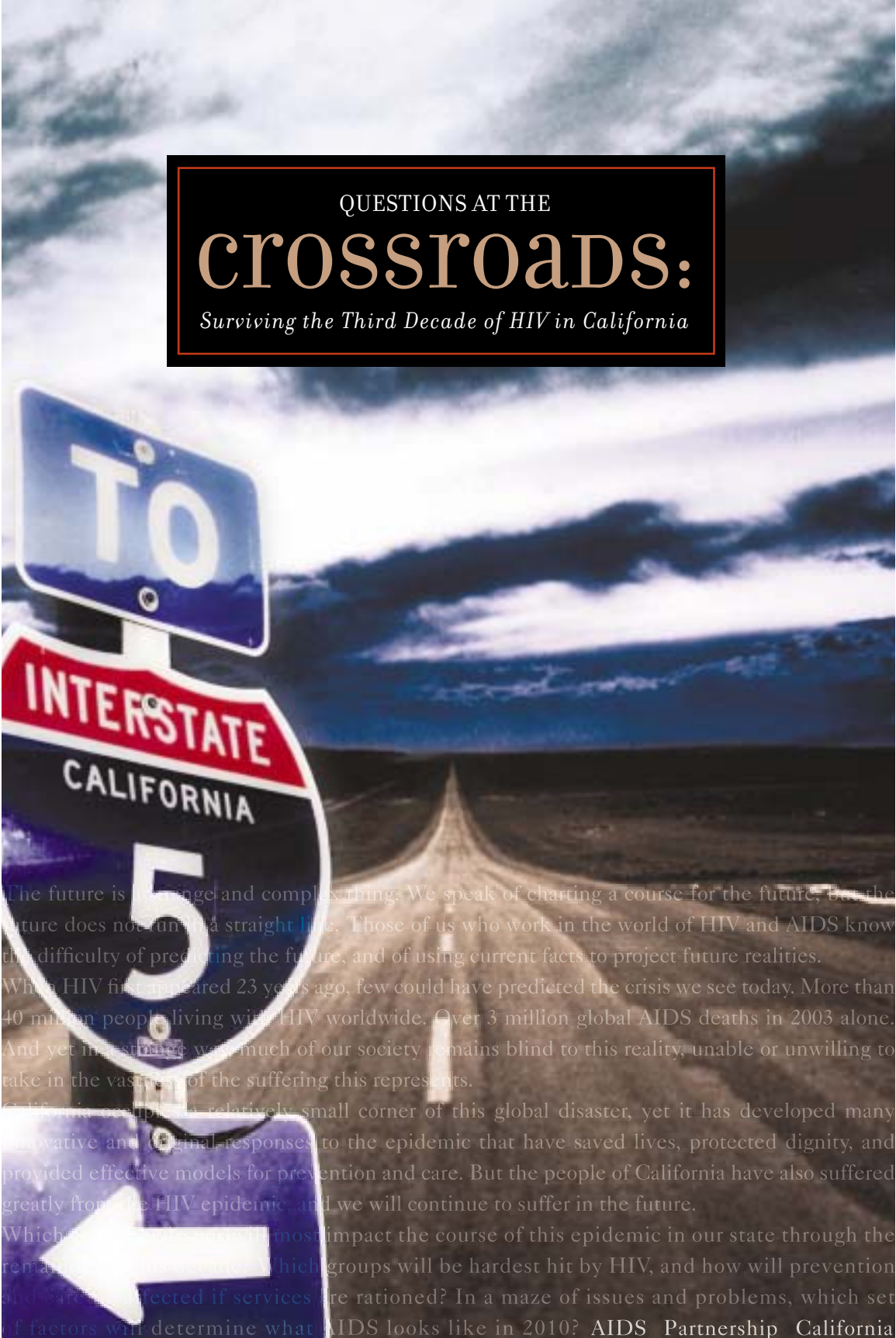




QUESTIONS AT THE
CROSSROADS:

Surviving the Third Decade of HIV in California



The future is a strange and complex thing. We speak of charting a course for the future, but the future does not run in a straight line. Those of us who work in the world of HIV and AIDS know the difficulty of predicting the future, and of using current facts to project future realities.

When HIV first appeared 23 years ago, few could have predicted the crisis we see today. More than 40 million people living with HIV worldwide. Over 3 million global AIDS deaths in 2003 alone. And yet in a strange way, much of our society remains blind to this reality, unable or unwilling to take in the vastness of the suffering this represents.

California occupies a relatively small corner of this global disaster, yet it has developed many innovative and original responses to the epidemic that have saved lives, protected dignity, and provided effective models for prevention and care. But the people of California have also suffered greatly from the HIV epidemic, and we will continue to suffer in the future.

Which factors will most impact the course of this epidemic in our state through the remainder of the decade? Which groups will be hardest hit by HIV, and how will prevention and care be affected if services are rationed? In a maze of issues and problems, which set of factors will determine what AIDS looks like in 2010? AIDS Partnership California

HOW THIS REPORT WAS COMPILED

In order to develop this report, AIDS Partnership California and its consulting agency, LaFrance Associates LLC, conducted a series of interviews with two dozen leaders throughout the state in the areas of HIV/AIDS prevention and care.

These key informants encompassed a diverse group including people with HIV, clinicians, providers of prevention and care services, foundation executives, directors of public programs, and founders of community-based organizations (see list at the conclusion of this document). The group varied by discipline and by constituency, and represented a wide range of populations, including people of color; gay men; injection drug users and their sexual partners; women; and sexually active youth. We also reviewed articles and publications recommended by respondents.

Interviews were conducted and transcribed using a protocol that sought to explore topics of significance to California, including issues where greater understanding and plausible interventions could make a difference in altering the course of the epidemic. We sought to identify future challenges so that they might be met head-on, with eyes open. Perhaps the best way to sum up the enterprise is as a search for new potential opportunities in the fight against HIV, and a way to brace for the coming crunch if caseloads continue to grow while funding remains static or decreases.

INTRODUCTION: TO SEE THE FUTURE

The future is a strange and complex thing. We speak of charting a course for the future, but the future does not run in a straight line. Those of us who work in the world of HIV and AIDS know the difficulty of predicting the future, and of using current facts to project future realities.

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This report, based on interviews with two dozen HIV/AIDS leaders throughout California, is one step in what we hope becomes a broader effort to open our eyes wider, and to examine key issues affecting the future of HIV prevention and care in our state. While it is impossible to know where the precise future of HIV lies, we can certainly do a better job of addressing it if we anticipate and plan for different potential realities now.

Otherwise, we risk the future continuing to lead us.

The Changing Face of HIV-Affected Populations in California

The profile of HIV in California has shifted dramatically over the past decade toward an increasingly devastating impact on women, young people, and people of color. Between 1992 and 2002 alone, the proportion of new AIDS cases diagnosed among women in the state doubled from 7% to 14%.

The shift in the California epidemic is perhaps most dramatic in regard to communities of color. In 1992, only 39% of all AIDS cases diagnosed in California were among people of color. But by 2002, fully 61% of all AIDS cases diagnosed in California were among ethnic minority populations. If this rate of increase continues, by 2010 nearly 75% of new AIDS cases could be diagnosed among Californians of color.



HIV IN CALIFORNIA: **BACKGROUND AND CONTEXT**

Although usually discussed in broad-brush terms, the notion of an “HIV epidemic” blanketing the country is misleading. In reality, HIV is more like a series of “micro-epidemics” of varying character, with differing mixes of cases from the perspective of transmission routes, demographic characteristics, and prevention and care needs.

Approximately 135,000 Californians have been diagnosed with AIDS since the beginning of the epidemic. Today, between 108,000 and 125,000 people are estimated to be living with HIV disease in California, with 8,000 to 9,000 new infections each year.

In California, the epidemic today remains composed largely (77%) of gay men, including 9% who also inject drugs. This “West Coast” profile differs dramatically from central and eastern states, where AIDS affects much higher percentages of injection drug users and women. The remaining cases of AIDS in our state are among male and female injection drug users (11%) and female partners of injection drug users and bisexual men (5%).

People of color account for a majority of new cases, especially among women and young gay men. Between 1992 and 2002 alone, the proportion of new AIDS cases diagnosed among women in the state doubled from 7% to 14%. Over the same period, the rate of new AIDS diagnoses among young people between the ages of 13 and 19 quadrupled, increasing from .2% of cases in 1992 to .8% of cases in 2002. Increases are also occurring within California’s vast immigrant population, which includes at least 2.2 million undocumented immigrants – 32% of all undocumented immigrants in the nation – and over 9 million permanent legal immigrants.

Some 19 months into California’s new non-names-based

surveillance system, nearly 30,000 of an estimated 60,000 prevalent cases of HIV (not AIDS) have been identified. While there are many points of view about whether the new system is working, there is no question that the results so far continue to point to a growing epidemic among gay men and other men who have sex with men (MSM), people of color, women, and young people, and that the numbers suggest an ominous future.

THE CHALLENGES OF HIV: **QUESTIONS AT THE CROSSROADS**

The questions are old but persistent. Time and again, our key informants apologized for singing the same songs, for asking the same questions, and for urging some of the same solutions that they have for years.

How can we alert people to the magnitude of the HIV epidemic? What can we do about the stigma of AIDS? Why do so many at-risk people avoid being tested? How can we best address the epidemic among women and young people? Why is it so hard to talk about AIDS among gay black and Latino men, or to mobilize AIDS leadership in communities of color? Why do individuals continue to become infected at rates sufficient to fuel an unabated epidemic in the U.S.? How can this be explained when the knowledge of how to avoid infection exists, along with many resources to help take advantage of such understanding?

Some ponder the problem of targeting finite resources to confront the epidemic. What are the fault lines between prevention and care? Are the most promising prevention strategies to be found in behavior change or in scientific developments such as Pre-Exposure Prophylaxis, which

may soon allow individuals to take a daily pill to prevent HIV transmission? How much should our care

WHICH EMERGING ISSUES WILL MOST IMPACT THE COURSE OF THE HIV EPIDEMIC IN CALIFORNIA THROUGH THE REST OF THIS DECADE?

focus exclusively on HIV, and how much on related concerns, such as STDs, substance use, mental health, poverty, or homelessness? And most persistently, how can we save AIDS funding?

The challenges implied in these questions aren't novel, but they endure. Yet some questions are new, or at least different enough to warrant a new look.

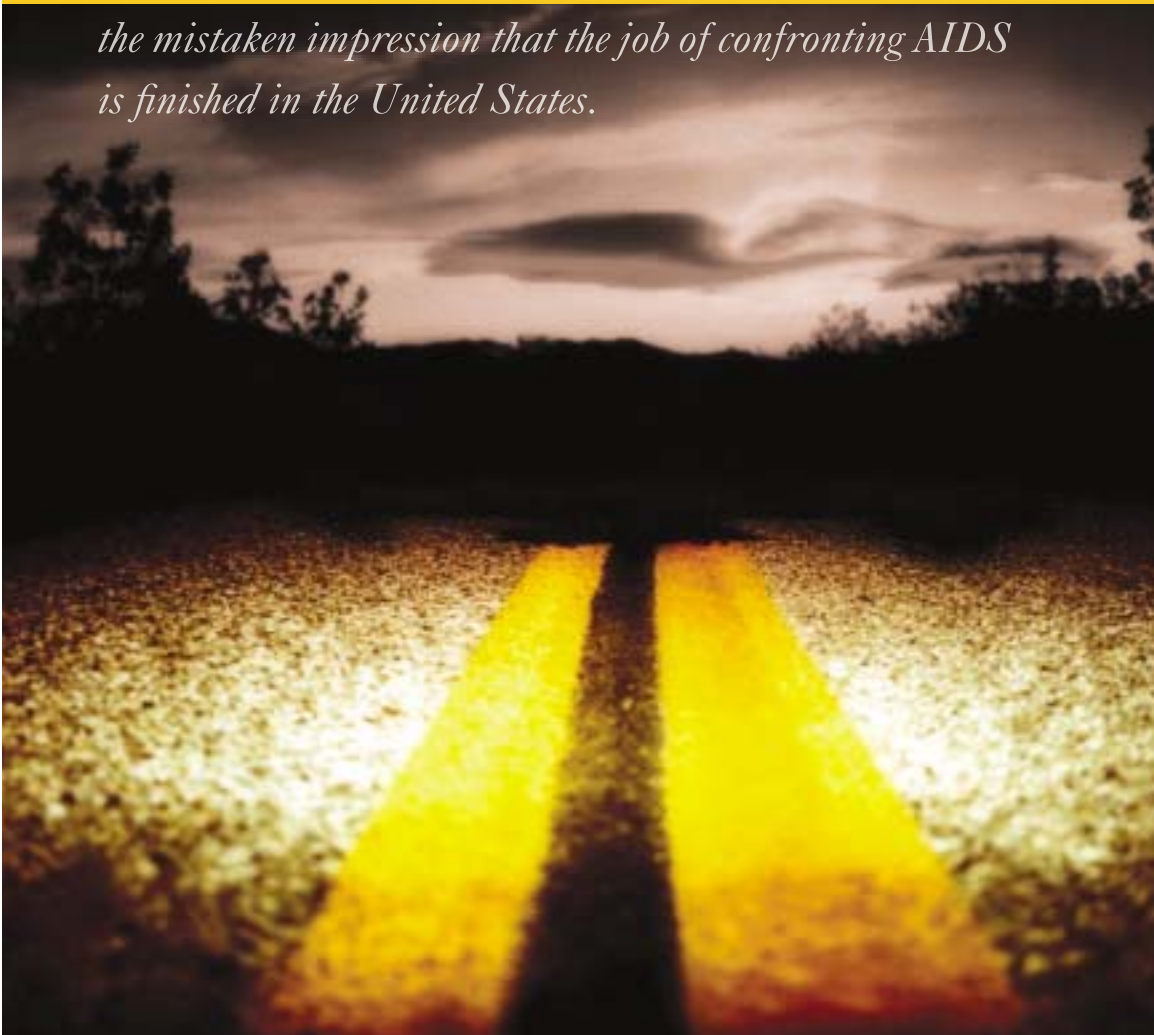
What kind of impacts are Internet dating, speed, party drugs, and Viagra having on HIV transmission in the gay community? How do we reach young people with HIV prevention messages when they do not live with the day-to-day reality of death and dying that an earlier generation experienced? How can we empower women to have more control over their own risk of HIV infection? Who stands likely to lose out if, as predicted, caseloads continue to rise and funding remains flat or declines?

A number of our interviewees, some of them working in HIV since the disease came to light in the early eighties, noted that HIV does not command the interest, attention, and energy it once did.

Perhaps this is inevitable. Although it may reflect neglect, it may also be part of coping with any epidemic over the long haul. Interviewees cited many examples of AIDS fatigue, whether it involved attention shifting abroad, the inability to raise funds at a previous pace, or the failure to maintain the interest of policymakers. But they also pointed out instances where HIV care has been integrated into mainstream health care with positive effect.

The widespread opinion among our key informants that interest in the epidemic has waned is backed up by polling data, revealing that

Many wonder what has happened to the time when AIDS seemed to matter. Two decades into the struggle against AIDS, media attention has shifted to the coverage of the raging epidemic in the developing world, perhaps leaving the mistaken impression that the job of confronting AIDS is finished in the United States.



HIV, especially at the domestic level, has lost its urgency in recent years. A July 2002 Kaiser Family Foundation poll found that health care ranked sixth overall among the most important issues Americans believe are facing them today, below terrorism, national security, the economy, and education. Even among health problems, HIV/AIDS ranked fourth, trailing cancer, rising costs, and health insurance coverage. In 1997, 38% of poll respondents had ranked AIDS as a major health problem. By 2002, this had declined to 17%.

Interviewees also expressed conflicting points of view about whether the non-names-based reporting system implemented in 2002 is working, and where California stands in terms of tracking cases and ensuring an adequate share of federal funds. Some believe that the current reporting system is working well. Others believe that a lack of confidential names-based reporting could lead California to significantly understate the true scale of its epidemic, resulting in slashed federal allocations.

Others wonder what has happened to the time when AIDS seemed to matter. Two decades into the struggle against AIDS, media attention has shifted to the coverage of the raging epidemic in the developing world, perhaps leaving the mistaken impression that the job of confronting AIDS is finished in the U.S. Domestic and international crises of other types have not helped re-focus attention on California's HIV epidemic. A few interview participants complained that what little coverage on HIV there is tends to be limited to the most lurid angles, such as the often apocryphal stories of "bug chasers" who willingly infect themselves with HIV.

Still others noted **HOW GREAT A ROLE DOES HOMOPHOBIA CONTINUE TO PLAY IN OUR INADEQUATE RESPONSE TO THE HIV EPIDEMIC?** the ways in which attitudes have changed about HIV.

The social support for avoiding becoming infected has frayed in the gay community, and many young people no longer believe that HIV is a fatal illness.

Some contradictory themes emerged. On the one hand there is AIDS burnout, fatigue, or ennui, whether measured in terms of declining conversations, volunteer hours, or newspaper column inches. Yet at the same time, HIV remains highly feared and stigmatized, as evidenced by the power AIDS still has to silence discussions about safer sex, HIV testing, or HIV risk behaviors.

Many of our key informants worried about the state of AIDS advocacy. They maintain that despite the vaunted reputation of the once-powerful “AIDS lobby,” in reality, its impact has dwindled and the ranks of committed, trained advocates have shrunk. The policy analysis and advocacy work of a number of local and statewide organizations has in many cases been downsized or abandoned due to resource constraints.

The shift in political climate in the current administration also prompted a number of observations about the ways in which policy analysis and politics are skewing rightward in the direction of

business approaches to healthcare and accountability tracking. Political considerations and the culture wars are increasingly driving policy.

WHAT ACTIONS CAN WE TAKE TO REVIVE THE SAME INTEREST AND CONCERN FOR THE HIV EPIDEMIC THAT EXISTED 10 YEARS AGO?

Some cited the need for more attention and support to train a new generation of advocates and activists

from the communities most at risk of HIV in California, especially gay men of color. Others lamented the decline of leadership within the gay community in particular, including an inability to confront the challenges of dealing with homosexuality in minority communities.

Some underscored the role of the church; others called for more advocacy devoted not just to drug development and access, but to prevention as well.

Ensuring the future of HIV prevention and care will require attention to all of the above issues and many more. Yet some issues present more immediate concern, and warrant more focused attention, than others. The following sections present a range of HIV issues that our key informants felt were most critical to consider today in light of the potential they have to impact our work in the future.

DECLINING FUNDING AND THE COMING OF RATIONED CARE

Nearly all interview participants are deeply concerned about the current and pending economic and state fiscal crisis and the painful choices facing providers and program managers. Most interviewees are working with agencies that are being forced to make some level of cutbacks, or to decide whom to exclude and whom to serve in an increasingly tight funding climate.

Rationing of HIV and AIDS services, if not already here implicitly, is looming explicitly. Many former assumptions about who should get care and how much care each person should get are up for grabs. How best can decisions about rationing HIV care be made? And how can we address

our collective unwillingness to make tough choices?

HOW CAN WE ENERGIZE THE HIV COMMUNITY TO LOOK HARDER AT THE FUTURE, AND TO DEVOTE MORE COLLECTIVE RESOURCES TO ADVOCACY AND POLICY ISSUES?
WILL THE RYAN WHITE CARE ACT CONTINUE TO BE REAUTHORIZED BY CONGRESS AND FUNDED AT OR NEAR CURRENT LEVELS? ARE WE FACING DRAMATIC CHANGES TO THE STRUCTURE OF THE CARE ACT?

In fiscal year 2003, nearly \$230 million in Ryan White CARE Act Title I and II funding was awarded to California, but this amount is not nearly enough to meet the needs of the current population living with HIV and awaiting care. This is especially true for populations living with substance use, mental illness, and other co-morbidities. These groups represent a growing percentage of low-income people with HIV in our state, and require heavy commitments of time and resources to treat adequately. Complicating the situation is the fact that the federal government's fiscal year 2004 Title I allocation to California decreased by nearly \$9 million, representing a cut of 8% over the previous year.

Even given slight increases in funding for HIV in the face of rising caseloads, the amount of federal funding available per person living with HIV is falling dramatically. The chart on the next page illustrates what would happen if Ryan White Title I and II funding for California continued to grow at recent rates, adjusted for new cases of HIV, with an

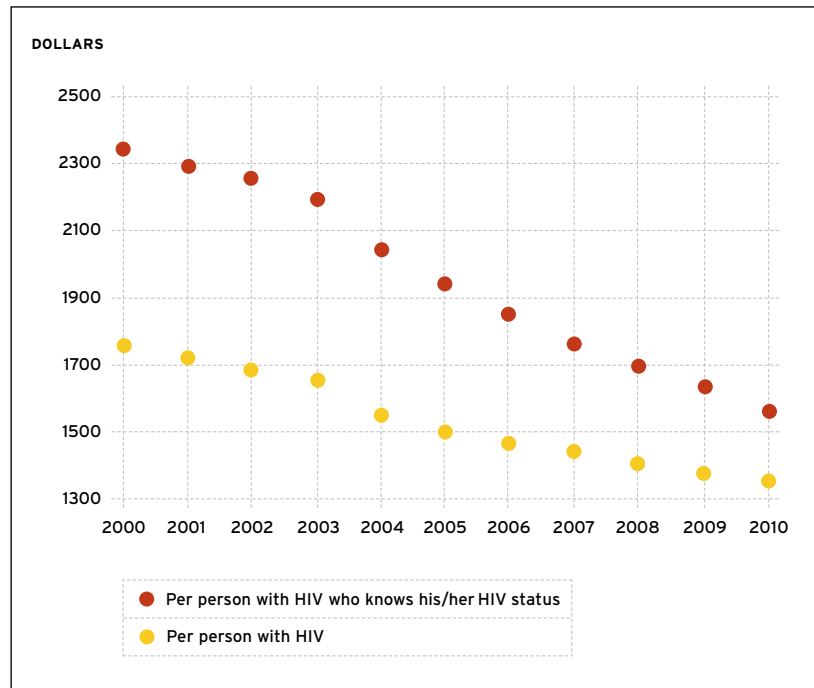
additional adjustment for the percent of people with HIV who know their HIV status.

IF HIV RESOURCES CONTINUE TO DECLINE OR REMAIN STATIC IN THE FACE OF CONTINUING CASE INCREASES, HOW WILL WE EFFECTIVELY ALLOCATE THE RESOURCES THAT ARE AVAILABLE? WILL FUNDS BE ALLOCATED TO MEDICAL CARE AT THE EXPENSE OF SUPPORT SERVICES?

Most experts agree that the numbers of individuals living with HIV disease will continue to grow even if the ongoing rate of seroconversions remains stable or even declines. HIV-infected individuals are living longer – at least for the time being – which means that instead of needing a few years of clinical care, most HIV-positive

individuals now have a lifetime of needs. This is a situation that the original HIV care system was not set up to handle.

RYAN WHITE CARE ACT FUNDING PER CALIFORNIAN



Added to this is the fact that many outreach programs are striving to identify as many HIV-positive people as possible over the coming years. This will address the need for people to know their serostatus and to seek treatment and support, which all interviewees agree is the right thing to do. However, this could also have the effect of overwhelming the care system and creating difficult choices for providers.

Many people at risk of and suffering from HIV have other health and social problems, some of which make it difficult to comply with drug regimens. Homelessness is certainly one of these. HIV stigma and homophobia – especially in communities of color – is another. Many also have substance abuse or mental health issues, or other diagnoses that require long-term treatment.

Nearly all interview participants are deeply concerned about the current and pending economic crisis and the painful choices facing providers and program managers. Rationing of HIV and AIDS services, if not already here implicitly, is looming explicitly. Many former assumptions about who should get care and how much care each person should get are up for grabs.



If cutbacks are necessary, can they be done in a fair manner, based on rational, moral, and clinically relevant factors? Would it be possible for patients, health care providers, payers and others to get together to identify core services that should, against all odds, be protected from the budget axe? Likewise, are there any ancillary services that can be delayed or shelved without imperiling getting drugs to HIV-positive people who need them?

Most interview participants believe that existing planning bodies are inadequate to address the complex convergence of issues facing the HIV community, and are incapable of making hard decisions on how to best spend limited resources. Unfortunately, interviewees are also strongly divided on how to fix these inadequacies.

Some advocate stronger representation by people living with HIV across all sectors of the epidemic. Others believe that planning bodies should be pared down, or incorporate experts who can reframe the way HIV decisions are

made, such as involving [ARE CURRENT LOCAL AND STATEWIDE HIV PHYSICIANS IN HIV PREVENTION PLANNING, OR INCORPORATING BUSINESS EXPERTS ON RYAN WHITE](#)

Planning Councils. Many also believe we should create new statewide bodies to address HIV care rationing needs.

More significantly, a majority of key informants believe it is time for the HIV world to reach outside its own limited domain in order to incorporate and integrate specialists in areas such as mental health, chronic disease, housing, and substance use. One respondent compared working in HIV to being in a “silo” in which HIV providers only work with other HIV providers, and do not turn their

attention to the outside world, or reach out to other providers to form alliances or share resources.

If we do not develop systems for confronting the future of the epidemic in an honest, “hard-nosed” fashion, we may risk losing the model system we have created. And that would be a loss not only for HIV, but for the entire U.S. health care system.

FUNDING AIDS MEDICATIONS AND TREATMENT

Virtually everyone fears the coming stresses on the AIDS Drug Assistance Program (ADAP), the state-managed program that provides drugs for the uninsured. In California, an estimated 26,000 people depend on ADAP and the more than 150 drugs in its formulary for survival. The program was funded at \$212.6 million in fiscal year 2003-2004. If estimates hold for the next budget cycle, a shortfall of \$40 - \$50 million for California is possible, particularly given rising caseloads.

According to some key informants, ADAP was lucky to be funded at the level it was in 2003. Governor Davis had proposed major co-payments on the magnitude of \$30 to \$50 per prescription per month, which could have cost an average ADAP consumer – most of whom make under \$17,000 a year – \$300 a month or more. This would have forced people with HIV to choose between medications and other essentials such as food or housing, and would have led many to forego medications, in turn leading to faster progression to AIDS. As it was, policymakers were forced to make a “Sophie’s Choice” last year by cutting viral load and resistance testing coverage, rather than drug coverage, and hoping that people would be able to get their viral load testing elsewhere.

Unfortunately, the number of people with HIV keeps increasing, and because a large percentage of these individuals live on low incomes,

ADAP enrollments grow significantly every year. However, the state will be facing a budget deficit next year in the billions of dollars. At the same time, there is a wide gap between the level of funding available for ADAP and the steadily growing need. Nationally, it has been estimated that at least an additional \$300 million is needed from the federal government to ensure that ADAPs across the country can appropriately provide treatment. But the federal government's contribution to ADAP nationwide for fiscal year 2004 increased by only \$35 million.

Advocates also hope that ADAP can be maintained without undue resort to co-payments, limitations on monthly prescriptions, reductions in the numbers and types of drugs on the formulary, or the creation of waiting lists. Given nationwide state budget crises, all of these measures have been tried in other states. At last count, 15 states had ADAP waiting lists, and on a few occasions, patients have died while waiting to receive HIV medications.

Several key informants pointed to successful efforts to preserve ADAP programs at current levels without waiting lists, and without imposing co-payments. A few months ago, ADAP programs in the largest states (California, plus Florida, Maryland, Massachusetts, New Jersey, New York, North Carolina, and Texas) negotiated \$65 million in price reductions from eight AIDS drug makers. So far, it seems that at least in California, creative one-time solutions are saving the day and keeping the wolves at bay. Directors of state ADAP programs are continuing to seek reductions in drug costs and to develop strategies to enhance their purchasing power.

Most observers predict growing pressures on ADAP. However, there appears to be a new willingness to explore hitherto unmentionable

solutions, such as co-payments, tighter means testing, and formulary limits, which could have the end result of saving the program.

EMERGING ISSUES IN HIV PREVENTION

HIV prevention can be a hard sell. The benefits of disease prevention programs are not always as compelling or dramatic as interventions to treat the sick and lengthen people's lives. After all, if HIV prevention works, nothing happens – infections are averted and statistical lives are saved. Yet respondents are certain that prevention programs are having a decisive impact, and that the epidemic would be much worse without their presence.

In some ways, with the advent of antiretroviral drugs, treatment became easier and prevention more difficult. At least in the developed world, an HIV diagnosis is no longer necessarily a death sentence. Antiretroviral drugs are helping to extend lives and improve the quality of life, at least for those who can gain access to them. As a result, the fear of contracting HIV may not be as palpable as it was a decade or more ago, when the virus decimated a generation of gay men, injection drug users, and their sexual partners and children.

WITH LIMITED RESOURCES,
WHAT KINDS OF SOCIAL
MARKETING EFFORTS CAN WE
UTILIZE TO OVERCOME THE
DEVASTATING STIGMA AGAINST
BOTH HIV AND THE BEHAVIORS
THAT TRANSMIT IT?

Many interview participants underscored the difficulties of carrying out HIV prevention in a political climate often hostile to those at risk of HIV. Prevention programs dealing directly with sexuality, especially where homosexuals and young people are involved, are constantly tripped up in political controversies and culture wars. However, California has been fortunate to

create an environment that is less hostile to HIV prevention than that created by the federal government. Strong laws are on the books in California, for example, that permit comprehensive sex education in schools – an HIV prevention advantage that many states do not share.

Technology and changing social relationships pose even greater challenges. Interviewees were mixed on whether Internet ‘hook-ups’ and dating – which can greatly increase the speed and frequency of MSM encounters – pose a new kind of challenge, with some saying the fear of these new phenomena is overblown if they are considered a natural extension of bars and bathhouses.

But others say the difference is not one of style or degree, but really one of kind – a change in the way relationships are organized that promotes mixing across lines of race, culture, age and serostatus that otherwise might not occur, while allowing for a greater frequency of sexual encounters. Experts expressed concern about the mix of speed, Viagra, and Ecstasy and other party drugs and their impact on risk behavior and safer sex resolve.

California’s proportion of HIV infections attributed to injection drug use and the sharing of contaminated equipment is significantly lower than other parts of the country. Experts interviewed [HOW CAN WE CONTINUE TO ENSURE CALIFORNIA’S SUCCESS IN DRAMATICALLY SLOWING THE HIV EPIDEMIC AMONG INJECTION DRUG USERS?](#) attributed some of this disparity to the success of syringe exchange programs throughout California.

Key informants applauded syringe exchange efforts, but warned they continue to operate with fragile legal underpinnings. Not all California localities have embraced syringe exchange. A recent report by Human Rights Watch reviewing approaches to syringe exchange in seven

California counties alleges “cases of drug users being arrested, harassed, searched, and otherwise penalized based on possession of sterile syringes and other items obtained at legal syringe exchange programs.”

HOW CAN WE BETTER MOBILIZE RESPONSES AGAINST HIV WITHIN CALIFORNIA'S IMMIGRANT COMMUNITIES? Current California law permits needle exchange programs, but they may operate only under temporary emergency permits that must be renewed by county decision every 14-21 days. Ten California counties, as well as the cities of Los Angeles and Oakland, have declared, and continually renew, these states of health emergency measures to authorize local needle exchange programs.

Many interviewees are concerned about impending rises in HIV cases among California's impoverished illegal immigrant populations, many of whom are not reached by traditional HIV prevention messages, and do not access the health care system. Frequencies of unprotected sexual encounters with prostitutes and among men may pose a significant challenge among these groups. Meanwhile, along the Mexico-California border, there are indications that increasing rates of prostitution and substance use – particularly among young men – are contributing to an impending HIV transmission crisis.

HIV caseloads also continue to rise dramatically among women as a percentage of the overall HIV-infected population. Between 1992 and 2002, new AIDS cases among women increased from 7% of the total

HOW CAN WE INFUSE THE FIELD OF WOMEN'S HEALTH WITH A GREATER EMPHASIS ON THE GROWING HIV CRISIS AMONG WOMEN OF ALL ETHNICITIES? AIDS-diagnosed population to 14%. Many of these cases are attributable to male injection-drug users who pass the virus on to their partners, and to men who identify themselves as

heterosexual but who have secret or undisclosed sex with other men.

The increasing emphasis on providing HIV prevention support to people already living with HIV in order to help curb the spread of the virus also continues to challenge the HIV community. Since every case of HIV infection involves at least one person who already has the virus, many believe that prevention with positives is a cost-effective and impactful prevention approach. However,

many of our interviewees fear that an increasing emphasis on prevention with positives will draw dollars away from HIV prevention for at-risk populations – programs already under

DOES THE GROWING ‘MEDICALIZATION’ OF HIV PREVENTION THREATEN HIV PREVENTION AS WE KNOW IT?

siege due to budget cuts. Others believe we do not yet have the tools to effectively conduct wide-scale prevention with positives interventions, while others are concerned that HIV prevention is beginning to become the province of HIV care providers, rather than experienced prevention agencies.

The following sections describe additional emerging challenges that are already influencing the future of HIV prevention in California.

THE EMERGENCE OF RAPID TESTING

Most HIV testing in the U.S. has involved an initial blood draw with results delivered at a counseling session in one or two weeks. This delay has proved costly in both personal and public health terms. According to the CDC, between 850,000 and 950,000 individuals in the U.S. are infected with HIV, but as many as 300,000 of them do not yet know it. At the same time, the CDC estimates that between 20% and 30% of

people who undergo HIV testing nationwide do not return to receive their test result.

It is easy to see, then, why one of the most eagerly anticipated developments in HIV prevention is the rapid test. A rapid HIV test, which offers 99.6% accurate results within twenty minutes, was licensed for use in the U.S. in November 2002.

In 2003, the Bush administration committed to making rapid HIV testing available in 100,000 clinics and doctors' offices nationwide.

Officials hope that by making instant tests available in a wider variety of settings, including STD clinics and bathhouses, they can close the gap between the number of people who are infected with HIV and those who know their status.

WITH EFFECTIVE MEDICATIONS NOW AVAILABLE TO TREAT HIV, WHY DO SO MANY PEOPLE WHO KNOW THEY ARE AT RISK STILL AVOID BEING TESTED FOR HIV?

people who are infected with HIV and those who know their status.

In California, the test has been available in at least nine jurisdictions since January 2004, and officials expect the test will become available statewide by the summer of 2004. Prevention advocates are eager to see rapid testing offered in settings where those at high risk congregate, in hospitals and clinics to supplement laboratory-based testing, and in settings not reached previously.

That said, however, there are legitimate concerns related to the rapid test, most involving disclosure of positive test results. Many prevention specialists fear that the short timeframe of the test does not give people adequate time to prepare for a positive test result. This means that immediate and extensive counseling is required to guide people through their emotional reactions and ensure that they are linked to service and support programs. In some settings, this protocol can

average as long as three hours. Such steps make it difficult to imagine rapid testing being easily implemented on the street or in clubs, as some have suggested.

THE METHAMPHETAMINE EPIDEMIC

Methamphetamines such as speed and crystal trigger the release of dopamine and norepinephrine, resulting in euphoria, increased energy, confidence, and libido. Many interviewees are concerned that methamphetamine is increasingly being used by gay and non-gay identified men who have sex with men (MSM) who frequent venues that facilitate sexual behavior, such as bars, sex clubs, and circuit parties. The ease of making “party and play (PNP)” connections over the Internet – a code term for sexual encounters involving meth – is also believed by some to be fueling this epidemic, particularly among young gay men. Because methamphetamine can cause erectile problems, users sometimes mix it with Viagra, which can be ground down and snorted for a more direct effect.

WILL METHAMPHETAMINE USE INCREASE THE SPREAD OF DRUG-RESISTANT HIV STRAINS?

There is an increasingly alarming association being drawn between methamphetamine use and the spread of HIV. For example:

- A study conducted in San Francisco in 2002 estimated that about 30% of those who recently became infected with HIV had used methamphetamines during the previous six months.
- In a California study of over 63,000 gay men and other MSM tested for HIV, 7.1% of HIV-positive individuals were methamphetamine users, while only 3.7% were HIV-positive non-methamphetamine users.
- In a San Diego study of 25 HIV-positive MSM using methamphetamine,

80% reported engaging in marathon sex while under its influence, and 93% of these individuals reported engaging in receptive anal sex without a condom.

- A recent study in New York City found that MSM who use methamphetamines are 2.9 times more likely to contract HIV through receptive anal intercourse than MSM who do not use the drug, and are more likely to contract drug-resistant strains of HIV than non-methamphetamine users.

Emerging findings in the literature also point to rising HIV risk related to the use of Viagra, especially in combination with methamphetamines. Twenty-three percent of those responding to a recent San Francisco study of MSM, for example, said that they combined Viagra use with methamphetamines. Other studies have demonstrated a strong association between high-risk sexual behavior and Viagra use, especially among MSM who seek services through sexually transmitted disease clinics or who attend circuit parties.

The methamphetamine epidemic may be particularly dangerous because meth is such a hard drug to kick. Key informants noted that achieving sobriety from meth is a long, hard climb that most of those addicted fail to complete on their second or even third try. Once an individual is infected with HIV as a result of meth-influenced behavior, he may also feel there is no reason to fight to stay sober. Continued methamphetamine use by people living with HIV may hasten the progression to later-stage infection and AIDS.

PRE-EXPOSURE PROPHYLAXIS

Could the same drugs used to treat HIV infection also help prevent the spread of HIV?

What if a small dose of one of the currently available antiretroviral treatment drugs taken daily or weekly could prevent infection in individuals who are exposed to HIV disease? Would such a prevention strategy be: possible? ethical? practical? politically feasible? cost-effective?

The strategy is known as “pre-exposure prophylaxis,” or PREP. Some researchers have begun to suggest that PREP is an approach to prevention that just might work, being especially useful for individuals at very high risk for HIV over limited periods of time. PREP could be used as part of a substance abuse rehabilitation program, in conjunction with a vaccination program, during periods of commercial sexual activity, or during periods of sexual activity with known sexual partners. Resorting to PREP could be particularly useful for populations in which behavioral interventions have had limited success.

HIV prevention has long been hampered by the lack of a female-controlled HIV prevention method. Women need an HIV prevention strategy that, unlike the male condom, does not require the cooperation – or even awareness – of their male partners. Research into microbicides has been proceeding along these lines, but in fits and starts. This in part explains the turn to PREP.

Studies of PREP bring into sharp relief inherent ethical tensions. HIV is spread, after all, by unprotected sex and unsafe drug use. HIV prevention issues are inextricably linked with sex and substance abuse, meaning they are seldom easy, straightforward, or devoid of controversy. PREP is certain to come in for criticism in that its use could abet irresponsible or in some cases illegal behavior.

Still, if PREP holds even some of the promise researchers claim it might, it seems it should be studied both faster and more deliberately. The few published reports to date hint only a bit at how controversial PREP might become.

CONFRONTING THE FUTURE: **POTENTIAL STRATEGIES**

If the future demands a response, strategies are needed to shape it. Our key informants offered many novel approaches to the challenges ahead. These included the following:

- It is critical that the HIV system continues working toward the goal of a single payer health care system for America. Only through a universal system of healthcare access can we secure the long-term right and ability of people with HIV to fully access care and treatment.
- Developing new approaches to cost containment and service rationing is critical for ensuring the future of HIV care. Many cost saving approaches are already being implemented, such as negotiating price reductions with pharmaceutical companies in the case of ADAP. Public and private agencies across California should aggressively pursue cost containment and service allocation activities in order to ensure the continuation of the existing system of care.
- Expanded support is urgently needed for increased advocacy efforts to help maintain and increase state and federal HIV funding. This includes developing new advocates and policy specialists who represent communities of color – including gay men of color – and women, and expanding support by private foundations for advocacy efforts.
- Prevention programs are critical to address the growing HIV epidemic among young people, especially young gay men of color, women, and immigrant communities in California. Such programs must be culturally and developmentally competent, and offer effective empowerment options that help people take responsibility for their own HIV risk.

- Allowing injection drug users to buy sterile needles in drugstores is an approach that has worked in Connecticut and that could be successful in California. In October 2003, Governor Davis vetoed SB 774, which would have allowed Californians to purchase syringes at pharmacies without a prescription, citing arguments from opponents saying that expanded syringe exchange would result in increased drug use and crime. In fact, in the year following implementation of the Connecticut law, needle sharing among injection drug users dropped by 40%. Numerous studies show that syringe exchange programs do not lead to increasing crime rates.
- Key informants suggested that one approach to addressing the weakness of the current HIV planning system would be to bring representatives from other fields to the table, such as drug and alcohol service providers, mental health specialists, and even business consultants with expertise in budgeting, strategic planning, and marketing.
- In order to strategize a response to the future of HIV, some interviewees suggested a week-long statewide planning summit that would bring together the “best and the brightest” minds working in HIV prevention and care in order to plot a course addressing multiple future scenarios. Another suggested approach is to convene a series of two-day meetings to expand networking opportunities and conduct joint problem solving. Participants in these sessions would consist of staff and stakeholders from throughout the state, including, for example, representatives of the state’s eight Title I EMAs; representatives of non-Title I counties; and Co-Chairs of Ryan White Planning Councils and HIV Prevention Planning Councils.

- Many key informants believe that private foundations underestimate how hard it is to establish and start-up new organizations, particularly in minority communities. Extended, multi-year support by foundations for organizational capacity building, rather than one to two years of support for new programs only, would help newer agencies serving hard-hit populations thrive and grow.
- The nascent but growing gay men’s health movement seeks to address the plethora of wellness-related issues facing men who have sex with men in an integrated manner. This includes, for example, linking HIV prevention and care to programs that build self-esteem and combat internalized homophobia, or that address substance use and mental health issues. Harnessing a focus on the broader issue of gay men’s wellness could help reinvigorate portions of the gay community to rejoin the fight to fund HIV care and prevention.
- Many individuals do not seek HIV testing and care because of the stigma attached to HIV and its risk behaviors. Others have an historical mistrust of the medical system. One strategy to help overcome these barriers is to incorporate HIV prevention, testing, and care into larger interdisciplinary wellness programs, rather than focus on HIV directly.
- Because the HIV epidemic in California counties that border Mexico is linked with the HIV epidemic in Baja California, cross-border HIV prevention efforts should be significantly enhanced and strengthened, particularly between California’s Imperial and San Diego Counties and the Mexican cities of Tijuana and Mexicali.
- A statewide coalition of HIV prevention stakeholders could work together to create a common agenda and advocacy strategy, and to support prevention advocacy work on a statewide basis.

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On the following page is a list of the individuals who were interviewed for this report.

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ABOUT AIDS PARTNERSHIP CALIFORNIA

AIDS Partnership California (APC) is a statewide public/private collaboration that includes private foundations, corporate funders, and the State Office of AIDS, plus a strategic alliance with CompassPoint Nonprofit Services. Through grantmaking, convening, training, and the dissemination of findings, APC supports the development of a system of HIV prevention for Californians of color with HIV; strengthens the capacity of community organizations to provide HIV services; advances research on the future of the HIV epidemic in California; increases the effectiveness of HIV public and private grantmaking; and supports efforts to shape California's HIV/AIDS-related public policy. Together, these activities aim to help arrest the escalating rate of HIV in California, inform sound policy decisions, and strengthen the system of HIV care and treatment. This work benefits persons with HIV or at risk for HIV, community-based organizations providing HIV services, health departments, and foundations.

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A note about the timeline

The attached timeline charts two different histories of HIV. The portion of the timeline that runs from 1981 to the present charts key milestones in the first 23 years of our battle with AIDS in California. Beginning in mid-2004, the timeline changes course, depicting two series of contrasting events, one a more optimistic view of the future of HIV, and the other a more pessimistic view. All of these future events are hypothetical. At any time, a new medical discovery, a significant shift in the economy, or a new political climate could dramatically alter the sample events we present.

Dr. Alvin Friedman-Klein in New York notices a rare cancer, Kaposi's sarcoma, in two young gay men and speaks to physicians at UCSF who have seen a similar case

In May, a *New York Times* article announces a "Rare Cancer Seen in 41 Homosexuals"

In June, the Federal Centers for Disease Control (CDC) reports the first case of the illness that will be known as AIDS

By the end of the year, 152 AIDS cases and 128 AIDS deaths have been reported in the U.S.

The CDC warns blood banks of a possible AIDS-related problem with the U.S. blood supply

The Denver Principles articulate for the first time the ethos of the people with AIDS (PWA) self-empowerment movement

AIDS Project East Bay - the first HIV care and prevention agency in Alameda County - is founded as a program of the Pacific Center for Human Growth in Berkeley

4156 AIDS cases and 1,503 AIDS deaths reported so far in the U.S.

The FDA approves the first HIV antibody test; the California legislature subsequently passes a law guaranteeing the confidentiality of HIV testing in that state that is eventually adopted nationwide

A national poll shows that 72% of Americans favor mandatory testing; AIDS activists demand more aggressive battles for those infected with HIV

On July 25, Reck Hudson discloses he has AIDS, focusing unprecedented national attention on the epidemic

20,470 AIDS cases and 8,161 AIDS deaths reported so far in the U.S.

In February, the AIDS Coalition to Unleash Power (ACT UP) is founded to end the AIDS crisis through direct, confrontational political action

In March, Zidovudine (AZT), the first drug approved to fight HIV itself, is marketed for use by people with AIDS; the ACT is the most expensive drug in history

On May 31, President Ronald Reagan mentions AIDS for the first time in public; later that year, Vice President George Bush calls for mandatory HIV testing

59,572 AIDS cases and 27,909 AIDS deaths reported so far in the U.S.

Under pressure from the AIDS community, AZT manufacturer Burroughs Wellcome lowers the price of the drug by 20%

The Helms Amendment is passed, barring the federal government from funding research that is seen as promoting homosexual activity; directors of dozens of AIDS organizations arrested in civil disobedience at White House

Bienestar, the first freestanding organization in California specifically responding to the HIV crisis within Latino/Hispanic communities, is founded in Los Angeles

115,786 AIDS cases and 70,313 AIDS deaths reported so far in the U.S. - more Americans than died in the Vietnam War

Former L.A. Laker Earvin "Magic" Johnson announces that he has tested positive for HIV during a routine physical examination, and is retiring from basketball

399,250 AIDS cases and 194,354 AIDS deaths reported so far in the U.S.; AIDS has become the leading cause of death for young adults in 64 U.S. cities

The CDC expands the definition of AIDS to reflect the wider spectrum of the disease, in part by adding conditions specific to people with HIV; the change adds significant numbers of AIDS-diagnosed individuals to the national case load

A federal government study concludes that giving clean needles to injection drug users helps prevent the spread of AIDS

519,486 AIDS cases and 264,796 AIDS deaths reported so far in the U.S.; HIV has become the leading cause of death for men between the ages of 25 and 44

In June, Saquinavir (Invirase), manufactured by Hoffmann-La Roche, becomes the first drug to be approved for use outside of clinical trials; the drug's release marks the beginning of effective combination treatments for HIV

President Clinton establishes the first Presidential Advisory Council on HIV/AIDS and hosts the first White House Summit on AIDS

677,434 AIDS cases and 413,090 AIDS deaths reported so far in the U.S. - more Americans than died in World War II

1981

1982

1983

1984

1985

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1997

30 YEARS OF AIDS IN THE U.S.

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2006

2008

In April, the Kaposi's Research and Education Foundation - the organization that will become the San Francisco AIDS Foundation in 1984 - is founded in San Francisco

In September, the illness doctors are calling GRID (Gay-Related Immune Deficiency) is officially named Acquired Immunity Deficiency Syndrome (AIDS) by the CDC

In October, the organization that will become AIDS Project Los Angeles is founded at the Los Angeles Gay and Lesbian Community Services Center

1,300 AIDS cases and 460 AIDS deaths reported so far in the U.S.

AIDS is identified as being caused by a human retrovirus named HTLV-III, later renamed HIV

San Francisco closes all gay bathhouses in the city

9,920 AIDS cases and 3,498 AIDS deaths reported so far in the U.S.

Rep. William Danneberg places a mandatory AIDS testing initiative on the California ballot while Lyndon LaRouche places an anti-AIDS initiative on the California ballot for the second time; both initiatives are defeated

The U.S. bans discrimination against federal workers with HIV, and mails 107 letters to households throughout America

Largely as a result of the work of AIDS activists, the Food and Drug Administration approves the first drug used to make promising therapies available sooner for patients with life-threatening and severely debilitating diseases

The World Health Organization declares December 1 World AIDS Day

In April, 18-year-old Ryan White succumbs to complications from AIDS outside the Republican Convention; in May, the Ryan White CARE Act is passed, authorizing \$881 million in emergency relief to 16 cities devastated by the epidemic; however, Congress appropriates less than \$350 million

In November, Bill Clinton is elected 42nd President of the United States, promising full-scale health care reform, positive immigrants, full funding of the Ryan White CARE Act, a new AIDS "czar," and targeted and honest HIV prevention

Ronald Reagan apologizes for his neglect of the epidemic while he was President

In August, AIDS activists are cordoned off and beaten by police as they protest outside the Republican Convention; in August 8, the FDA approves new labeling for AZT to include use in preventing vertical transmission of HIV from infected mothers to their infants

On December 23, the FDA approves GrSure, the first non-blood-based collection kit utilizing oral fluid for use in the detection of HIV antibodies

Pedro Zamora of MTV's "The Real World" emerges as a new voice for people with HIV on television

On August 8, the FDA approves new labeling for AZT to include use in preventing vertical transmission of HIV from infected mothers to their infants

On December 23, the FDA approves GrSure, the first non-blood-based collection kit utilizing oral fluid for use in the detection of HIV antibodies

In May, the FDA approves the first HIV home testing system that can be purchased over the counter

In June, the first test measuring HIV viral load is approved

In June, Saquinavir (Invirase), manufactured by Hoffmann-La Roche, becomes the first drug to be approved for use outside of clinical trials; the drug's release marks the beginning of effective combination treatments for HIV

President Clinton establishes the first Presidential Advisory Council on HIV/AIDS and hosts the first White House Summit on AIDS

677,434 AIDS cases and 413,090 AIDS deaths reported so far in the U.S. - more Americans than died in World War II

On February 7, the first National Black HIV/AIDS Awareness and Information Day is held, spotlighting the ongoing crisis of HIV within African-American communities

President Bush contributes \$200 million to the global AIDS fund; advocates note that the United Nations estimates that \$7 - \$10 billion is needed annually to fight HIV in the developing world

Attacks on the World Trade Center and Pentagon on September 11th draw focus of U.S. emergency and health systems to the development of responses to terrorist attacks

844,439 AIDS cases and 485,298 AIDS deaths reported so far in the U.S.; more than 20 million people have died of AIDS worldwide, including more than 75,000 Californians

On October 15, the First National Latino AIDS Awareness Day is held, highlighting nationwide events highlighting the growing HIV epidemic among Hispanic populations

In December, the New York City Department of Health announces that women now account for more than a third of all new HIV diagnoses in the city

930,904 AIDS cases and 516,719 AIDS deaths reported so far in the U.S.

By the end of the year, at least 2,100 low-income individuals are reached through increased HIV outreach and testing programs - are awaiting admission to the state's General Assistance Program

Fourteen HIV agencies throughout California have been forced to close their doors over the past 24 months due to escalating costs and decreasing levels of support

National demonstrations from the White House to condemn the use of pre-exposure prophylaxis (PREP) and any behavior-based interventions that do not stress abstinence

California hospital emergency rooms begin reporting unusually high numbers of persons admitted with advanced pneumocystis pneumonia

1,525,973 AIDS cases and 734,691 AIDS deaths in the U.S. - many more Americans than died in the Revolutionary War, World War I, World War II, the Korean War, the Vietnam War, or the Gulf War combined

1999 2001 2003

In June, African-American leaders in Alameda County declare AIDS "State of Emergency" within the African-American community; the first proclamation of its kind in the U.S.; the declaration provides impetus for Minority AIDS Initiative later that year

The CDC announces that the AIDS death rate has dropped an incredible 46% since 1995

rate of new HIV infections - 40,000 a year - does not appear to be decreasing

Among gay and bisexual men, new AIDS diagnoses in the U.S. among African-American and Latino men exceed that of white men for the first time

In March, Los Angeles County officials report that they have discovered 23 cases in gay men after discovering 23 cases in six weeks; because of a strong, rapid response, the outbreak is declared contained by June 7

The first large-scale study of HIV infection among young gay men in New York City finds that large numbers have become infected with HIV over the past two years

African-American men with the six highest rates of HIV infection are 18.4%

803,212 cases and 467,896 AIDS deaths reported so far in the U.S.

On July 1, non-needle-based HIV reporting begins in California; counties must collect and report all cases of HIV infection using unique identifiers. California is one of the last states to adopt an HIV reporting system

On November 7, the FDA approves a new rapid HIV testing device, OraQuick, a test that is easy to use and that produces reliable results in 20 minutes; the device is required to be administered by certified health care workers

During fiscal year 2001-2002, California's HIV/AIDS program, established in 1987, provides over 688,580 prescriptions for nearly 24,000 low-income individuals throughout the state

In January, a CDC analysis of new HIV infections in 23 states that have needle-based HIV reporting - not including New York and California - finds that 35% of new HIV infections between 1999 and 2002 resulted from heterosexual sex, of which 14% were women and 14% were African-American

In March, seven of nine federally-funded Ryan White Title I regions in California receive additional funding for HIV care and services

By the end of the year, the availability of HIV rapid testing expands throughout California

1998 2000 2002 2004

WHAT EVENTS COULD WE SEE IN THE FUTURE?

2005 2006 2007 2008 2009 2010

The President signs the Early Treatment of HIV Act; California takes action to add this coverage to the state Medi-Cal program, greatly expanding the number of persons with HIV

The FDA approves the first pre-exposure prophylaxis (PREP) medication, a version of Viread which has shown to be over 90% effective in preventing HIV infection in high-risk persons; the drug appears to have only minor side effects

The first large-scale demonstrations demanding increased access to AIDS care in nearly 15 years take place in cities throughout California, and helping shift public opinion toward support of expanded HIV funding

The Governor signs the Health Equity Act, expanding health care coverage to all Californians

Emerging data suggests that the rate of new annual HIV infections in California has been reduced by nearly 50% since June 2000; pre-active HIV treatment and expanded access to health care are cited as reasons for the shift

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QUESTIONS AT THE
Crossroads:

Surviving the Third Decade of HIV in California

How can we alert people to the magnitude of the epidemic? What can we do about the stigma of AIDS? Why do so many people at risk for HIV avoid being tested? How can we best address the HIV epidemic among women and young people? Why is it so hard to talk about AIDS among gay black and Latino men, or to mobilize AIDS leadership in communities of color? Why do individuals continue to become infected at rates sufficient to fuel an unabated epidemic in the U.S.? How can this be explained when the knowledge of how to avoid infection exists, along with many resources to help take advantage of such understanding?

Some ponder the problem of targeting finite resources to confront the epidemic. What are the fault lines between prevention and care? Are the most promising prevention strategies to be found in behavior change or in scientific developments that may soon allow individuals to take a daily pill to prevent HIV transmission? How much should our focus be exclusively on HIV, and how much on related concerns, such as STDs, substance use, mental health, poverty, or homelessness? And most persistently, how can we save AIDS funding?

AIDS Partnership California