDS in 1981 through 1999 when medical advancements were beginning to make HIV a treatable, manageable disease, not dissimilar to other chronic health conditions. I believe now is the time to remember those years.

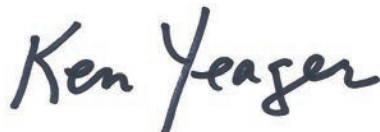
Although the LGBTQ community has endured countless hardships, perhaps nothing has cut so deeply as HIV/AIDS, and I recognize that no retelling can truly capture the pervasive fear, enormous suffering, and agonizing sorrow this merciless disease inflicted. I remember losing many friends. During those years, hope was in short supply.

Looking back, we find selfless heroes in the battle against HIV/AIDS. There was amazing tenacity, bravery, generosity, and self-sacrifice. I have called attention to a handful of the many Santa Clara County HIV/AIDS heroes. Another entire account could be devoted to the brave and dedicated others.

However, there were also villains who perpetuated bigotry and discrimination for political gain, which greatly exacerbated the suffering and slowed the progress of research and treatment.

HIV/AIDS continues to claim lives, particularly in certain communities. Far too many people are not taking advantage of early and easy testing options and preventive medications. As part of our continuing effort to fully eradicate this disease, it is helpful to reflect on the losses we've suffered, while also celebrating the hard-earned advances we've achieved.

For those who weren't old enough to experience these early years of the AIDS epidemic, I hope this account will inform you. For those, like me, who lived through the darkest days, I hope this serves as a reminder of how far we have come in many aspects of societal changes. For all, I hope it will inspire you to become involved because we can all make a difference.

A handwritten signature in black ink that reads "Ken Yeager". The signature is written in a cursive, slightly slanted style.

DECEMBER 2018

BATTLE AGAINST HIV/AIDS

A Look Back at the First Decades of the Santa Clara County Experience

1981 - 1982

In 1981, the LGBTQ community in Santa Clara County was still in shock following the overwhelming defeats of Measures A and B, which would have established anti-discrimination ordinances by the County for all the unincorporated areas and in the City of San Jose. The political campaigns in favor of the two ordinances had been plagued by disorganization and in-fighting. The community was demoralized and, by all appearances, mostly disinterested in further political action.

With all this, it is not surprising that the first media reports of a new mystery illness affecting gay men did not resonate in the South Bay when they appeared in May and June of that year. The San Francisco Chronicle covered the June 5, 1981, announcement by the Centers for Disease Control that five young, previously healthy gay men had come down with a rare lung infection, but the San Jose Mercury News did not.

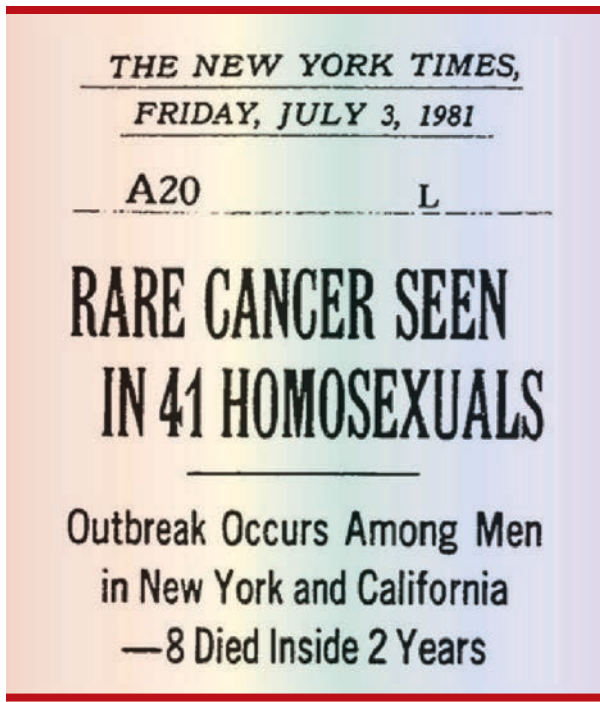
The South Bay's LGBTQ newspaper at the time, the Lambda News, did not publish their first article about AIDS until December 1982, more than 18 months after the first CDC reports and after it had already been the subject of articles in Time and Newsweek magazines and a report on ABC's Good Morning America.

In his 2002 book "From Closet to Community," Ted Sahl recalled the first case of AIDS in San Jose was reported "in early 1980," affecting a "popular activist in the community." However, his memory of the early 80's was "still, life went on. You never heard any conversation about AIDS, either in the bars, nor at any gay events. The community was in denial for another three years."

My friend Karl Vidt, who would become a prominent HIV/AIDS advocate—including a multi-year term as chair of the Santa Clara County World AIDS Day committee—reflected the prevailing South Bay attitude of the early 1980s. He said during that period AIDS was "something affecting people in San Francisco."

Dr. Ira Greene knew differently.





In 1981, Greene saw some of the first local AIDS cases when otherwise healthy men began coming down with Kaposi's sarcoma, a rare type of skin cancer. He noticed that these patients also had swollen glands, lethargy, and other symptoms that came to be associated with AIDS.

IRA GREENE

In 1981, Dr. Ira Greene was already a well-respected and beloved doctor. As the Chief of Dermatology at Santa Clara Valley Medical Center (VMC), he began seeing an increasing number of patients with Kaposi's sarcoma (KS). At the time, he didn't know that he was treating an illness that would soon grow into an epidemic.

Greene attended medical school at the University of North Carolina, and after initial training as an internist in Arizona, he made his way to Stanford for a residency in dermatology. He eventually became a clinical professor there, in addition to his role at VMC.

The KS cases Greene saw in the early 1980s caught his attention because they began appearing in relatively young men. Until that time, KS was

an extremely rare condition that mostly afflicted elderly patients. Because Greene had experience in internal medicine, he also took note of the strange mix of skin lesions, swollen glands, lethargy, pneumonia, and other symptoms affecting these patients.

That laundry list of symptoms soon became associated with the syndrome doctors would come to call AIDS. Greene's knowledge and background as a gay health care professional made him a logical choice for leading the effort to combat the emerging disease. Alongside Dr. David Stevens, Greene established a specialty treatment center at VMC that eventually became known as the Partners in AIDS Care and Education (PACE) Clinic. However, it was his empathy and connection to his patients that truly made him the right person for the job.

By 1988, Greene became associate director of Santa Clara County's AIDS program. Even though that leadership role took much of his time, Greene never stopped seeing people with AIDS one-on-one as a primary care physician. His compassion during these often bleak years was steadfast. He did all that he could for his patients, often securing experimental treatments in a last-ditch effort to save the dying.

Friends who knew Greene saw the emotional toll that this work exacted. He developed many close personal ties to patients who ultimately succumbed to the epidemic. Still, he continued to make visits to AIDS patients through the 1990s.

"When you work with dying people, you learn a lot about yourself. You are forced to confront your own feelings about death. You feel very mortal," Greene said in an interview with the San Jose Mercury News in the late 1980s.

Tragically, Greene died in 1998 when his Palo Alto home caught fire. It was a shocking loss for the community.

On a personal note, I was fortunate to have been good friends with Greene. During the early days of BAYMEC he advised me on our policy work on AIDS issues. In 1988, I had the pleasure of joining him on a trip to his home town in Tennessee to meet his family.

It was on that trip that he noticed a dark spot on the back of my arm. He thought it might be a melanoma, a form of skin cancer that can be fatal if left untreated. Upon returning to San Jose, I had it biopsied. It was in fact melanoma, and it was removed. Thanks to Greene, it was treated early. Thirty years later, I am skin cancer free. I owe my life to his friendship and caring.

Throughout his life, Greene received numerous professional awards for his work as an inspiring teacher and a skilled physician. Friends and colleagues, though, will most remember him for his kind heart and dedication to treating a community that was desperate for care yet often shunned and misunderstood. Today, the PACE Clinic bears his name, a fitting tribute to a man who made a huge impact in the lives of so many and helped lead this community through crisis.

In 1981 and 1982, Dr. Marty Fenstersheib, who would later go on to become Santa Clara County's Health Officer and Public Health Director, was living in San Francisco and working part-time at the city's Health Center One, located on 17th Street in the Castro District.

"Guys were coming in and they had swollen lymph glands. We knew there was this new disease going around but we didn't have a name for it. There was no etiology; we were calling it GRID," Fenstersheib recounted in a 2017 interview. Gay Related Immune Deficiency was a term used for the disease in its earliest months. By the middle of 1982 it had been replaced by AIDS.

"There was nothing to do for these guys. I remember they came in, and there was nothing, nothing. It was basically people coming in with these strange symptoms. A lot of them were very sick and went right to San Francisco General, Ward 86 there. They did not do very well; most of them were dead within nine months," Fenstersheib recalled.

1983

10 AIDS Diagnoses; 5 Deaths

By 1983, AIDS arrived in Santa Clara County. The Public Health Department reported the County's first confirmed AIDS diagnosis in April.

The South Bay LGBTQ publication *Our Paper* published a story on June 29 illustrating the rampant fear at the time regarding contact with AIDS patients. The story reported that two nurses at Santa Clara Valley Medical Center resigned rather than treat someone thought to have AIDS.

Bob Sorenson, later to become executive director of the nonprofit group the Aris Project, shared a glimpse into the trauma experienced by persons with AIDS, and by those trying to assist them, in a presentation in 1983. He emphasized the emotional shock young people felt when told they have a terminal disease, as well as the rejection they experienced from family, friends, and co-workers. As the person became progressively disabled, people around them were having hysterical responses, worried it was contagious.

1983 also saw the formation of the Santa Clara County AIDS/KS Foundation. Many kinds of fundraisers were held to raise money to start a local chapter of the foundation and to support its services. An association of gay bar owners and bartenders raised \$5,000. One bar in San Jose, HMS, alone donated more than \$1,000. Local volunteer and activist Jeff Barber was instrumental in securing a \$3,500 donation from IBM's Fund for Community Service, and donations large and small came from numerous sources.

Organizers of the local chapter began holding weekly meetings at private homes. The meetings were attended by a cross-section of concerned individuals, both gay and non-gay, including medical doctors, science professors, nurse practitioners, counselors, businesspeople, political consultants, and representatives of county agencies and non-profit organizations.

Their immediate focus was on providing information and referrals through a hotline and drop-in availability at their office. Educational materials were designed to alert people at risk to the danger of AIDS and to dispel hysteria among the public. Support services for people with AIDS, and possibly home care and even housing, were planned as resources permitted. The chapter also organized a legal committee to help with administrative problems and provide advice to patients.

An article in *Our Paper* stated: "The chapter board itself experienced some of the public hysteria when a landlord reneged on an oral agreement for office space in a building on The Alameda. Contacts with other landlords proved unfruitful whenever the term "AIDS" was mentioned." The chapter finally found a home on North First Street near San Jose's Civic Center.

One of the chapter's first requests was to the County Public Health Department for a nurse to help in teaching about the disease. Millicent Kellogg was selected. She related how difficult it was because of how little was known. "You had to say so often, 'I don't know. We don't know that yet. That doesn't seem to be the case. Well, that's what we understand, but it doesn't sound right,' or 'Yes, that's the way it is.'"

The Santa Clara County Health Department's Public Health Bureau AIDS Program was formed in 1983 to conduct community education. Kellogg and health education specialists David Burgess and Valerie Kegebian were hired. They formed a team led by Fenstersheib, who had been employed as the director of the Santa Clara County Public Health Department Immunization Program. Utilizing a small grant from the state, the team began to educate people in jails, gay bars, and elsewhere. They also distributed condoms. In November, Santa Clara County obtained its first state funding for AIDS. The Public Health Department received \$37,545 for AIDS control activities.



On the national scene in 1983, AIDS was first reported among the female partners of men who had the disease, suggesting it could be passed on via heterosexual sex. The first cases of AIDS in children were also reported. Researchers concluded they had probably been directly infected by their mothers before, during, or shortly after birth. By September, the CDC had identified all major routes of transmission and ruled out transmission by casual contact, food, water, air, or surfaces.

By the end of the year, 10 people in the County had been diagnosed with the disease and five of them had already died. The death toll would continue to increase each year for the next decade. The number more than doubled in 1984 and then doubled again the following year.

1984

**32 HIV Diagnoses;
15 New Deaths, 20 Total Deaths;
23 Living with HIV/AIDS**

Before 1984, education and prevention efforts were hampered by the fact that so little was known about the disease. It was not until April of that year that French and American researchers announced that they had jointly discovered the virus that causes AIDS. It was given the name HIV.

In a 1995 interview with Sahl, Fenstersheib recalled what AIDS education was like during these early years: "We would go anywhere, meet with anybody, wherever anybody would listen to us. Sometimes the group would speak to audiences with as few as four people. We would ask, 'How many of you know anything about AIDS?' Over and over again the response would be the same: 'Nothing.'"

"It was an uphill battle all the way," he continued. "Nobody, not even the medical community, was recommending testing because they could not offer people anything more than knowledge. On top of that was the discrimination the client might experience and all the other negative things, like family rejection and loss of employment and housing that went along with testing positive for the AIDS virus.

"I remember thinking that we were sending people back out on the street with the knowledge, but there was no place for them to go. What we really needed was a screening clinic where trained personnel could sit down and talk to clients, ask them how they were doing, and possibly refer them to a medical care facility where they might receive additional help."

MARTY FENSTERSHEIB



Born in Pittsburg, Pennsylvania, Dr. Marty Fenstersheib received his B.S. at Tulane University, M.D. at Universidad Autonoma de Guadalajara, and M.P.H. at U.C. Berkeley. He is Board Certified in Pediatrics and Preventive Medicine. He always craved big challenges. He left his first job in private practice because he found it too easy. He entered U.C. Berkeley's Public Health program and, as a fluent Spanish speaker, was soon working in a Spanish-language clinic in San Francisco's Mission District.

In 1984, he joined Santa Clara County's Public Health Department as director of the immunization program. This was in the early days of the epidemic. "I actually was the first person in the health department that gave results to people that they were HIV positive. The test came out in 1985 and nobody knew what to do, so no one wanted to give the results. So, I did," Fenstersheib said. "It soon became known that if you got the test and I came in the room—it wasn't good news. After that, there was nothing else to tell them."

AIDS scare leads to paranoia

(IGNA) Numerous cases of half-hysteria over the assumed contagion of AIDS have begun to crop up around the United States.

Although health officials have stated again and again that AIDS is a disease that is only transmitted through sexual contact or the blood (and even this is not completely proven), people in several cities have reacted with paranoia.

In San Francisco, several television technicians refused to be in the same room with two AIDS patients who were to be interviewed.

Studio personnel refused to put microphones on two AIDS sufferers when they agreed to appear on KGO-TV's "A.M. San Francisco" program.

The two men agreed to be interviewed by telephone from an adjoining room. The two were not shown on camera, but their voices were heard.

In yet another incident, an AIDS patient left a Superior Court jury in San Francisco after fellow jurors wrote to the judge and said they did not want to sit in the same room with him.

In a recent issue of *New York* magazine, incidents of increasing hostility towards AIDS patients and

including a mother who wanted to know if her children should wear gloves while riding the subway.

Also in New York, the state's largest association of morticians recommended that its members refuse to embalm victims of AIDS. They also demanded that the remains of all AIDS victims be placed in sealed pouches and permanently closed caskets or containers.

Just recently, here in San Jose, two registered nurses resigned rather than treat a patient suspected of having AIDS.

One of the nurses who resigned said she believed the hospital's precautions were inadequate to protect those coming in contact with the suspected AIDS victim. "I think most nurses would agree...there really isn't anyone who wants to go in the room," she said.

Anne Moses, special assistant to the director at the facility, said the hospital guidelines call for placing AIDS patients in isolation and for attending staff to wear protective clothing.

The upsurge in excessive concern about contracting AIDS appears to be the result of large amounts of media coverage of the disease but limited understanding on the part of general readers on the difficulty of getting the disease from anything but the most intimate contact. ■

Fenstersheib achieved national prominence when he pioneered a then-revolutionary AIDS treatment that meshed medical care with education to keep infected patients from spreading the virus. He helped open a County clinic to provide education, referrals, and support. The approach was profiled in the Journal of the American Medical Association.

The HIV Early Intervention Clinical Program he started in 1987 became the model for the State of California. More than two dozen similar clinics were subsequently established and funded across the state. When Congress significantly expanded the federal funding for AIDS care in 1990 with the passage of the Ryan White CARE Act, Fenstersheib's program became the national model for AIDS treatment clinics.

Throughout the epidemic, Fenstersheib continued to serve as a hands-on clinician, caring for HIV patients for more than 27 years, even after becoming the County's Public Health Officer and later, after adding the role of the Public Health Department Director.

The epidemic had a profound impact on Fenstersheib personally. His partner was diagnosed as HIV positive in 1984 and died in 1992. In addition, Fenstersheib has sung with the San Francisco Gay Men's Chorus since 1983, and he reflects on the loss of more than 300 members of the chorus who have died of AIDS since the epidemic began.

Meanwhile, Burgess, Kegebian, and Kellogg kept the education program moving forward. Burgess, who was very unabashed, did some of the first safe-sex classes—using a banana to demonstrate the correct method of putting on a condom. Everybody loved him. Kellogg also had a special approach in her delivery—drawing simple pictures and explaining things so well that people really understood what she was talking about.

During this terrifying era of AIDS, many bathhouses were shutting down. In October 1984, the San Francisco Public Health Director Dr. Mervyn Silverman moved to close San Francisco's gay bathhouses and sex clubs. San Jose's Watergarden was one of only two bathhouses that remained open in the entire Bay Area, largely attributable to Watergarden founder Sal Accardi who pushed for

safe sex practices from the beginning. Accardi was one of the first bathhouse owners to work with public health officials to set up a program to stop sexually transmitted diseases. Sadly, he would die of AIDS in 1994.

In 1984, the first support group for people with HIV and AIDS began meeting at the Grace Baptist Church in San Jose. However, when some church members found out and expressed fear of contracting the disease from toilet seats or other surfaces, the meetings moved to the home of community activist Bob Clayton.

This was also the year that I came out publicly in a Mercury News op-ed. Within weeks of coming out, I began planning how to politically organize the South Bay's LGBTQ community. Discussions with Wiggys Sivertsen led to our founding the Bay Area Municipal Elections Committee (BAYMEC) that summer.



While passing civil rights legislation and supporting LGBTQ candidates were BAYMEC's primary goals, increased funding for AIDS research and treatment was not far behind. Our first fundraiser was held in October, featuring then-Assemblyman Art Agnos as a speaker. The press announcement said, "Other issues of primary concern to the committee include increased AIDS funding, the Equal Rights Amendment, equal pay for equal work, and the enactment of non-discriminatory government, police, and corporate personnel policies to protect lesbian and gay civil rights."

Also in October, the State Department of Health Services awarded a second grant to Santa Clara County for AIDS-related services. The FY84-85 allocation was \$52,905.

1985

**148 HIV Diagnoses;
33 New Deaths, 53 Total Deaths;
148 Living with HIV/AIDS**

There were 33 AIDS deaths reported in the County and 148 people diagnosed with HIV in 1985. At BAYMEC, we were busy trying to grow our new organization and get local elected officials to take us seriously. Still, almost every one of our monthly board meetings included at least one AIDS-related topic.

That year was also when the first HIV test became available, and the Public Health Department opened an HIV testing clinic in San Jose.

Fenstersheib again took on the difficult role of telling people they were HIV positive. In a 2012 San Jose Business Journal interview, he recalled the reactions of those earliest patients, “They would run out, bang doors, sometimes they’d cry, sometimes they’d scream. It was horrible.”

1985 also saw an explosion of media coverage of the AIDS crisis following movie star Rock Hudson’s announcement in July that he had the disease, and his subsequent death in October.

AIDS hit home for me and BAYMEC in the late summer of 1985 when founding board member Doug DeYoung, who had been diagnosed the year before, grew steadily weaker. My sorrow and concern for him led me to write an op-ed in the Mercury News that was published on September 30. “Local officials perceive it to be political suicide to support any issue concerning AIDS. To be on the record as favoring AIDS education or patient care might categorize them as ‘sympathetic’ to the gay community and hand an opponent a weapon to be used at election time. Because gays and lesbians have been discouraged or made to feel

unwelcome by city hall—much as women and minorities before them—the awareness by officials of the disease is minimal.”

I also directly linked the slow government response to the political atmosphere that had led to the defeats of Measures A and B in 1980: “Gays and lesbians have no choice in their sexual orientation, but they do have a choice in whom they tell. Many in Santa Clara County choose to remain silent. Fear of repercussions by employers, landlords, and co-workers makes them conceal their identities. Added to the low visibility is a lack of political power.

“The clout of the Moral Majority may be real or imagined, but local politicians believe in it,” I continued. “Only a handful of politicians are courageous enough to speak out against the bigotry and hatred aimed toward homosexuals. Anti-gay rhetoric is increasing in velocity and voracity as fundamentalist preachers learn of its fund-raising potential. Since few non-gays demand that the tactic be stopped, the religious right has become more powerful as coins drop in the coffers.”

At the time I was writing the op-ed, the only public funding being spent on AIDS in Santa Clara County was the state grant that partially paid the salaries of the nurse and health educators. Local non-profits such as the AIDS/KS Foundation and the Aris Project, which provided counseling and support programs to AIDS patients, did not receive any funds at that time from either the County or local cities. There was no health care facility where AIDS patients with chronic cases could receive ongoing treatment. Santa Clara Valley Medical Center only treated the acute patients who were gravely ill. As I noted in my op-ed, this was “irresponsible and inhumane.”

DeYoung died in the summer of 1986. As a political consultant who was an early specialist in using data management for voter outreach and targeting, he played a key role in the electoral successes of Anna Eshoo, Tom Nolan, and Jackie Speier. He also mentored Doug Winslow, who took over DeYoung’s business and went on to help elect Democratic candidates throughout the Bay Area.

Other groups were slowly starting to form that devoted substantial efforts to the battle against

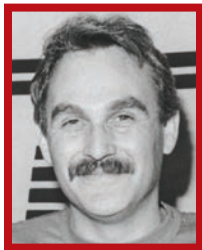
AIDS. High Tech Gays (HTG) was founded in 1983 in San Jose by Rick Rudy and several others as a social organization of gays employed in the technology industry. They quickly broadened their scope and in 1984 gained a high public profile by challenging the U.S. Department of Defense policy that routinely denied necessary security clearances for tech professionals who were known or thought to be homosexual.



HIGH TECH GAYS

By 1985, HTG took on AIDS as a major issue. Their April newsletter reported they had formed a group called Mobilization Against AIDS to provide education and political action on AIDS and AIDS-related issues. "Since its formation only a few months ago, the members have been very active in the Bay Area and in Sacramento. The war against AIDS is just beginning. Your help is needed. HTG has joined as a group sponsor in remembrance of Jim Kline. Jim was a member of HTG. He recently passed away, at the age of 34, as a result of AIDS."

RICK RUDY



Today, the tech industry is hailed as a model of inclusiveness. It is considered to be one of the most LGBTQ-friendly industries in the U.S. Tim Cook, the CEO of Apple, the world's most valuable tech company, is openly gay.

This reputation did not happen naturally, or overnight. It took years of struggle by LGBTQ engineers, programmers, and other tech workers. Rick Rudy played a key role in that struggle.

Rudy was born and raised in New York City. He received his bachelor's and master's degrees in engineering from MIT and afterwards began a career in the tech industry that brought him to San Jose in the early 70s.

Editor's note: The following editorial appeared in the San Jose Mercury News. It was written after the author learned that Doug De Young, a member of BAYMEC's board of directors, was diagnosed as having AIDS.

By Ken Yeager

A good friend of mine has been diagnosed as having AIDS. My sorrow and compassion for him is as piercing today as the moment I heard the news.

My friend is a veteran of the struggle by homosexuals to be free of discrimination. I hesitate to refer to him as "gay" or as a "gay activist" because those labels overpower other important facets of his life. To those who love and admire him, he is foremost a friend, a relative, a neighbor, a co-worker.

Professionally, he is a political consultant in a nearby county. His expertise — along with his kind heart — has endeared him to numerous local, state and federal officials, many of whom partially owe their election or re-election to him. Feminists, union members, minorities and the state Democratic Party also have benefited from his advice and skills.

Statistically, most of the reported 12,000 AIDS cases in the United States have been diagnosed in large cities, not in suburban areas like San Jose. Suddenly that is changing as the epidemic follows its predictable path to all localities and to all segments of the population.

Presently, 82 cases have been diagnosed by doctors in Santa Clara County, although health authorities believe the number would be twice as high if it weren't necessary for residents to go to San Francisco for treatment.

Despite the dramatic increase in AIDS cases, our city and county officials still live in a pre-AIDS world. Few policy-makers have experienced the personal agony and resulting sense of urgency to find an immediate cure. Consequently, mayors and council members avoid the health crisis by saying that it's a county problem, and county supervisors do the same by saying it's a city or state problem.

In addition, local officials perceive it to be political suicide to support any issue concerning AIDS. To be on record as

favoring AIDS education or patient care might categorize them as "sympathetic" to the gay community and hand an opponent a weapon to be used at election time.

Because gays and lesbians have been discouraged or made to feel unwelcome by city hall — much as women and minorities before them — the awareness by officials of the disease is minimal. If it is true that the common denominator of politics is response to matters in one's back yard, then it is inevitable that public acknowledgment by local officials has not been forthcoming.

Gays and lesbians have no choice in their sexual orientation, but they do have a choice in whom they tell. Many in Santa Clara County choose to remain silent. Fear of repercussions by employers, landlords and co-workers makes them conceal their identities. Added to the low visibility is a lack of political power.

The clout of the Moral Majority may be real or imagined, but local politicians believe in it. Only a handful of politicians is courageous enough to speak out against the bigotry and hatred aimed toward homosexuals. Anti-gay rhetoric is increasing in velocity and voracity as fundamentalist preachers learn of its fund-raising potential. Since few non-gays demand that the tactic be stopped, the religious right has become more powerful as coins drop in the coffers.

My friend's diagnosis will affect some politicians very deeply. Unlike certain types of cancers, AIDS cannot be treated or go into remission. Medical research has stopped making cancer the death warrant it once was. Unfortunately, this is not true of AIDS. To date, no one has been cured.

Should my friend not survive, I hope his legacy is the depoliticization of AIDS by elected officials. Instead of steering clear of the crisis, they must speak to the problem. The public turns to elected officials for guidance on matters such as public health, and they must provide leadership in combating the disease.

Politicians can't keep AIDS at arm's length

More money and resources must be allocated in Santa Clara County. Currently, the only funds being spent are from a state grant that partially pays the salaries of two county employees. These people have sole responsibility for the dissemination of information within the entire county.

Local organizations such as the AIDS Foundation and ARIS must raise their own funds to support their counseling and support programs. Not one dime of city or county money goes toward their invaluable work of helping AIDS patients. If these organizations are to be successful, they will need monetary as well as public support to remain in operation.

A facility for people chronically ill with AIDS is essential. Valley Medical Center does what it can for patients who are acutely ill; chronic patients have nowhere to go for treatment in this county. This is irresponsible and inhumane.

It is my fervent hope that the elected officials in Santa Clara County who know my friend will gain some bravery to enable them to stand up to public misconceptions about AIDS. When an issue becomes personal — no longer just political — consequences become secondary. Sadly, this only occurs when non-gays experience the tragedy of AIDS through someone they know and love.

My friend has long understood the importance of gay and lesbian involvement in politics. When some members of the gay community were apathetic and thought politics a waste of time, he knew the opposite was true. He knew a wrong could be made right.

Now his very life is in the hands of the politicians, as well as the scientists and all those who believe the needless suffering of one person diminishes us all.

Ken Yeager is treasurer of BAYMEC, a local gay/lesbian political action committee.

In June 1982, Rudy was one of a handful of tech industry workers who met in San Jose to form a South Bay chapter of the San Francisco-based Lesbian and Gay Associated Engineers and Scientists. Within months, the organization had separated from San Francisco and was renamed High Tech Gays. Rudy became its first president and help write the by-laws.

Rudy was a board member of BAYMEC from the very beginning. He hosted some of the earliest meetings at his home, helped write the by-laws, and generated early publicity through the High Tech Gays newsletter.

Rudy made the time for BAYMEC when he was busier than ever. He had gotten involved in gay rights at a national level, joining the board of the National Gay and Lesbian Task Force in 1985. This led to interviews both locally in the Mercury News and nationally in the Advocate and the Wall Street Journal.

Rudy's life, however, was filled with much more than just tech and gay politics. He was a theater lover, especially Gilbert and Sullivan. He was a

longtime performer with San Jose's Gilbert and Sullivan Society. He also spent a decade as the theater critic for Our Paper.

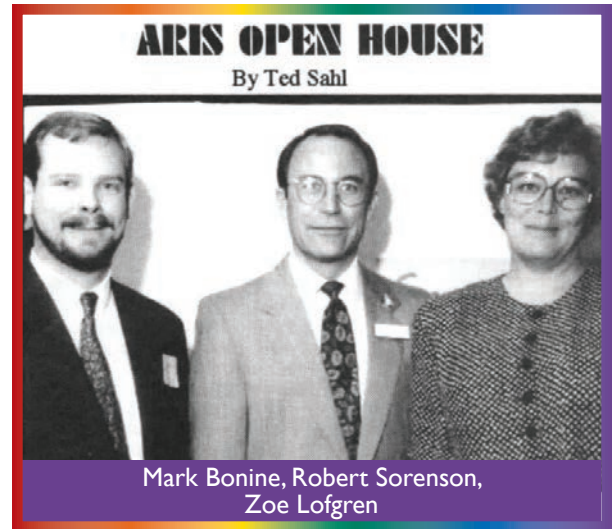
I remember visiting Rudy in O'Connor Hospital. We were all required to wear special clothing from head to toe. Despite that, it was good to see him one last time to say goodbye before he died.

Rudy's life was tragically cut short at age 44. He was one of the more than 2,500 Santa Clara County victims of the AIDS epidemic.

In 1985, Reverend Randy Hill founded a church in San Jose, eventually known as the Hosanna Church of Praise. His background was as a pastor of the Southern Baptist Church in Knoxville, Tennessee. However, he left that position when he felt he couldn't meaningfully serve in that role as a gay man.

Hill's San Jose church emphasized outreach for the homeless and indigent. He relied on donations of clothing, food, and monetary assistance and often found donated items at his front door. With the help of co-founder Gary Givens, this grew into Necessities and More, a group created to help people living with HIV or AIDS. He also started a 24-hour AIDS hotline. Initially operated only with volunteers and donations, these programs both grew as the numbers of infected people swelled. In the late 1980's, Hill moved his church to the Billy De Frank Lesbian and Gay Community Center on Park Avenue.

In 1985, Yolanda Perez, Raymond Aguilar, Bernie Greer, Toby Nelson, Pat Mayberry, Ed Bilger and Art Beaten joined together to form the Imperial AIDS Foundation (IAF) in San Jose. Its purpose was to provide personal and financial assistance to people with HIV or AIDS. Grassroots efforts, ranging from spaghetti dinners and stage shows to car washes, provided the funds used to help clients pay rent, utilities, and prescriptions. Of particular value, IAF delivered food to clients who were unable to get out of bed, as well as transportation to medical appointments.



That year also saw the founding of The Aris Project, which would become the major nonprofit group in Santa Clara County focused on providing care, services, and support to people with HIV/AIDS. It was founded in the living room of Santa Clara County Social Services Agency worker Bob Clayton.



Aris is the word for bear used by the Ohlone tribe of Northern California. As such, it is spelled lower case, until it changed to an acronym which is chronicled later. Initially the group was closely modeled on the San Francisco-based group Shanti Project. Shanti had been founded in 1974 to provide services and emotional support for terminal cancer patients. However, it quickly became one of the most important organizations for AIDS patients in San Francisco during the early period of the epidemic.

BOB CLAYTON



James Robert Clayton, known to everyone as Bob, was born in 1934. He was working for the Social Services Agency in 1981 when a man seeking help walked into his office suffering from a new and unknown malady. The man was one of

the first county residents with AIDS. For the rest of his life, Clayton would be at the forefront of the Santa Clara County effort to deal with the disease and care for its patients.

In 1985, Clayton opened his home as the first AIDS residence in the county. In March of that year he helped form a weekly support group for AIDS patients that initially called itself "Freedom from Fear." By January 1986, that group had incorporated as a nonprofit and become the Aris Project.

In 1994, Clayton received national recognition when he was presented with the Family AIDS Network's National AIDS Caregiver Award. His nomination announcement noted that "Bob cries easily, never afraid to share his grief with other caregivers. Yet, he talks about the pain he carries each day as a 'small price to pay' for the rewards he has found reaching out to other people in need. Bob talks about each of the people he has been a caregiver for as a proud parent talks about their child- with love and unconditional acceptance."

One of the highlights of his life came in 1996 when he carried the Olympic torch in San Jose as it made its way to Atlanta.

At the time of his death in 2003, Clayton was serving as interim director of ARIS.

Bob Sorenson was a member of the Metropolitan Community Church and volunteered in the same informal AIDS support group as Bob Clayton. His day job at the time was being the administrator of the Santa Clara/Santa Cruz Counties Council of Campfire, providing him with experience managing

Our Paper Paper

Volume IV, Issue 18 Next Deadline: October 4 — Next Issue: October 11 September 27, 1985

Published biweekly in Santa Clara County by Our Projects, Inc.

Call for Quarantine:

'Spread Panic, Not AIDS'

By Dot James

Brian Lance, candidate for the U.S. Senate in 1986, is calling for nationwide blood-testing and a quarantine of all People With AIDS (PWA's). Lance met at the LeBaron Hotel Sept. 18 with other members of the National Democratic Policy Committee (NDPC), a political party formed by Lyndon La Rouché, to announce the NDPC program on AIDS.

'AIDS will be the hottest political issue of 1986, spilling over into '88.'

La Rouché calls himself a Democrat; however, the Democratic Party has repudiated La Rouché and his National Democratic Policy Committee line and time again because of their conservative bias.

"AIDS will be the hottest political issue of 1986, spilling over into '88," Lance stated, emphasizing the questions about AIDS asked of President Reagan in his recent press conference.

The NDPC leaflet at the main post office for a week before its "AIDS Forum" in hopes of drawing a crowd to its meeting. Only a handful of people showed up, mostly NDPC members and several gay activists.

In response to a question from Gay Community Center executive director, David Treadwell, regarding the NDPC's anti-gay literature, Lance stated that the

NDPC is "pro-human; we're not anti-gay."

A member of the audience declared that "homosexuality is itself a disease." Lance then admitted, "We don't view homosexuality as a healthy lifestyle."

Lance went on to say he believes "gay bathhouses are little pest holes for the spread of AIDS."

Later responding to the accusation, Sal Accardi, president of The Watergarden, commented, "Lance's charge is not new, but

actually bathhouses are not a part of the problem, but a part of the solution.

"At The Watergarden we provide condoms, education and literature on safe-sex practices, and, most important, an atmosphere that is conducive for people expressing themselves in a healthy and safe manner."

"Lance is using gay bathhouses as a red herring," Accardi

continued. "His statement is ignorant, misleading, and downright dangerous."

Lance claimed the NDPC is launching a nationwide campaign to "spread panic, not AIDS" by lobbying for signature to a Memorial Bill. City council, county boards of supervisors,

'You interview him, find out who he's been with, and track them down.'

(1) A mass screening to determine who has AIDS, with people licensed by the state health department ("hair dressers, nurses") or working in areas inspected by the health department ("restaurant workers") to be tested first and on a regular basis.

(2) After screening, isolating those who have the AIDS virus in institutions where they will be treated and used as research subjects. "Quarantine them; take them out of social circulation," demanded Lance. "AIDS is spreading into your neighborhoods, into your schools — bringing it home."

(3) Setting up a crash program for research on AIDS and "diseases of aging," such as cancer and coronary disorders.

(4) Addressing the economic conditions which lead to unsanitary living conditions in places such as Bell Grade, Florida.

Initially, Lance focused his speech on the latter two points of

Electronic firm faces suit for AIDS-Test firing

By Matt Thompson

Attorney Grace Ybarra, representing a 27-year-old electronics employee, has threatened to take legal action if Sunnyvale Electronics does not reinstate her client or pay damages for his allegedly unlawful termination.

Greg Duff was "laid off" by the firm on Sept. 1. According to Duff, his employer gave the reason that he had "low seniority" and that "times are tight."

Duff, however, believes that he was fired for refusing to take the controversial AIDS antibody test. He states that in the month immediately prior to his termination, he was repeatedly pressured to produce test results or "face the consequences."

"California law prohibits testing of a person's blood for AIDS without written consent of the subject of the test," wrote Attorney Ybarra in a Sept. 13th letter to Peter Abrico, president of Sunnyvale Electronics. "That law further prohibits using the results of a blood test for AIDS to determine suitability for employment."

Citing California Health and Safety Code Sections 199.21(f) and 199.22, Ybarra informed Abrico that her client was "exercising his lawful rights in refusing to take the test."

"Termination of our client's employment because of his refusal to take the test is a violation of the law," she wrote, "and may subject you to substantial liability for wrongful termination of his employment."

In an interview with Our Paper, Duff related that Jerry Bell of Sunnyvale Electronics informed him on Aug. 16 that it was assumed by the company that he was a homosexual. Bell stated that Duff needed to take the AIDS test before Aug. 23 to "protect other people in the company" or "face the consequences."

Duff reported that he was subjected to verbal abuse at work in the following weeks, including being "called out to fight" with a co-worker. On Sept. 1, Duff was told that "after careful deliberation," the company had decided to lay him off. His position was filled the very next day by a new employee, according to Duff.

Ybarra has given the company 15 days to respond to her letter before taking further legal action. Duff says that he will "go as far as I have to go" with the case.

OUR PAPER is changing its publication schedule and will be appearing every Friday. For new deadlines, see Page 2.

Catching some sun at the Castro Street Fair in San Francisco are openly lesbian Municipal Court Judge Mary Morgan (right) with her partner, Attorney Roberto Achenberg and their infant son, Benji Alexander. More Castro St. Fair photos on p. 7. Photo by Ted Saki

The Watergarden received a "special recognition" from the Santa Clara County Department of Public Health. Pictured (left to right) are Dr. Bernadette Eckmann, Gary Crawford, Bernice Zehrowski, Sal Accardi (front), and Watergarden staffers Alex Mendelblat, Chris Retio, Bob Farner, John Gambler, and Kent Olson (rear). Story on Page 2. Photo by Ted Saki

non-profit groups. So, when the support group decided they needed to formalize their organization and incorporate, he was the natural person to become the first executive director of Aris. He would hold the job for eight crucial years. During his tenure, the group would grow from volunteers meeting in a living room to one of the leading social service organizations in the county, with annual revenue of more than \$1.1 million.

11

1986

**159 HIV Diagnoses;
43 New Deaths, 96 Total Deaths;
264 Living with HIV/AIDS**

In January, I went before the Santa Clara County Board of Supervisors, representing BAYMEC, to present a nine-point proposal for County-provided AIDS services.

Our request to the Board was to:

- Provide the Aris Project with \$180,000 in funding over the ensuing 18 months
- Allocate funds to establish a residential care facility for chronically ill AIDS patients
- Establish a program to educate County employees who may work with AIDS patients, including deputy sheriffs, probation officers, social workers, and health department staff

- Create a Board-sponsored task force to assess needs and develop a comprehensive AIDS program for the County
- Allocate additional funds for education and educational materials targeted to high risk groups
- Increase staff levels of the AIDS Project in order to provide more proactive outreach to community groups
- Publicize the County's ability to care for AIDS patients at Valley Medical Center
- Direct the Mental Health Department to establish a working relationship with the Aris Project to coordinate mental and emotional support for AIDS patients.

The supervisors responded positively to our proposal, embracing the recommendations. Progress was finally being made, albeit in small steps.

The Board gave Aris an immediate cash infusion. This was a major step forward for the fight against AIDS and for the Santa Clara County LGBTQ community. No longer was the

BAY AREA REPORTER GREATER BAY NEWS

BAYMEC Takes AIDS Package to S. Clara Sups.

So. Bay Group Presents Nine-Part Proposal to County; Calls for Education Campaign, Treatment, Support Services

by Dot James

For the first time in history, the Board of Supervisors of Santa Clara County was asked to fund projects of special interest to the South Bay gay community. The requests could result in an expenditure of more than a quarter-million dollars in county funds within the next year and a half.

The Bay Area Municipal Elections Committee (BAYMEC), a tri-county gay political action committee based in San Jose, presented a nine-point proposal to the Board on Jan. 14 requesting "adequate service to AIDS patients in Santa Clara County."

Specifically, the BAYMEC proposal asks the Board to:

- Allocate \$60,000 in Mental Health contracts to the AIDS Referral Information Services (ARIS) Project to provide staff, counseling, and services; allocate \$120,000 in FY 1986-87;
- Allocate funds to establish a residential care facility for chronically ill people with AIDS;
- Establish a program to educate county employees who may work with AIDS patients, in-

cluding deputy sheriffs, probation officers, social workers, and health department staff;

- Create a board-sponsored AIDS Task Force to assess needs and develop a comprehensive program for the county.
- Allocate additional funds for education and educational material targeted to high-risk groups;
- Increase staff levels of the Health Department's AIDS Project in order to provide more ac-

tive outreach to community groups;

- Increase educational outreach to doctors, nurses and other health professionals to ensure high quality care in the county;
- Publicize the county's ability to care for AIDS patients at Valley Medical Center (VMC);
- Direct the Mental Health Department to establish a working relationship with the ARIS Project to coordinate mental and emotional support for those with



Bernadette DeArmond, M.D., Communicable Diseases Officer for the Santa Clara County Department of Public Health, and Ken Yeager, treasurer of BAYMEC (Photo: Dot James)

AIDS.

The proposals were presented to the Board of Supervisors by Ken Yeager, treasurer of BAYMEC; Ron Taylor, ARIS Project board member; and Ira Greene, M.D., chief of dermatology at VMC.

Until recently, no county money has ever been allocated for AIDS-related projects. However,

on Jan. 7 the board voted unanimously to contribute \$10,000 to a \$50,000 AIDS educational project to be directed by the Association of Bay Area Governments (ABAG) in nine Bay Area counties.

In presenting the BAYMEC proposal, Yeager pointed out that \$10,000 is insufficient funding to

(Continued on page 18)



community solely responsible for raising funds to keep AIDS volunteer programs in operation. The volunteers were now able to devote more time and energy to providing support services to patients and their families.

At that time, the relatively new Aris Project focused on the daily needs of people with AIDS, as well as their emotional health and wellness. Ultimately, it would provide services including numerous weekly emotional support groups for different communities, transportation services, a monthly food basket program, housing assistance, and HIV prevention education. It dissolved at the end of 2003 following the death of Bob Clayton.

This historic action by the Board was the end result of a long, methodical process. BAYMEC board members had been meeting with individual supervisors before I presented our nine-point proposal. We impressed upon them just how significant a public health crisis the AIDS epidemic was and could become if left unaddressed.

I was honored to be named Chair of the new Santa Clara County AIDS Task Force by Board President Susanne Wilson. We held our first meeting in April. In addition to myself, BAYMEC was represented by Wiggys Sivertsen and Ron Taylor. The other six members of the task force included Dr. Roger Kennedy from Kaiser Permanente, the largest health care provider in the County;

Dr. David Stevens from VMC; Robert Mackler, Director of the Hospital Conference of Santa Clara County; Sharron Miller of the Visiting Nurses Association; Helen Miramontes of the California Nurses Association; and Campbell City Councilmember John Ashworth.

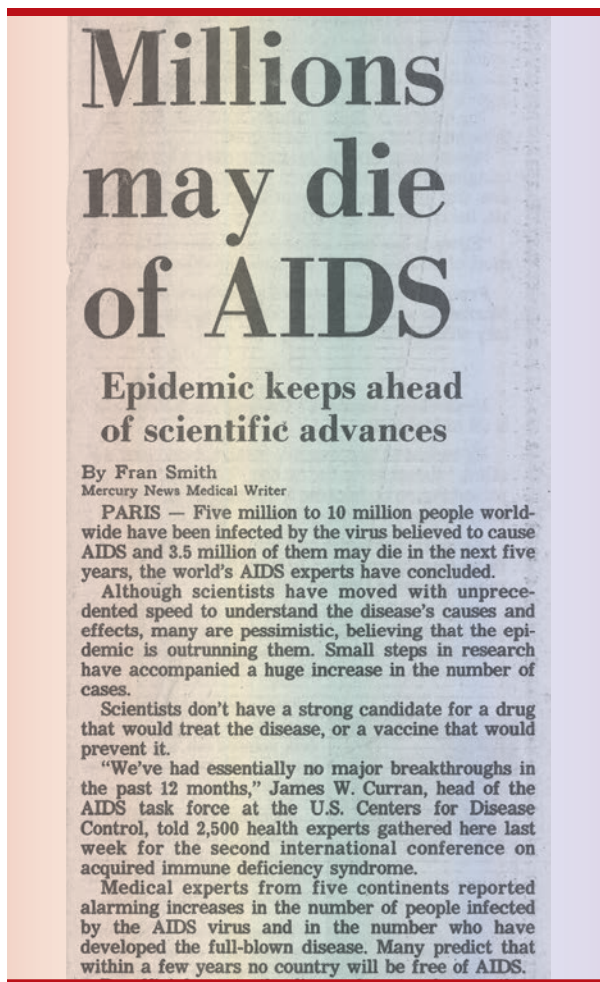
Unfortunately, while our supervisors saw AIDS for the health crisis that it was, homophobia and misinformation continued to dominate conversations about AIDS in the rest of the state. In July 1986, Republican Governor George Deukmejian vetoed a bill that would have extended anti-discrimination protections to HIV/AIDS patients. Much more disturbingly, conservative gadfly Lyndon LaRouche obtained enough signatures to put a statewide initiative on the November 1986 ballot, Proposition 64, that would have effectively quarantined AIDS patients and anyone diagnosed with HIV.



In 2017, I wrote a history about how BAYMEC led the effort in the South Bay and on the Peninsula to defeat Proposition 64 in 1986. The campaign was enormously successful, with three-quarters of the region's voters rejecting the LaRouche initiative.

After the defeat of Prop. 64, I found myself dealing with more AIDS-related matters. The epidemic, and the lack of an adequate government response to it, was becoming the dominant issue in the LGBTQ community from the mid-1980s on.

Headlines in the Mercury News and throughout the country constantly blared grim news about the disease. A June 1986 conference on AIDS in Paris led to a large front-page headline: Millions may die of AIDS. "Five million to 10 million people worldwide have been infected by the virus believed to cause AIDS and 3.5 million of them may die in the next 5 years, the world's AIDS experts have concluded."



Life expectancy from diagnosis to death was around two years. People got sick and died so fast. I remember a friend learning he had AIDS who was dead five months later. His family didn't even know he was gay. In the course of the epidemic, tens of thousands of families learned for the first time that their sons were gay only after they became sick. Often parents had to simultaneously come to grips with their son's sexuality and their deaths.

Against this backdrop, during the 11 months after its formation in February 1986, the Santa

Clara County AIDS Task Force worked extremely hard and accomplished numerous objectives. We assisted in the development of an AIDS policy handbook for County employees, investigated the Sheriff Department's medical unit policy on AIDS, and reviewed the need for anti-discrimination ordinances for people with HIV or AIDS.

The battle against AIDS was moving into a new phase, both nationally and in the South Bay. In October, Surgeon General C. Everett Koop shocked the political and public health worlds by issuing a report on the AIDS epidemic that forthrightly talked about how the disease was transmitted, and strongly advocated for increased sex education in the public schools and the widespread use of condoms to prevent the spread of the virus.

Locally, the LGBTQ community no longer felt like we were fighting the epidemic on our own. The Board of Supervisors adopted all of the Task Force's recommendations, and even as the County was facing tight budget times, they were committing critical dollars to AIDS services.

BOB REED



Bob Reed moved to the South Bay from Idaho in 1982, the year before Santa Clara County's first HIV infections and AIDS deaths were recorded. He first read about the infection that became known as AIDS in 1981. Even though he was a nurse, Reed continued to have unprotected sex and embrace an "eat, drink, and be merry lifestyle," as he describes it, for the first half of the 1980s.

By 1986, he knew he had HIV. That was confirmed with a terse phone call from his doctor after he got tested. He recalls the doctor saying only "you're HIV positive" and then following that with "You're a nurse so you know what that means. Call me if you need anything," and then hanging up. The entire call lasted less than two minutes.

Reed recalls even then, five years into the epidemic and the year after Rock Hudson's death, there was still a tremendous amount of ignorance about HIV and AIDS in the county.

His doctor told him he would be dead within six months. His apartment manager worried that he might infect other tenants just by living in the same building. In a hospital lobby, he helped himself to a bowl of popcorn put out for patients but was then reprimanded for contaminating it and making it unsafe for others.

Like many HIV/AIDS patients, Reed internalized a tremendous amount of self-loathing and felt at the time that he deserved a certain amount of this mistreatment.

A turning point came when he began receiving services from the County's Early Intervention Program. Under the leadership of Fenstersheib, it was one of the few dedicated HIV/AIDS clinics in the nation at that time. It did not do a significant amount of advertising. He learned about it the way most patients did, through word of mouth. He described its services as "life-saving."

Ultimately, Reed would spend three years working as a nurse at the clinic. His personal experience as someone living with HIV made him especially effective. This was particularly true in the years before the AIDS cocktail became widely available, when an HIV diagnosis was considered akin to a death sentence. Reed provided an example for so many others in those years just by living his life and doing his job.

In 2004, Reed became a member of the County's HIV/AIDS Planning Council for Prevention and Care, now known as the Santa Clara County HIV Commission. He has been elected co-chair of the commission on two separate occasions.

Reed says overall Santa Clara County is an "exemplary" place to live for the LGBTQ community, and the County's response to the HIV/AIDS crisis was one of the best in the nation. "I've lived here since '82, and I've stayed here because there are no villains."

On a personal level, it was in March 1986 that I learned a friend of mine had died of AIDS. I was saddened by his death, but because of a brief encounter we had a year earlier there was the possibility I might have become infected.

I was fortunate to know Dr. Denny McShane, a gay physician who was one of the few doctors on the Peninsula who worked with AIDS patients. I met him through his partner, Rich Gordon, who was president of BAYMEC at the time. McShane and his medical partner, Dr. Bill Lipple, started a private practice that included AIDS patients, the only one between San Francisco and Los Angeles. They were very involved in getting their patients into medical trials.

We discussed the pros and cons of getting tested. Because there were no medications available, the results weren't all that useful. There was also the risk that a person's HIV status could be used to deny them medical coverage or be subject to discrimination. "It was damned if you do, damned if you don't," he laughed when I interviewed him in 2015.

I decided to have the test, mainly because I started dating someone a few months earlier who would become my partner for 5 years. I was frantic that I might have passed the virus on to him. He and I talked extensively about our options; we both decided to get tested.

At the time, it took two agonizing weeks to get the results. Today the rapid HIV test takes 20 minutes. The anxiety and self-reflection that occurred over those 14 days was grueling. It was with relief when we both heard from Dr. McShane that we were negative.

I tell this story because it is reflective of the thousands of frightening experiences of gay men in the 1980s and early 1990s. Testing was terrifying because a positive result was analogous to a death sentence. The odds seemed great that any sexually active gay man would encounter someone who carried the virus, creating a prevailing atmosphere of fear that we all may become HIV positive.

I think back on all the people who died of AIDS, their lives cut short, their potential never reached. Testing negative has given me 30-plus years so far to have a wonderful career and life—30 years that so many others did not have. It's one reason I have worked so hard on the Getting to Zero campaign in Santa Clara County: "Zero Infections, Zero Deaths, Zero Stigma."

1987

**235 HIV Diagnoses;
76 New Deaths, 172 Total Deaths;
423 Living with HIV/AIDS**

While things were changing on the political front, the epidemic continued to grow rapidly. 1987 was the first year that more than 200 people were diagnosed with HIV in a single year in Santa Clara County. It was also the first year that the County recorded more than 100 AIDS-related deaths. The infection rate would continue to grow every year until 1993. The death rate did not stop increasing until 1995.

In the first years of the epidemic, getting information from the County Public Health Department was often difficult. Questions about the effectiveness of current programs, new programs in development, and funding sources for educational programs went unanswered far too frequently. However, that started to change in 1987. The department became more open about how it was addressing the epidemic, and it formed a committee of people and organizations involved in the fight against AIDS to exchange information and coordinate and combine resources. It was a very welcome step.

The County was also getting a little more financial help from Sacramento. In the summer of 1987, the State of California Health Services Department increased its annual allocation for Santa Clara County to \$90,000 for AIDS services for the 1987-88 fiscal year.

The Task Force issued a 12-page final report in March that contained multiple recommendations in the areas of medical needs, education, social services, mental health, housing, AIDS policies in

the jails, and needed County legislation. We also concluded that the Task Force should remain in existence in order to oversee the successful accomplishment of the recommendations in our final report.

Over time, the County made steady progress in implementing the recommendations. However, continual pressure by BAYMEC on the Board of Supervisors and other local elected officials was required. As the organization approached its third anniversary, its vital role in the LGBTQ community was becoming clearer.

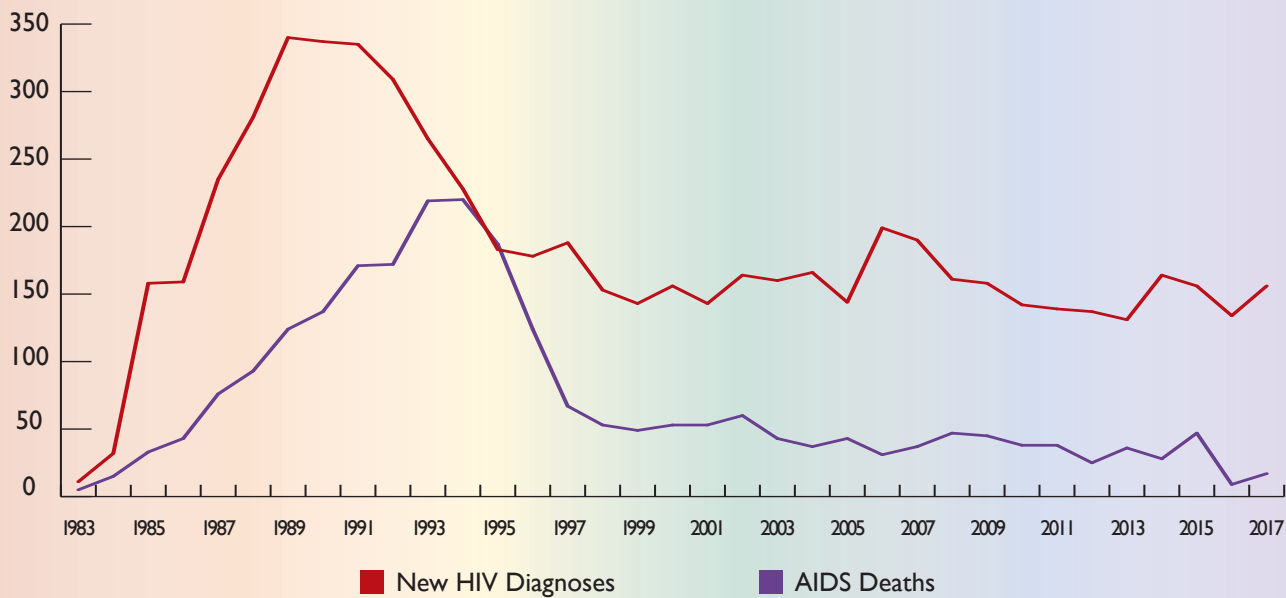
I remember 1987 as being a year when persons living with HIV/AIDS were being discriminated against out of fear about contracting AIDS. This was the basis of an article I wrote for the Task Force about the discrimination that was happening in Santa Clara County.

“Because AIDS is not spread by casual contact, a person with AIDS or ARC (AIDS-Related Complex) poses no health threat to the general public. However, in Santa Clara County there are reports that certain services have been unnecessarily denied to patients with AIDS. Based on our projections, the number of AIDS cases in Santa Clara County will increase almost geometrically over the next five years. With increasing numbers of individuals with AIDS and ARC, increased cases of discrimination are anticipated.

“The Task Force does not know the full extent of current discrimination. We do know that certain publicly supported groups turn away AIDS patients. In the past, the prominent United Way agency refused to provide services to AIDS patients. To our knowledge, all long-term care facilities, i.e. nursing homes and convalescent hospitals, have not allowed admission to AIDS patients.

“While paramedic services appear to be available, AIDS patients are charged an additional fee of \$50 to ‘sterilize’ the ambulance after usage. Similar fees are not applied to other patients. The Sheriff’s Department routinely isolates individuals testing HIV positive.

Number of AIDS Deaths vs New HIV Diagnoses by Year



“Families and friends of AIDS patients also face discrimination. Helen Miramontes, President of the California Nurses Association and a member of the Task Force, reported a case in Santa Clara County where the fear of AIDS led one employer to fire the husband of an AIDS patient.

“Unfortunately, certain political and religious groups have taken advantage of the AIDS epidemic and have morally condemned the victims. Without the force of law to stop this bigotry, these individuals can perpetuate the myth that AIDS patients must be separated from the community. Fortunately, the defeat of the LaRouche-sponsored AIDS initiative indicates that a large majority of the voters in Santa Clara County believe that AIDS patients do not pose an undue threat to the community.”

BAYMEC again demonstrated its effectiveness in November when the supervisors unanimously passed an ordinance prohibiting discrimination against people with HIV/AIDS. The ordinance made it illegal to refuse housing, employment, property loans, medical care, or business services to anyone solely because they had AIDS, or a high risk of developing AIDS. It also mandated that agencies or businesses that receive County funding could not discriminate against people with HIV/AIDS.

This ordinance had been one of BAYMEC’s main priorities for the year. I spent many hours talking with individual supervisors and other County officials about it. This was the first time that elected officials in Santa Clara County approved a non-discrimination ordinance championed by the LGBTQ community since the defeats of Measures A and B in 1980. The County ordinance had a limited impact because it only applied to unincorporated areas, but it set a precedent that we intended to use in 1988 to convince cities in the South Bay, especially San Jose, to adopt their own ordinances.

I stepped down as chair of the County AIDS Task Force at the end of 1987 as I had begun working on my Doctorate in Education at Stanford. I was extremely gratified with what the Task Force accomplished in my almost two years as chair. Overall, I was hopeful as we headed into the late 1980s. I wrote to BAYMEC members that spring that we were moving towards a future where “instead of two steps back for each step forward, it will be two steps forward, one step back.”



One big step forward in 1987 was the release of the first AIDS treatment drug, Azidothymidine, or AZT.

Researchers had been trying to find a treatment or vaccine for AIDS ever since the HIV retrovirus had been identified as the cause of the disease in 1984. At the National Cancer Institute, Dr. Sam Broder and colleagues Hiroaki Mitsuya and Robert Yarochan began testing already developed drugs to see if they would be effective against HIV.

AZT was originally synthesized in 1964 as a possible cancer treatment. It was shelved shortly after development when it proved to be ineffective in tests with mice. A decade later, a researcher in West Germany found that AZT could halt the replication of the retrovirus that caused a type of leukemia in mice. However, this attracted little further attention from the scientific or medical community because, in 1974, there were no known human diseases caused by retroviruses.

Broder and his colleagues pulled AZT off the shelf and in February 1985 began testing it against HIV. They got positive results almost immediately. In June the NCI and drug maker Burroughs-Wellcome, now known as GlaxoSmithKline, applied to the Food and Drug Administration for permission

to begin testing AZT on human patients. That permission was granted in seven days. On July 3, 1985, the first patient enrolled in the AZT clinical trials in Bethesda, MD.

In September 1986, the second phase of AZT clinical trials were halted after preliminary results showed that patients treated with AZT had a significantly higher survival rate than the placebo group (1 death in 145 vs. 19 of 137). By mid-October, the FDA was making AZT available to physicians treating AIDS patients who requested the drug, even though it was still unlicensed. In March 1987, the FDA approved AZT as the first drug to treat AIDS. The time between the first demonstration of AZT's effectiveness against HIV and its approval by the FDA was just 25 months, the shortest approval period in recent history.

Sadly, the hope generated by AZT was short lived because HIV proved to be a very hardy retrovirus. It had the ability to quickly mutate and develop resistance to the drug. It would be almost another decade before researchers found a way to finally contain HIV. Far from perfect and somewhat controversial, at least there was finally some medication to treat HIV.

On May 1, 1987, President Ronald Reagan delivered his first speech on AIDS and called for widespread testing. However, this was after 36,058 people already had been diagnosed in the U.S. and 20,849 had died. Not only that but he quipped: "When it comes to preventing AIDS, don't medicine and morality teach the same lessons?"

The health, science, and environment editor at the Washington Post wrote, "Reagan was silent at a time when silence equaled death. His cowardice in the face of the crisis will forever tarnish his legacy."

**281 HIV Diagnoses;
93 New Deaths, 265 Total Deaths;
611 Living with HIV/AIDS**

As the debate over the effectiveness of AZT grew, the number of deaths continued to increase. With more individuals being diagnosed and falling ill, there was a growing demand for beds to treat the patients. In January, the Santa Clara County Senior Care Commission took under consideration the difficulty in finding beds in nursing care facilities for people with AIDS.

In order to reduce the burden on hospitals and provide needed services for individuals suffering from complications due to AIDS, the Department of Health recommended funding a Visiting Nurse Association program for in-home treatment of people with AIDS.

Norm Robinson, who would become Aris director in 1994, remembers how fearless the nurses were. He recalls how they had no hesitancy to work with people with AIDS and would aggressively

intervene when patients were not being properly cared for in their nursing homes or hospice situations. "There was nothing they hadn't seen or heard before. Nothing phased them. They were wonderfully caring," he added.

However, despite the epidemic being years old at this point, little had been done in schools to inform the public about the importance of testing or how to prevent the disease. A Mercury News story in February reported that "nearly two years after the U.S. Surgeon General began urging

AIDS education for students of all ages, only a handful of Santa Clara County's 37 school districts are teaching students how to avoid the deadly disease."

In May, the U.S. Surgeon General mailed an eight-page report to all 107 million households in the United States, marking the first federal authority to provide explicit advice to U.S. citizen on how to protect themselves from AIDS.

BAYMEC continued lobbying cities to adopt an anti-discrimination ordinance similar to what the Board of Supervisors did in 1987. When the City of San José put one up for a vote in June, the Religious Right came out in opposition, much like they did for Measures A and B at the beginning of the decade. Rev. Stewart Smith of the Los Gatos Christian Church cited numerous Bible verses, including, "The Lord said to Moses 'Command the people of Israel that they put out of the camp every leper...'"

San Jose Mercury News ■ Thursday, Sept. 8, 1988 7B

Commentary

AIDS brought home by 'slight chance' of infection

ALLISON can't play this afternoon," I told her friend's mother. She has ... an appointment.

Between the verb and the article of that sentence, my mind was going through a high-speed schizoid workout.

Half my brain was saying to me, "Don't say it's a blood test. She might ask what for, and then you'll have to say AIDS, and then she won't want her kid to play with Allison. She'll be mad at you for not warning her. Don't tell her it's AIDS."

The other half of my brain was saying, "Don't be ridiculous. This is an intelligent woman. Why are you acting like she's a fool? Why are you acting like a fool?"

AIDS does that. It makes people act stupidly.

I've been reading and writing about AIDS for a long time now, but it took that appointment to make me really understand why it's not just another disease.

My daughter is 7½ years old. She is a very healthy child. But when she was born in early 1981, she was very sick. The diagnosis was "overwhelming sepsis," respiratory distress syndrome and jaundice.

The doctors gave her blood to keep up her "blood gases" when the respirator couldn't provide any more oxygen — so much blood they worried it would make her overworked heart fail.



Joanne Jacobs

When the Red Cross suggested testing for blood recipients last year, I called up AIDS experts and asked whether a healthy 6-year-old who'd received blood in 1981 was really at risk. They said the only reason to have her tested was to make me feel better. I decided not to give in to AIDS hysteria, and I succeeded.

But you know the story about the con man who sells villagers the secret of turning stones into gold? All you have to do is stir the pot, and not think of monkeys. When I found out that Stanford thought enough of the risk to try to contact 20,000 transfusion recipients, I kept thinking of monkeys.

I called Allison's pediatrician, and my own doctor. They said: Do it.

I asked the woman at Stanford if she knew of any transfused child to be infected with AIDS and not show any symptoms for seven years. There was one case, she said. An 8-year-old child, who had received blood elsewhere, not screened for CMV.

So I let them stick a needle in Allison — she knew they were testing for "a virus" — and waited a week and a half for the results.

A very slight chance.

In some ways, it was a lot like the time four years ago, when the pediatrician told me Allison had one of the risk factors for cystic fibrosis. The chances of her having

the disease were slight, he said, but it might be a good idea if I took her in for a test. At my convenience.

Like AIDS, cystic fibrosis is a disease for which there is no cure. Sitting around waiting for test results, wondering about a slight chance that your kid has any fatal disease, is not a whole lot of fun.

The difference is that cystic fibrosis would only have killed Allison; it would not have made her an outcast.

AIDS is not just another communicable disease, to be dealt with scientifically and apolitically like any other public health threat. AIDS is leprosy. Fear and loathing — and stupidity — are part of the disease.

There's yet another AIDS initiative. Proposition 102, on the overlaid November ballot. LaRouche III some are calling it, though this one is sponsored by Southern California conservatives.

Claiming to treat AIDS like any other disease, Proposition 102 would ban anonymous testing, breach confidentiality protections and let employers discriminate against AIDS victims, among other things.

Proposition 102 isn't really meant to fight AIDS, but to make war on AIDS victims, as though stigmatizing them were the next best thing to treating them.

By contrast, the president's AIDS commission, despite its conservative membership, called for strict confidentiality, vol-

I've been reading and writing about AIDS for a long time now, but it took that appointment to make me really understand why it's not just another disease.

untary cooperation and anti-discrimination protections to encourage those at high risk to be tested and protect those who test positive.

This is not about gay rights; it's about doing what's necessary to deal with a disease that's not just like any other.

If HIV-antibody testing is a way to decide who's a leper and who can live and work in our society, then AIDS will go underground. It will not go away.

Allison tested negative. She isn't an AIDS leper.

Nobody should be.

Joanne Jacobs, whose column appears on Mondays and Thursdays, is a member of the Mercury News editorial board.

Mercury News columnist Joanne Jacobs published a brilliant response to that sentiment in her September 8 column: "If HIV-antibody testing is a way to decide who's a leper and who can live and work in our society, then AIDS will go underground. It will not go away."

In that same September column, she illustrated how stark the anxiety and paranoia about HIV had become in the general public's mind. Her daughter had to get tested for HIV because of a blood transfusion several years earlier and Jacobs fretted over how much to tell people, especially the parents of her daughter's friends. "Don't say it's a blood test. She might ask what for, and then you'll have to say AIDS, and then she won't want her kid to play with Allison. She'll be mad at you for not warning her. Don't tell her it's AIDS."

Jacobs was a strong ally in the fight against AIDS, regularly writing about the need for more funding for research and treatment. In the column, she described the argument she had with herself about her daughter's test. "The other half of my brain was saying, "Don't be ridiculous. This is an intelligent woman. Why are you acting like she's a fool? Why are you acting like a fool?...AIDS does that. It makes people act stupidly."

Ultimately, Jacobs decided to get her daughter tested. "Allison tested negative. She isn't an AIDS leper. Nobody should be."

Despite the opposition from the Religious Right, the San Jose City Council approved the non-discrimination ordinance in a 9 to 2 vote. Of the dissenting votes, Councilmember Lu Ryden was a religious conservative who was offended when Councilmember Susan Hammer used the Bible verse "love thy neighbor as thyself" in support of the ordinance. The other no vote was Councilmember Bob Putnam who gave a 15-minute speech that only proved he didn't know anything about how AIDS was spread.

Unfortunately, all that lobbying might have been fruitless if a new ballot initiative in California passed because it would only further such discrimination.

Proposition 102 was scheduled to be placed on the November ballot. It would have "required

doctors, blood banks, and others, to report patients and blood donors, whom they reasonably believe to have been infected by or tested positive for AIDS virus, to local health officials."

It would have permitted insurance agencies and businesses to require HIV testing results to qualify for health insurance or employment. Additionally, it ended all confidentiality or anonymity when receiving the test by requiring your name be attached to the results. It went even further, mandating that health professionals report positive test results to the government, insurers, employers, and the courts. It even required the mandatory contact tracing of sex partners by the government.

Needless to say, this would have been a huge step backwards for AIDS patients and the LGBTQ community. We couldn't match the campaign funding available from the insurance industry or the Religious Right but at BAYMEC we were determined to leverage all our resources to defeat the proposition.

In the end we were successful; the proposition overwhelmingly failed with 69.6% voting no across the state. We were extremely proud of Santa Clara and San Mateo Counties, where our lobbying had the most influence, for achieving 71.2% and 73.4% no votes, respectively.

Another initiative, Proposition 96, which mandated testing for victims of sex crimes and emergency services workers where bodily fluids may have been exchanged passed with 62.4% of the vote. Thankfully Prop 102 prevented the reporting requirement of positive test results.



This was also the year World AIDS Day was created by the United Nations. It was designed as a celebration of victories in the AIDS movement, such as increased access to treatment and prevention services. The

day lives on, serving as a day of remembrance to commemorate those we have lost to HIV/AIDS and to continue to build awareness until we eradicate the disease. It takes place annually on December 1.

1989

**340 HIV Diagnoses;
124 New Deaths, 296 Total Deaths;
827 Living with HIV/AIDS**

As the 1980s came to a close, the death toll from AIDS continued to rise, easily crossing the 100 mark in Santa Clara County in 1989. Even with AZT now on the market, so many people continued to die so quickly.

One moment of light was inspired by the darkness of all the deaths: The AIDS Memorial Quilt. San Francisco LGBTQ activist Cleve Jones conceived of the quilt in 1985. While planning the annual candlelight march in San Francisco to commemorate the assassinations of Supervisor Harvey

Milk and Mayor George Moscone, he learned that more than 1,000 people in the city had already died from AIDS. He asked marchers to write the names of friends and loved ones who had died on placards and at the end of the event all of the placards were taped to the walls of the federal building in San Francisco, making it look like a patchwork quilt.

Jones and some friends made plans for a much larger permanent memorial. He made the first quilt panel in memory of his friend Marvin Feldman who had died in October 1986 after a two-year battle with AIDS. The response to the quilt idea was immediate and enthusiastic. Panels were sent in from all over the country. By the time it was first publicly displayed in October 1987 at the National Mall in Washington, D.C., the quilt contained almost 2,000 panels and covered a space larger than a football field. More than 500,000 people visited the quilt during its first weekend on display.





Ken Yeager, Supervisor Susie Wilson,
Rep. Norm Mineta, Wiggy Sivertsen

In May, part of the quilt came to San Jose as part of a nationwide tour. Panels were laid out on the floor of the San Jose Convention Center. Among the many visitors who came to see the quilt was Congressman Norm Mineta. Less than five years earlier, when BAYMEC was first formed, Mineta was one of the many elected officials reluctant to meet with us or to publicly support our issues. However, the times had changed and Mineta became a strong supporter of the LGBTQ community. He attended our annual dinners frequently and supported federal legislation protecting the rights of the LGBTQ community.

In August, Aris began offering housing for Santa Clara County low-income AIDS patients. Back in December 1987, an Aris task force had concluded that there were dozens of local AIDS patients who were in unstable housing situations. However, it took almost two years to secure funding and find a suitable location before Aris could open its first residential housing. The initial funding came from three sources: the County of Santa Clara, the State of California, and United Way.

By 1989, I was busy getting my doctorate at Stanford University. I had stepped back from much of the day to day political activity with BAYMEC that occupied so much of my time during the previous five years. However, I was still being called regularly by the media for comment on stories about the LGBTQ community or AIDS. One of the big stories that year was the increasing militancy of some activists in the fight against AIDS.

Playwright Larry Kramer had founded the AIDS Coalition To Unleash Power, ACT UP, in New York in 1987. The group used direct action and civil disobedience to draw attention to the lack of government funding for AIDS research and services and to the high prices that drug maker Burroughs Wellcome, now known as GlaxoSmithKline, was charging for AZT, as much as \$10,000 a year. In 1988, ACT UP activists managed to shut down the Washington, D.C. headquarters of the Food and Drug Administration for a day. In October, seven ACT UP activists chained themselves inside the New York Stock Exchange to protest Burroughs Wellcome.

In the Bay Area, activists from ACT UP and other groups closed the Golden Gate Bridge during rush hour in January 1989, and in September they crashed the opening of the San Francisco Opera season, traditionally one of the highest profile events among the society page crowd in the city.

While I understood the anger and passion behind these direct-action efforts, I told the Mercury News in an October that those type of tactics were not something that BAYMEC took part in because we were having success at the local level by working through more traditional channels.

In the federal fiscal year that began on October 1, 1989, the County's Health Department received \$250,000, its largest federal grant to date for community AIDS planning services.

1990

**337 HIV Diagnoses;
137 New Deaths, 433 Total Deaths;
1,027 Living with HIV/AIDS**

The early 1990s were some of the darkest times of the AIDS epidemic. Death tolls continued to increase locally and nationally. 1993 and 1994 were the years of highest deaths: 219 in 1993 and 220 in 1994. Aris and other community organizations were strained to capacity with the sick and the dying. More volunteers were needed as caregivers, and it turned out they came from within the LGBTQ community.

Over the decades, gay men and lesbians have often kept to their own communities, but AIDS changed that. As Wiggys Sivertsen noted, "The AIDS crisis brought lesbians and gay men together because women knew how to take care of people. That's what we are trained to do as women. We all had to work together, and it evolved into a more cooperative group of relationships than used to exist."

HIV had proven to be a cagey and deadly virus, evolving at a rapid enough rate to negate much of the effectiveness of AZT. The hope that I and many others felt upon the drug's release was slowly extinguished as months and years went by and the death toll continued to rise.

One particular death in early 1990 did galvanize the public and lead to some notable progress in treating the epidemic. Indiana teen Ryan White was a hemophiliac who was diagnosed with AIDS in December 1984 following a blood transfusion. He was one of the first children and first hemophiliacs to come down with the disease. He gained national attention and became a symbol of the misinformation surrounding AIDS and the discrimination sufferers faced, when his local school district tried to prevent him from attending classes and his parents sued.



White was initially given a maximum of six months to live, but he surprised his doctors and survived for more than five years after his diagnosis, dying in April, one month before his high school graduation.

In August Congress passed, and President George H.W. Bush signed into law, the Ryan White Comprehensive AIDS Resources Emergency, or CARE Act. It provided funding for health care and other services for low-income, uninsured, and underinsured AIDS victims and their families. It was the largest federally funded program in the country for people living with HIV/AIDS, and it quickly became the third largest federal healthcare program after Medicare and Medicaid.

Also in 1990, the Board of Supervisors formed an AIDS Planning Advisory Committee to help formulate an expanded HIV/AIDS services plan. The committee included community representatives, service providers, industry and nonprofit representatives, as well as HIV/AIDS patients.

Although there had been successful Walks for AIDS in major cities across the country, there was never one held for the Peninsula, East Bay, South Bay, or coastal communities. On September 16, the first four-county Walk for AIDS took place to benefit AIDS service organizations within

Santa Clara, San Mateo, Alameda, and Santa Cruz counties. The goal was to raise \$400,000 for 29 non-profit AIDS organizations.

1991

**335 HIV Diagnoses;
171 New Deaths, 604 Total Deaths;
1,191 Living with HIV/AIDS**

A November Mercury News article, “AIDS Program to Get \$1.3 Million Boost” reported, “The federal government has promised Santa Clara County \$1.3 million to expand its much-admired services for people who have just learned of their infection with the AIDS virus.

The money, part of a nationwide dispersal of funds under the Ryan White Act, which Congress approved last year, will be distributed over a three-year period. Since 1986, the ‘early intervention’ program has offered counseling, information, lab tests, and medical exams.”

KARL VIDT



Karl Vidt moved to Santa Clara County in 1969. When the AIDS epidemic began in the early 1980s, he did not pay much attention to it, believing it was “something affecting people in San Francisco.”

Vidt became much more aware of the disease and the toll it was taking in 1985 when he joined the board of the Metropolitan Community Church, one of the first denominations in the South Bay to provide a welcoming and inclusive atmosphere for the LGBTQ community. Coincidentally, the church became the original home of the Aris Project the same year that Vidt joined its board.

Despite his work with the church, Vidt did not get tested until 1989 when he learned that he was HIV positive. He remembers being “just numb” after getting the news. He says that the tester who told him he was positive, Sandy Gudino, was kind and spent more than an hour with him answering questions and giving him information.

Vidt told few people about his diagnosis. “I just picked up and went on.” However, by 1991 he had gotten sick and was taking regular medications. In the fall of 1992, he came down with *Pneumocystis carinii*, the strain of pneumonia that had been closely associated with the AIDS epidemic since the early 80s.

In 1993, he developed an infection in his eyes that eventually led to his blindness in December 1996. Throughout the early 90s, Vidt survived with virtually no T-cells whatsoever. Luckily, by the mid-90s his T-cell count began to grow with the introduction of new medications. This led to an overall improvement in his health.

He got his first guide dog in 1999, which significantly improved his self-sufficiency and mobility. He was able to play an active role in the community again and continued working at Metropolitan Community Church as the half-time church administrator.

Vidt also threw himself into the thick of the fight against HIV/AIDS in the South Bay. He joined the Santa Clara County HIV Planning Council for Prevention and Care in 2002. He spent multiple years as chair of its Care and Treatment Committee. He also served a stint as the chair of its Planning and Resources Committee. In addition to his HIV Planning Council service, Vidt also served on the City of San Jose’s Disability Advisory Commission and spent four years as chair of the Santa Clara County World AIDS Day Committee.

Vidt says all of the volunteer service is just his way of contributing to the health care system that he believes has taken such good care of him since his diagnosis. “There was a time when I thought my parents would have to take care of me. Who would have guessed that now I am taking care of my mom,” he said.

In 2008 I was honored to present to Vidt the Leslie David Burgess Lifetime Achievement Award. It was well-deserved recognition for a man who has not just provided countless hours of service to HIV/AIDS prevention and care. He is also an inspiring example of how to live a full life even after coming down with some of the worst illnesses associated with HIV and AIDS.

1992

**309 HIV Diagnoses;
172 New Deaths, 776 Total Deaths;
1,328 Living with HIV/AIDS**

In late 1991, basketball star Magic Johnson announced he was HIV positive, once again reinforcing the fact that HIV/AIDS could strike anyone.

The idea of AIDS as a strictly “gay disease” was finally starting to recede in the mind of the general public. Thankfully, more than a quarter of a century after his announcement, Magic is alive and healthy, still a major public figure. His health is a testament to the rapid progress in AIDS treatment that would come in the 1990s.



The first major medical treatment breakthrough occurred in 1992 when combination drug therapies were introduced. They proved much more effective than AZT alone in controlling HIV and slowing the virus’s mutations and development of drug resistance. However, it would still be a couple of years before the AIDS “cocktail” would come into its own and dramatically change the trajectory of the epidemic.

By the end of 1992, Aris’s housing program had expanded to four houses with 18 bedrooms. “They are intended for independent living. We do not have live-in staff at those houses, but it does provide a place where primarily the Visiting Nurses Association comes in and provides in-home nursing care and case management services for those people who are at least on disability income and otherwise are, for other reasons, homeless. Some of those reasons include being rejected by family or living in roommate situations where their HIV status is not acceptable to their friends and family,” said Aris Executive Director Sorenson on a panel before the Santa Clara County Medical Association in January 1993.

1993

**265 HIV Diagnoses;
219 New Deaths, 995 Total Deaths;
1,374 Living with HIV/AIDS**

In 1993, AIDS became the number one cause of death for Americans between the ages of 25 to 44.

“A lot of my friends died in the spring of 1993. There was about one every two weeks. That was a tough time,” said Aris volunteer Pat Duffy.

The local fight against HIV/AIDS continued to experience periods when the momentum either stalled out or seemed to shift dramatically into reverse. The larger economic trends of the early 1990s led to local government budget cuts. The end of the Cold War had devastated California’s defense and aerospace industries, resulting in a significant drop in tax revenue. This hit Santa Clara County especially hard as defense contractor Lockheed was the region’s largest employer for much of the 80s.

In 1993, this situation threatened almost a decade’s worth of progress on AIDS care in Santa Clara County.

The Director of Public Health, Delia Alvarez, proposed cutting nearly \$1 million from the County’s AIDS programs. This included the elimination of the County’s five-member HIV education program; \$173,000 or 18% of the Aris funding; four staff members in the early intervention program clinic, which provided medical treatment and counseling to 1,200 recently diagnosed patients; and five of 14 employees in the family planning unit, which was part of the AIDS program. Everyone was stunned.

As I wrote in a March BAYMEC newsletter, “Any cuts to the budget for fighting an epidemic which is growing exponentially could be construed as inappropriate, but Alvarez’s budget strikes deep at the heart of the individuals and groups which are on the front lines.”



Santa Clara County AIDS Budget Threatened

The AIDS budget for Santa Clara County is being threatened by severe cutbacks. Director of Public Health Delia Alvarez had proposed cuts of up to 60% to the AIDS Program and in county contracts to Aris Project. Any cut to the budget for fighting an epidemic which is growing exponentially could be construed as inappropriate, but Alvarez's budget strikes deep at the heart of the individuals and groups which are on the front lines.

The proposed budget calls for the elimination of all county funded HIV educators, cuts

in testing site services, and cuts to Aris Project for housing and services for people with AIDS. However, little money is being cut from administrative expenses. The proposed budget cuts to the county program total \$800,000. Aris Project's proposed cuts total \$170,000. These cuts would take county commitment to AIDS back to the level of 1985, when the county first funded AIDS services.

Alvarez has since resigned from her post because of the fallout from this budget proposal. However, there is little indication

continued from page 1
Aids Funding

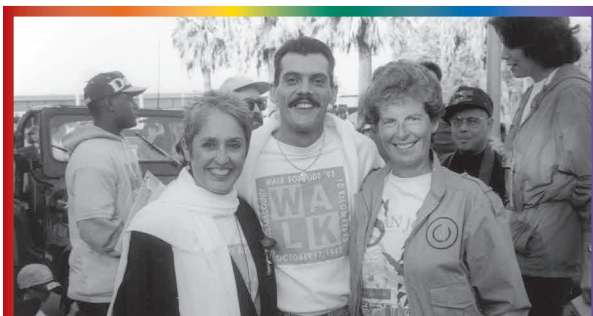
that the situation will improve unless our voices are heard. If you are interested in getting involved in challenging these proposed cuts in the AIDS budget, contact Bob Sorenson or Tom Myers at Aris Project-408/370-3272. You can also get your message across by writing to: Ron Gonzalez, Chair, Santa Clara County Board of Supervisors, 70 West Hedding St., San Jose, CA 95110. ▼

I explained that the proposed budget called for the elimination of all County-funded HIV educators, cuts in testing site services, and cuts to Aris Project for housing and services for people with AIDS. However, little money was being cut for County administrative expenses. "The cuts would take the County's commitment to AIDS back to the level of 1985, when the County first funded AIDS services," I added.

With a broad coalition of organizations and support from several supervisors, we were able to prevent the cuts from taking place. Alvarez eventually resigned from her post because of the fallout from this budget proposal. However, I knew that unless we kept up the pressure to continue having services funded, we would always be vulnerable to budget cuts.

With public dollars being threatened, fundraising for AIDS services took on a new urgency, and in San Jose one effort got some high-profile help in 1993. While the four-county AIDS Walks were raising much needed dollars, there was some controversy over how money was being distributed to organizations and whether it was better for each county to have its own walk. Thus, in October, the fourth annual Walks for AIDS was held in downtown San Jose with singer-songwriter Joan Baez participating.

According to the Mercury News, Baez, who lived in Woodside, said she would be at the march not only to support fighting AIDS but to be with her cousin, local AIDS activist Peter Baez. Organizers hoped to raise \$275,000 for Aris and other local groups.



Joan Baez, Peter Baez, Mayor Susan Hammer

PETER JOHNSON



Days after the walk, the Mercury News ran an article that illustrated just how devastating the epidemic was in those years.

"As the fourth annual Walk for AIDS drew near, every visitor to the bedside of Peter Johnson had to make a

pledge. “He was dying and he was asking people to sponsor him,” said his mother, Helen Johnson. “On Monday, Peter Johnson—down to 100 pounds from his normal 150, 6-foot-1—confided to his friend Bob Clayton: “It’ll be a chair-athon for me (Sunday).” I said, ‘Fine. We’ll all push.’”

Regrettably, Peter Johnson didn’t make it to the annual fund-raising walk for the disease. He died of AIDS on October 13, 1993, just under two months after his 30th birthday.

Throughout his illness, Johnson drew strength from the support of his family. His mother, Helen, volunteered at Aris alongside him and walked in the AIDS Walk with him every year. She continued to walk for many years after Johnson’s death.

Johnson had graduated from Overfelt High School in 1981. He was diagnosed with HIV at the end of the 80s and shortly afterwards began volunteering with Aris. By early 1991, he was a member of the Aris board with the group’s executive director Bob Sorenson telling the Mercury News that Peter was “one of our best interpersonal ambassadors.”

In 1992, he was appointed to the County AIDS Commission. He attended every commission

meeting, even those where there was not a quorum present. Sadly, his time on the commission was too short.

I still see his parents at events every World AIDS Day. They have kept boxes of documents and articles about his life and about AIDS, some of which helped me in the writing of this history. When I saw them recently, I sensed they miss their son very much, even after 35 years.

That year also saw efforts begin for one of the first permanent memorials to victims of the epidemic in San Jose: the AIDS Grove. The nonprofit group Our City Forest assembled a coalition of AIDS service organizations to plan a permanent memorial grove. More than \$10,000 was raised privately and, after an extensive search, a site near the Children’s Discovery Museum in Downtown San Jose was selected in December 1994.

In September 1995, volunteers planted 30 Chinese pistache trees on the site. The pistache were chosen for the grove because they are deciduous and renew themselves every year. They also thrive when planted in groups where their branches can intertwine. The grove was dedicated on September 30 by then-Assemblyman John Vasconcellos.



1994

**228 HIV Diagnoses;
220 New Deaths, 1,215 Total Deaths;
1,332 Living with HIV/AIDS**

Despite the challenging budgets and cutbacks of the early 90s, the Board of Supervisors did not shy away from embracing new programs for dealing with HIV/AIDS in this period.

In September 1994, the Board declared a state of local emergency “due to extreme peril to the safety of persons caused by the significant risk of HIV infection among injection drug users in the county, their sexual partners, and offspring.”

At the same time, the Board also approved the establishment of a countywide needle and syringe exchange program. Santa Clara County became only the fourth jurisdiction in California to initiate a needle exchange program. However, the County was the only jurisdiction that used public funds and government employees from the Public Health Department to provide people who inject drugs with clean needles.

It was hugely controversial at the time. I was a vocal advocate for it as a member of the County’s AIDS Task Force. In 1994, more than 11% percent of HIV/AIDS patients were people who inject drugs and that percentage had increased every year for the preceding decade.

The needle exchange program would not only help stop the spread of HIV/AIDS but also other poten-



tially deadly blood-borne pathogens such as Hepatitis B and C. The program also gave health workers the opportunity to interact with people who inject drugs and offer them information and referrals to substance abuse programs and other services.

The program would remain controversial for a number of years. In 1996, California’s then Attorney General, Republican Dan Lungren, forced it to shut down after threatening to sue the County. The County continued to grant money to non-profit groups that operated needle exchanges, but the professionals from the Public Health Department were not directly involved again until 2000 when Governor Gray Davis signed legislation that effectively legalized needle exchanges.

Norm Robinson, who became director of Aris in January 1995, remembers what a turbulent time it was. “We had everyone involved: San Jose Police Department, District Attorney’s Office, Public Health, outreach workers at the sites,” he said. “We had a rule of exchange: One needle for one needle. SJPD told their sergeants not to hassle any of the participants. The City and the County were incredibly supportive,” he added.

The effectiveness of the County’s needle exchange program has been well established since 1994. A study that looked at the first 16 years of the program found that it prevented an average of eight new HIV infections each year in the County and saved an estimated \$21 million in avoided treatment costs. That worked out to approximately six dollars saved for every one dollar spent on the program.

AIDS patients continued to die in a relatively short time span. At the end of 1994, the Public Health Department produced an analysis of the first 10 years of the AIDS epidemic in the County. It revealed that in all but the most recent four years more than 90% of individuals diagnosed with AIDS had died within the same year. In both 1983 and 1986, every single individual in Santa Clara County died the same year they were diagnosed with AIDS.

Thankfully, 1995 would bring some hope for HIV/AIDS sufferers. A medical breakthrough, whose impact continues to be felt today dramatically transformed an AIDS diagnosis from a likely death sentence to a serious but manageable health condition.

1995

**183 HIV Diagnoses;
187 New Deaths, 1,402 Total Deaths;
1,378 Living with HIV/AIDS**

In 1995, progress was finally being made in the fight against AIDS in Santa Clara County. One significant step was the establishment of the Santa Clara County HIV Health Services Planning Council by the Board of Supervisors.

The council became the body that would apply for and designate the local uses of federal Ryan White CARE Act funds. It included 24 members, and more than a quarter of the council slots were reserved for people who were living with HIV/AIDS. In that first year, the council secured \$2.8 million in federal Ryan White funding for Santa Clara County.

There have been a number of mergers and name changes over the years. The council is now known as the Santa Clara County HIV Commission, but the work continues. The HIV Commission is one of the key bodies responsible for implementing the Getting to Zero initiative.

HELEN MIRAMONTES



Helen Miramontes' nursing career began in 1972 in Kaiser Santa Clara's critical care unit. It later continued at Valley Medical Center where she worked for 20 years, ultimately as a nurse supervisor.

Her involvement with AIDS policy and services came about because of her family. In the 1980's, one of her sons was openly gay and suffering from alcoholism. "In the beginning, she sort of got into it because she needed to know what this is about because (my parents) thought I was going to get sick," said her son David Miramontes during an interview with me in October 2018.

David's twin brother, Jonathan, was also gay but still in the closet at that time. He would ultimately die of AIDS in 2006.

The epidemic was not the first time that Helen had gotten involved in a cause. "My mother was involved in the civil rights movement, the Vietnam War movement, and the migrant farm worker movement in the 60s. I remember being next to her with my siblings, all six of us, listening to Cesar Chavez," said David Miramontes. "She always said that social work helped her really get started doing AIDS work."

She developed one of the first train-the-trainer programs that addressed the need for cultural competency in HIV/AIDS care. The course provided nurses straight-forward information, focusing on the role of stigma, ignorance, misconceptions, and intolerance in undermining treatment and research toward a cure. She explained the course's direct approach by saying, "You don't change attitudes with slides and didactic lectures."

As she became nursing's "go-to" person about HIV/AIDS, she also served on a host of committees and boards, including Santa Clara County's AIDS Task Force. As chair of the Task Force I got to know her and saw firsthand the dedication and passion she brought to her work.

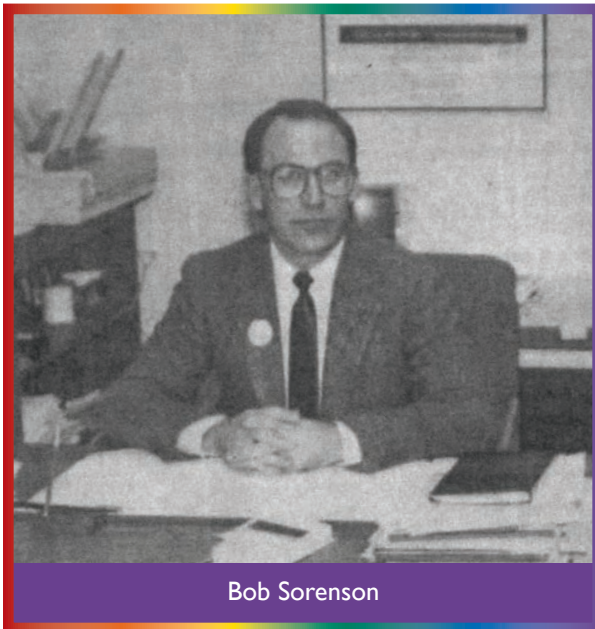
In 1993, Miramontes became an Associate Clinical Professor in UCSF School of Nursing's Department of Community Health Systems. She taught and mentored faculty and students and was involved in the UCSF AIDS Research Institute. She continued her public service on numerous local, national, and international boards. In 1995, she was appointed to President Clinton's Advisory Council on HIV/AIDS, serving on both the research subcommittee and executive subcommittee on international issues.

Miramontes retired from UCSF in 2000 as Full Clinical Professor and relocated to be closer to her children in the Las Vegas area. Her activism continued there. During this time, she also cared for her son Jonathan. She died in May 2016, six days shy of her 85th birthday. Her name, and Jonathan's, have been inscribed on the Circle of Names at the AIDS Memorial Grove in San Francisco's Golden Gate Park.

The second significant event at the County level in 1995 was the opening of the PACE Clinic. PACE was the combination of the early intervention clinic that Fenstersheib began operating in the 1980s for people with AIDS that was profiled in the Journal of the American Medical Association and the hospital clinic for AIDS care that Greene was running at VMC.

PACE offered patients at all stages of HIV infection state-of-the-art primary care in a friendly and compassionate environment. It stressed a holistic approach with comprehensive services ranging from primary care to nutrition and psychotherapy. Clinic workers also made a special effort to ensure that ethnicity, gender, gender identity, language, culture, residency status, and economic level were not barriers to care.

There were also big changes at Aris in 1995. After building the organization from scratch, Bob Sorenson stepped down as the group's executive director in July 1994 for other pursuits. The group spent four months searching for a new leader before hiring Norm Robinson from Stanford University.



In an interview with me, Robinson remembers that one of the first actions that he took was to call for a board retreat to develop a new strategic plan. The issue of the name "Aris" came up. The public was aware of the name, but there was always confusion over what it meant. "The bear just wasn't cutting it anymore," he said. "In the early days you couldn't have the word 'AIDS' in your name, but we didn't want to buy into that." Fortunately, the letters in 'Aris' ended up being a good acronym. Now capitalized, ARIS stood for AIDS Resources, Information, and Services.

However, the biggest HIV/AIDS-related developments in 1995 occurred not on the local stage, but globally. There was a major scientific breakthrough in treatment with the development and testing of the first protease inhibitor.

Protease is a type of protein that the HIV virus needs in order to replicate itself. It was identified in 1985 by researcher Steve Oroszlan at the National Cancer Institute. Scientists quickly realized that inhibiting protease could be a way to slow or stop the spread of the HIV virus in the body. Teams at several pharmaceutical companies, as well as at universities and the National Institutes of Health, began racing to see who could be the first to develop a protease inhibitor drug.

By the early 1990s research had progressed enough that study results began appearing in scientific journals and the first human testing began. Public pressure and the growing death toll from AIDS led the Food and Drug Administration to approve the protease inhibitor Saquinavir for use outside of clinical trials in June. Six months later, on December 6, the FDA approved Saquinavir for use in combination with other AIDS treatment drugs. The era of the AIDS cocktail had begun.

The official name for the new treatment name was Highly Active Antiretroviral Therapy, or HAART. It would not become widely used in the U.S. until 1996, but the earliest results were extremely promising. Perhaps not coincidentally, 1995 was the first year in which the number of AIDS deaths declined in Santa Clara County.

1996

**178 HIV Diagnoses;
124 New Deaths, 1,526 Total Deaths;
1,432 Living with HIV/AIDS**

AIDS deaths in Santa Clara County declined for the second straight year in 1996.

In September, the Public Health Department published a surveillance report of AIDS cases in the County. It found that the primary mode of HIV transmission was males having sex with males (MSM) at 78%, followed by MSM who also injected drugs at 8%, and injected drug use alone also at 8%. Each of the other modes of transmission comprised less than 2% of the County's cases.

Nationally, the Ryan White CARE Act was re-authorized by Congress through the year 2000, ensuring that there would be a steady stream of federal funds for HIV/AIDS programs for several years.

The FDA also approved the Home Access HIV-1 Test System, the first home HIV test. Taking this test was not a simple process. It required a blood sample, most often from a finger prick, and the sample had to be mailed in to a lab. Still, the results were generally available one business day after the lab received the sample. This was a big change from the two weeks I had to wait for results when I got tested in the 80s. The home test was also important because of its anonymity. People were much more likely to get tested if they did not have to make multiple trips to a public clinic.

The effectiveness of HAART, popularly known as the "cocktail," started showing up in national statistics. AIDS deaths declined in the U.S. that year for the first time since the epidemic began. HIV/AIDS also was no longer the leading cause of death for Americans between the ages of 25-44.

RUDY GALINDO



In 1996, San Jose was the site of one of the biggest upsets in American figure skating history when Rudy Galindo became the oldest male national champion of the modern era at age 26. Galindo was also the first openly gay figure skating champion, having come out before the competition began.

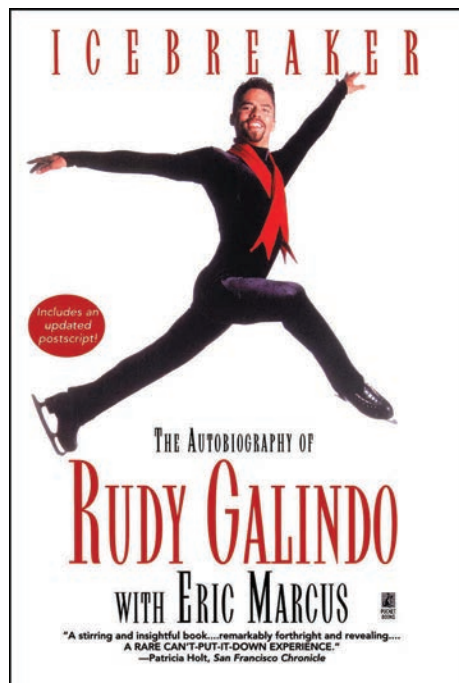
Galindo was raised in a trailer home in East San Jose with his sister Laura. He began figure skating at an early age and his career took off when he began skating pairs with Fremont native Kristi Yamaguchi.

As a team Galindo and Yamaguchi won three U.S. national championships. However, after 1990 Yamaguchi retired from pairs competition to focus on individual skating.

The AIDS epidemic had a major impact on Galindo's personal and professional lives. His and Yamaguchi's first coach, Jim Hulick, died of AIDS in 1989. In 1994, Galindo lost both his brother George and another coach Rick Inglesi to AIDS.

Despite those hardships, Galindo won the men's singles champion title in front of a hometown crowd as the U.S. Figure Skating Championships were held at the San Jose Arena in 1996. In the competition, he was the only male competitor to land combination triple jumps. After his performance Rudy chanted the names Jess, George, Jim, and Rick, who had all helped him to achieve the victory.

His championship defied the norms of the U.S. Figure Skating Association. Galindo later said he feared being an out skater might lower his score because of some judge's discomfort with his identity.



In 1997, he released his autobiography *Icebreaker*. Proceeds from the book were donated toward funding the expansion of the San Jose Public Library's Biblioteca Latinoamericana.

In 2000, Galindo announced he was HIV positive.

Today, he coaches figure skating at Sharks Ice in San Jose. His students include Kristi Yamaguchi's daughter.

He was inducted into the San Jose Sports Hall of Fame in 2011 and the U.S. Figure Skating Hall of Fame in 2013. He has set the path for numerous LGBT and HIV-positive athletes to be themselves.

1997

**188 HIV Diagnoses;
67 New Deaths, 1,593 Total Deaths;
1,553 Living with HIV/AIDS**

By 1997 the full effects of the “cocktail” were becoming apparent to public health officials in Santa Clara County as the year end statistics showed that only 67 people died of AIDS-related causes. That is a drop of almost 50% compared to the previous year.

The same declines were showing up across the U.S. as federal health officials reported that AIDS-related deaths dropped nationally by 47%.

However, while more people living with HIV or AIDS were finding that the disease could be managed with the new drug therapies, the spread of the virus continued.

“These figures mean the new treatments have been very effective in extending the lives of those who already have the HIV infection,” U.S. Secretary of Health and Human Services Donna Shalala said. “They do not mean that we have significantly reduced HIV transmission.”

In Santa Clara County, it was becoming evident that a disparity had developed in HIV transmission rates, with African American and Hispanic communities getting infected at higher rates. While the percentage of AIDS cases among White MSM had been steadily declining, from 66% in 1985 to 36% in 1997, the AIDS incidence among African American and Hispanic demographics had increased. The rate among African Americans rose from 10% in 1990 to 17%. Rates among Hispanics increased during the same period from 20% in 1990 to 27%.

The AIDS incidence among African Americans doubled from 8% of all cases in 1990 to 16% by 1997. In the same period, it declined among Whites from 66% of all cases to 51%. African-

American women alone accounted for 25% of the women with AIDS, and 17% of the women with HIV. The disproportionate representation among AIDS cases of African Americans is especially troubling when viewed along with the county's overall demographics. African Americans comprised less than 4% of the County's population during the 80s and 90s.

1998

**153 HIV Diagnoses;
53 New Deaths, 1,646 Total Deaths;
1,653 Living with HIV/AIDS**

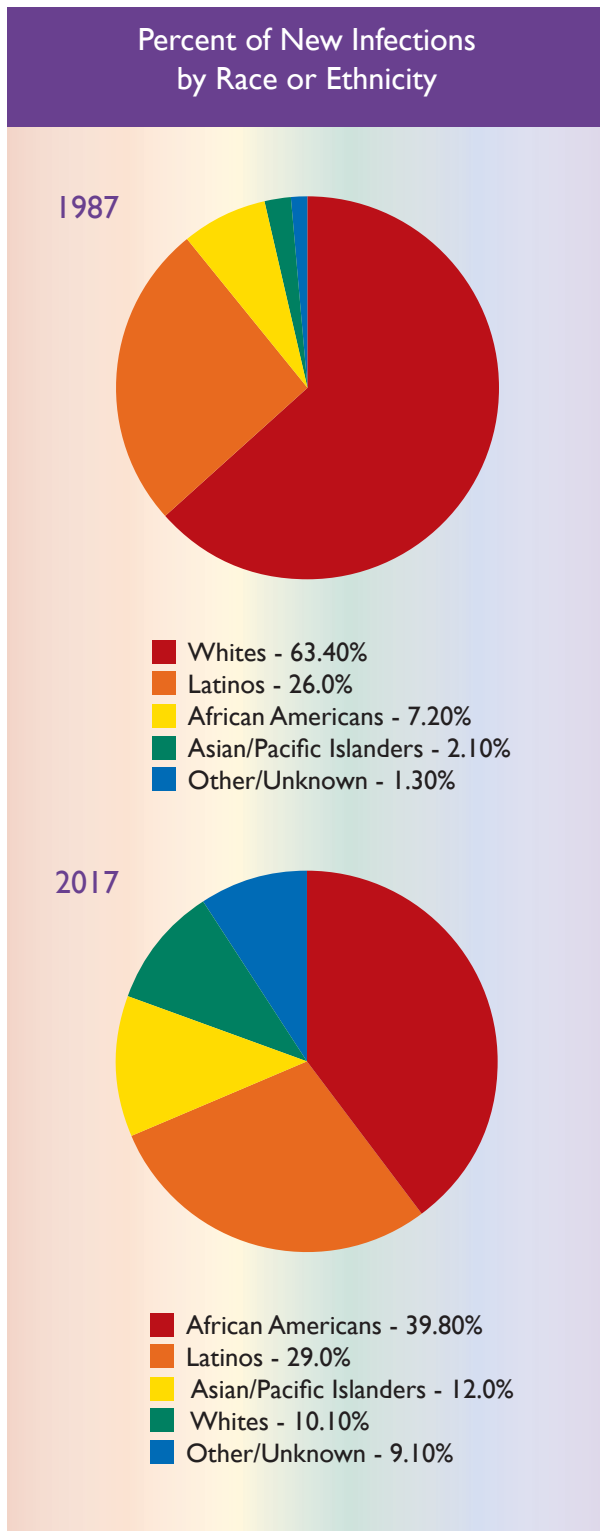
Santa Clara County health officials tried to address the disparity in African American HIV infection rates in 1998 by hiring an African American physician at the PACE Clinic.

They also developed a partnership with a leading African American community service provider for a significant outreach and educational effort in that community.

The County also made efforts to increase the reach of its HIV/AIDS services in other underserved communities. The PACE Clinic served monolingual and limited-English-proficient clients through eleven bilingual employees and one fluent in sign language. Outreach and case management services were established for Spanish-speaking clients by a community health care provider primarily focused on the Latino community. The County also expanded HIV/AIDS services in the geographically isolated, underserved, and heavily minority-populated South County area. Services for women were also expanded with risk reduction activities for women who have sex with women, production of a women-focused HIV/AIDS video, and a new women's clinic.

The PACE Clinic had become an invaluable asset for the County. More than 800 patients received services there in 1997. Approximately half of them were referred to one of the almost four dozen clinical research trials that were available at PACE, while more than 400 other patients were referred outside of PACE for services including biomedical research at university-based medical centers that offered experimental treatments for HIV/AIDS.

PACE patients were able to obtain their medications at an on-site pharmacy or at any of the seven other County public health pharmacies, all of which dispensed AIDS Drug Assistance Program (ADAP) drugs.





The clinic had a hospital liaison who worked closely with VMC medical staff, case managers, and discharge planners to coordinate the treatment of current and potential patients. Upon hospital admission, the liaison reviewed charts and contacted the patient's primary care physician as well as other relevant departments to share information crucial to the patient's treatment. At the time of discharge, the patient's case manager and discharge planner were also contacted by the liaison.

In addition, the County was collaborating with Chaboya Dental. Health officials recognized that common conditions such as tooth decay and gingivitis contributed to weight loss and general physical deterioration in HIV/AIDS patients.

The County's HIV/AIDS programs had grown so much since the early years of the epidemic. They now included confidential HIV outreach, testing and prevention services in both fixed and mobile facilities, client care coordination and case management, home health care, hospice services, respite care, mental health therapy and counseling, nutritional services, substance abuse treatment and counseling, transportation, client advocacy, housing assistance, direct emergency financial assistance, and alternative therapies.

The mobile service bus program was a good example of what the collaboration between the PACE Clinic and the Public Health Department had achieved. The bus travelled throughout the county targeting migrant populations, the homeless, needle exchange programs, gay and lesbian community centers, etc. It made approximately 1,500 outreach or testing contacts per year, spending time on eight college campuses and stopping at special events such as the Pride Festival, African-American Juneteenth Celebration, and the Gay Rodeo.

Changes in how HIV was being transmitted were also becoming apparent. Although MSM continued to be the largest risk behavior, with 71% of the county's cumulative cases reported to CDC through March 1998 (similar to the state average of 72%), MSM cases consistently declined, going from 76% in 1990 to 68%. At the same time, heterosexual transmission increased from 4% in 1990 to 10% in that period. The other major risk group was people who inject drugs and they accounted for 8% of the total cumulative AIDS cases through March 1998.

The changing demographics of the epidemic were readily apparent to those working on the front lines of treatment and social services in Santa Clara County, as ARIS Director of Volunteer Resources Pat Duffy told me during an interview in 2018.

“The kind of clients we had at ARIS evolved over the years. When ARIS first started, it was mostly gay white men, mostly in their 20s, 30s, and 40s, and kind of easy to relate to,” said Duffy.

“As the disease dragged on, as people were starting to live a little longer than six months, or 12 months, or 18 months, the people we started getting and retaining as clients were people who had other issues as well as HIV. So, they had been in the system for most of their lives. They had been in the correction system. They had substance abuse issues. So, there were other flowers in that bouquet besides AIDS.”

One area where ARIS continued to see a lot of demand was housing. By the end of 1998, the group was providing housing for 55 people at multiple facilities throughout the County. There were 25 beds of supportive, shared housing at six residences in Gilroy and San Jose, 24 studio apartments at Casa de Los Amigos in San Jose and a six-bed residence on Thornton Way in San Jose for those needing around-the-clock care and supervision. Despite all of these beds, the waiting list had 110 names on it by the end of that year.

1999

**143 HIV Diagnoses;
49 New Deaths, 1,695 Total Deaths;
1,747 Living with HIV/AIDS**

In 1999, the number of HIV/AIDS patients admitted to VMC was a little more than half the previous year's total: 38 compared to 61. Cumulative HIV/AIDS patient days at VMC also dropped significantly from 465 to 328. Clearly the plague days of the 1980s and early 1990s were now behind us.

AFTERWORD: GETTING TO ZERO

The discovery of protease inhibitors and the creation of the “AIDS cocktail” dramatically changed both the perception and reality of the epidemic. Almost overnight, HIV/AIDS went from being a near-certain death sentence to a manageable health condition if diagnosed and treated. This change was extremely welcome after more than a decade of darkness when friends and loved ones got sick, wasted away, and then died with blinding speed.

While it is true that the HIV epidemic has stabilized since the mid-2000s in Santa Clara County, African-American and Hispanic residents continue to be disproportionately impacted, with rates among African-Americans more than four times higher than rates among non-Hispanic Whites.

More work needs to be done. According to an October 2018 report from the County Health Department (First Annual Report on HIV/AIDS Epidemiology and Services), there were 156 new cases of HIV diagnosed in the County in 2017, increasing from 135 in 2016. This is after several years of slight decline.

As detailed in the report, the stable rates of new diagnoses have resulted in an increase in survival and improvement in care, with 84% of newly diagnosed patients linked to care within one month and 91% within three months. Overall, however, only 76% of all people living with HIV were in care, thus demonstrating that more needs to be done to test people who are unaware they are HIV positive or know their status and do not seek or maintain treatment.

JEFF SMITH



Decades before he became Santa Clara County's top administrator, Jeff Smith's first career was as a medical doctor. He went to medical school at the University of Southern California in the late 1970s and was doing his residency in family practice in Contra Costa County from 1980-83, during the first years of the AIDS epidemic.

Smith's experience in the early years of the AIDS epidemic was similar to that which physicians Greene, Fenstersheib, and McShane experienced in the early years of AIDS.

"All we knew for sure was that the syndrome was a guaranteed death sentence. Patients typically presented for care when they were extremely ill. They often had Pneumocystis pneumonia, at the time a very rare infection. Sometimes they presented with a very rare and aggressive cancer—Kaposi's sarcoma," Smith told me in October 2018. "Patients were always weak and debilitated. Their immune systems were destroyed, and they suffered from many other infections. Antibiotics didn't work. Invariably, they were lost."

Smith said in those early years the fear about the disease led to a lot of homophobia. The initial name for AIDS was GRID, Gay-Related Immune Deficiency. Even worse was the colloquial term that he heard much of the public use in those first years: the gay plague.

The doctors Smith was working with knew very little about the cause of the disease or how to treat it. Funding for care and treatment in Contra Costa County was very limited. "As a young phy-

sician, I watched many patients die as they were dehumanized with ineffective medical care and a cruel society. It was an unspeakably awful time," said Smith.

As Santa Clara County Executive, Smith has been very supportive of programs for the LGBTQ community, such as helping implement my proposal to create the nation's only county Office of LGBTQ Affairs, hiring openly LGBTQ department heads, and approving the flying of the Rainbow flag and Transgender flag every workday in front of the County building. These and other actions lead BAYMEC to award him the "Ally of the Year" award in 2018. As importantly, he helped make sure that the Getting to Zero initiative had the resources and staff it needed. Never once did he say to me, "slow down." The response to all my requests was always to proceed forward.



BAYMEC board of directors with Jeff Smith and Santa Clara County LGBTQ staff

It was at the 2011 United Nations World AIDS Day that the international Getting to Zero (GTZ) program was launched with the goal of achieving zero deaths, zero new infections, and zero stigma. In 2015, I worked with the County's Public Health Director Dr. Sara Cody and community stakeholders to explore how to start such a program in Santa Clara County. Once we knew how to create a GTZ program that suited our needs, I asked the Board of Supervisors in 2016 for funding and received approval for a \$6 million budget spread over four years to 2020. It was one of my proudest moments as an elected official.

The program has four focus areas: pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP) implementation, guideline-based sexually



Dr. Sara Cody, Supervisor Ken Yeager

transmitted disease (STD) and HIV screening, initiation and retention of HIV care, and reducing stigma.

PrEP is an HIV prevention tool based on taking a daily medication designed to prevent HIV RNA from replicating itself in the body. It was introduced as a pre-exposure prophylaxis in 2012 with the Food and Drug Administration's approval of Truvada, although it has been used as an antiretroviral since 2004. Daily use of the drug can reduce the risk of getting HIV from sexual contact by virtually 100% and from intravenous drug use by 74%.

PEP is a month-long course of antiretroviral medication that can prevent a patient from becoming infected with HIV if it is taken soon after exposure. Every hour counts. PEP loses all of its effectiveness if it is taken more than 72 hours after exposure.

Funding from the County was used to hire and train the County's first PrEP navigation specialist and to create a PrEP/PEP Action Team. From its first creation in January 2017 through June 2018 the PrEP navigator program has received 256 referrals, resulting in 171 clients successfully accessing PrEP and 18 completing PEP.

I was always aware that there was great skepticism in the medical field about PrEP. There was also a lack of information and misunderstanding about

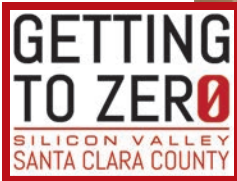
insurance coverage. Moreover, according to a health assessment conducted by the Public Health Department for the LGBTQ community, many gay people do not talk openly about their sexuality with their primary doctors. These are all significant barriers that had to be overcome.

This is why I was proud when the Santa Clara County STD/HIV program administrators began sending expert health education specialists to clinical sites to teach medical personnel about prescription barriers to PrEP and PEP and to offer personalized resources. They distributed 122 PrEP toolkits. The GTZ PrEP/PEP Action Team organized and conducted 13 PrEP/PEP trainings that reached 136 health professionals. As a result of these efforts, this year eleven new provider sites posted their availability to offer PrEP/PEP on the website www.PleasePrEPME.org. When I heard about the website last year, I recall being horrified to learn that there were only one or two sites listed for Santa Clara County. I am very pleased by how much more ground has been covered in 2018.

PrEP and PEP are remarkable tools in the fight against HIV/AIDS but have hurdles to implementation. Truvada, the only FDA-approved PrEP drug costs as much as \$2,000 a month. Much of the County dollars to cover the cost of the treatment for people who cannot afford it comes through Medi-Cal dollars and a federal program called 340B.

In 2017, the CDC announced that individuals with undetectable viral loads have essentially no risk of sexually transmitting HIV. This is a significant breakthrough that helps to reduce transmission, a pillar of Getting to Zero. This only applies to





Santa Clara County Public Health Department Getting to Zero team with Supervisor Ken Yeager

people who take antiretroviral therapy daily as prescribed and achieve and maintain an undetectable viral load.

One good way to encourage testing for HIV is when a person gets an STD test. If tested positive for an STD, it might be a sign of risky sexual behavior and thus possible HIV infection. That's why in 2016 I advocated for the creation of a full time STD/HIV Controller to elevate the County's STD/HIV prevention work through a dedicated, physician-level position. This position was filed by Dr. Sarah Lewis. In 2017, I worked with the Public Health Department to double the hours



Dr. Sarah Lewis

of the STD clinic and implement the first-ever mobile STD testing site during Silicon Valley Pride. Also in 2017, the Board allocated County general fund dollars for an additional Communicable Disease Investigator who works to improve the speed and thoroughness of HIV and STD investigations due to the increase of STD cases. A new nurse manager was also hired to oversee the STD/HIV Client Services Team.

In Getting to Zero's first year we furnished training to health care providers and youth peer educators oriented around reducing HIV/AIDS stigma to zero. Providers and educators are trained on how to have stigma-free examinations and encounters with patients and the public. GTZ funds also support a Health Education Specialist responsible for educating about public health in County schools with an emphasis on reducing HIV/AIDS stigma.

Of the three goals of Getting to Zero, reducing stigma is the hardest to quantify and requires the most sustained effort and funding. Through collaboration with the County's Office of LGBTQ Affairs, the GTZ initiative supported nine mini-grantees to conduct unique projects that reduced HIV-related stigma. Santa Clara County is the first county in the country to have an Office of LGBTQ Affairs, and I was proud to have proposed and advocated for its creation. The Office works on a wide variety of issues related to the LGBTQ community, with GTZ being just one of its initiatives.

Finally, at my urging, the County has sponsored two extensive marketing campaigns geared to inform young Hispanic/Latino men who have sex with men about the option of PrEP. According to a Public Health Department October 2018

memo, the first campaign—“Get Liberated”—resulted in more than 2.4 million media impressions; the second—“PrEP is for…”—received more than 13 million. A third PrEP Awareness campaign was specific to African-American residents.

We are about halfway through the four-year program and already we are seeing increases of more than 50% in PrEP prescriptions compared to the baseline before the County began Getting to Zero. The initiative set a new precedent for increased County STD clinic hours and staff, greater number of health care workers trained on PrEP/PEP, and other public health advancements that will continue after Getting to Zero sunsets.

Looking back, I am proud to have proposed the creation of the Santa Clara County AIDS Task Force and to serve as its first chair. This was very early in the epidemic, with less than 100 people having died from AIDS in the County. At the time, when a person was tested for the virus it took weeks to get results. We had no thoughts at that time of getting to zero deaths, zero new infections, or zero stigma.

We were just trying to get care for the sick and dying, funding for research, and recognition from an often-indifferent, if not genuinely hostile, society that this was a significant public health crisis.



Santa Clara County Office of LGBTQ Affairs staff with Supervisor Ken Yeager

From 1984 when the first AIDS deaths were reported in the County to the end of 2017 there have been a total of 2,498 deaths from AIDS. Such a tragic loss.

We have come so far since those early dark days. But much work still needs to be done. I am confident that the goals of Getting to Zero are within our grasp, and I remain committed to doing everything I can to ensure that we reach them. I've been fortunate to have had a public career spanning 32 years to work on an epidemic that has taken the lives of so many people in my community. My heart is full of both sadness and hope.



ACKNOWLEDGEMENTS

Initially, I had concerns about writing this manuscript because no one person can completely, or even adequately, tell the story of the AIDS epidemic, even when the story is confined to just one region. The epidemic affected so many lives; each individual who lived through it has their own deeply-felt experience.

My involvement was primarily in the political arena, but I wanted to accurately convey all facets of the epidemic in the County. Through research, interviews, and my own memories, I have tried to craft a framework of the complex story of the local response to HIV/AIDS.

I have always felt a deep obligation to stay involved in the fight against the epidemic that killed so many of my friends and members of my community. My work—from advocating for the first public dollars to be spent on HIV/AIDS services in Santa Clara County, to initiating the local Getting to Zero Campaign—has always required perseverance.

It has also always required the support of friends and allies, and the same is true with this manuscript. I could not have written it without the assistance and input of many people.

I would like to thank Jean McCorquodale for her support of this project from the very beginning. She helped greatly with research, organization of the material, and with editing. I owe her a debt of gratitude.

As he has done on numerous other projects, Michael Haberecht served as a good sounding board and editor of material. He is always of great help, especially when deadlines approach.

I would also like to thank Valerie Altham, Jason Bennert, and Dan DiVittorio for their assistance in producing this history.

In addition, I would like to thank my staff at the Board of Supervisors: Bryan Aubineau, Michelle Collins, Brian Darrow, Alexis Fields, Nolan Golden, Yvonne Jimenez, Baltazar Lopez, Mario Lopez, Daniel Vainish, and Jim Weston.

From the County of Santa Clara I would like to thank Laurel Anderson, Dr. Sara Cody, Dr. Sarah Lewis, Linlin Li, Wen Lin, Jim McPherson, and Dr. Jeff Smith.

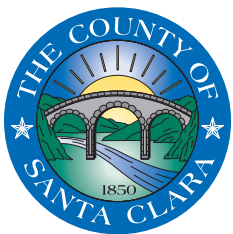
Many people graciously shared their time and memories of the years 1981-1999 with me including Jeff Barber, Mark Bonine, Denny Carroll, Pat Duffy, Dr. Marty Fenstersheib, Helen Johnson, Dr. Denny McShane, David Miramontes, Bob Reed, Norm Robinson, Bob Sorenson, and Karl Vidt.

LESLIE DAVID BURGESS LIFETIME ACHIEVEMENT AWARD



The individuals presented this award have demonstrated extraordinary commitment, dedication, and compassion providing education and services to the people with HIV in Santa Clara County.

- | | |
|--|---|
| Leslie David Burgess 1991 | Dr. Kristin J. Razzeca, Special Recognition 2003 |
| Millicent Kellogg 1992 | Florine Radatz, Health Care 2004 |
| Bob Clayton 1993 | Marty Grimes, Prevention & Education 2004 |
| Marianne Gallagher 1994 | Dena Dickinson, Care & Treatment 2005 |
| Dr. Marty Fenstersheib 1995 | Christopher Baldwin,
Prevention & Education 2005 |
| Ben Luckey 1996 | Supervisor Jim Beall, Special Recognition 2005 |
| Onnie Lang 1997 | Cynthia Barboza,
Health Care & Human Services 2006 |
| Dr. Robert Yao, Care Services 1998 | Charles Addams, Prevention & Education 2006 |
| Frank Salerno, Prevention Services 1998 | Jude Silva Barrios, Care & Treatment 2007-08 |
| Jeff Cormier, Prevention 1999 | Karl Vidt, Education & Prevention 2007-08 |
| Neil Christie, Client Advocacy 1999 | Susan Czark, RN 2009 |
| Manuel Fimbres, Community Planning,
Special Recognition | Lawrence McGlynn, MD 2010 |
| Helen Johnson, Advocacy 2000 | Robert Reed 2011 |
| Miguel Perez, Education/Prevention 2000 | Jill Parks 2012 |
| Kim Fredricks, Prevention/Education 2001 | Janet Childs 2013 |
| Geoff diBrandi, Health Care/Human Services 2001 | Jorge Omar Nunez 2014 |
| Michelle Covert, Prevention/Education 2002 | Robert Smart 2015 |
| Jerry Larson, Health Care/Human Services 2002 | Frederick J. Ferrer 2015 |
| Jeannine Jordan, RN, Special Recognition, 2002 | Manuel Monzon 2016 |
| Claire La Scola, RN, Special Recognition 2002 | Walter Williams 2017 |
| Frank Keillor, Health Care 2003 | |
| Linda Peerson, Prevention & Education 2003 | |



County of Santa Clara
County Government Center
70 West Hedding Street
San José, California 95110
www.sccgov.org