

HIV/AIDS Advocacy

How To Make A Difference in Four Easy Steps

By Paul Lovely, Editor

You've got a lot going on in your life. Today you have a doctor's appointment, there are errands to run, the house is a mess and you've got bills to pay. You know that times are tough for AIDS service organizations. Many have closed their doors, and the ones that are still open are trying to do more with fewer resources. Of

course you care about HIV, but with everything going on in your own life, how can you keep up with what's going on with ADAP

funding, health care reform or the latest California budget crisis? And even if you did have all the facts, you wonder how you can possibly make a difference with the small amount of time you've got to spare.

Your voice is a powerful force. In ways large and small, concerned individuals have a critical role to play in shaping America's

continued response to HIV/AIDS.

Step One: Get Informed

Groups in Washington DC, California and elsewhere in the country monitor Congress, state legislatures and other government offices on HIV-related issues. By joining one or more of these groups, you can keep up to date on national, state and local AIDS advocacy

Advocacy n. the act of arguing in favor of a particular issue, idea or person. Advocacy may aim to influence public policy and encourage social change.

issues. Registration is as simple as going to their website and signing up for updates and "Action Alerts."

Here are a few important organizations:

• **Project Inform:** www.projectinform.org (under ".policy/activism" tab, click on "Join PI Action").

• **AIDS Project Los Angeles:** www.apla.org (in policy and advocacy section, join "In The Loop," to stay informed of advocacy campaigns at every level of government).

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The Early Years of AIDS Action

By Bob Pond, Staff Columnist

I had heard of the "Gay Cancer" in New York, but it was far away, and I didn't pay much attention to the reports. Then

in 1984, I lost my first friend to AIDS, though his funeral service didn't mention he was gay, let alone had died from AIDS. That was closer to home. It still felt surreal until a night in 1986 when my partner, Jeff, was awakened by my groans at what I would discover was a gall bladder attack. His 911 call brought the paramedics. They took one look at our matching caftans and immediately put

on two face-masks and three pairs of gloves. They wanted me to walk downstairs so I wouldn't sully their gurney, even though I couldn't stand up. It was my first real taste of

AIDS discrimination. Now it hit home.

But the wheels of the pioneering AIDS activists were already turning...



1981: Gay Men's Health Crisis

Gay Men's Health Crisis (GMHC) began when a group of Gay men gathered at the home of controversial Gay author Larry Kramer. Frustrated by the epidemic being ignored by health officials, all the way to the Reagan White House, they decided it was time for action. Kramer and his friends

formed the GMHC as a formal tax-exempt entity. It was the largest volunteer AIDS organization in the world at that time. They

(See AIDS Action on page 6)

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C.A.R.E.
PROGRAM

People Who CARE

THE C.A.R.E. PROGRAM AND CLINICS ARE AFFILIATED WITH ST. MARY MEDICAL CENTER

Contact Information For Elected Officials

By David Challié, Staff Columnist

President

• **President Barack Obama (D)**
The White House
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Comment Line: (202) 456-1111

Congress

• **Senator Diane Feinstein (D)**
331 Hart Senate Office Building
Washington, DC 20510-0504
Phone: (202) 224-3841
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<http://www.feinstein.senate.gov>
Local Office:

11111 Santa Monica Blvd., #915
Los Angeles, CA 90025
Phone: (310) 914-7300
Fax: (310) 914-7318

• **Senator Barbara Boxer (D)**
112 Hart Senate Office Building,
Washington, DC 20510-0505
Phone: (202) 224-3553
Fax: (202) 224-0454
<http://boxer.senate.gov>
Local Office:

312 North Spring St., Suite 1748
Los Angeles, CA 90012
Phone: (213) 894-5000
Fax: (202) 224-0357

• **Representative Dana Rohrabacher (R, 46th)**
District including Huntington Beach, Costa Mesa, Fountain Valley, Seal Beach, Avalon, Rancho Palos Verdes, Rolling Hills, Palos Verdes Estates, Rolling Hills Estates and portions of Long Beach, Westminster, Santa Ana and San Pedro.)
2300 Rayburn House Office Bldg.
Washington, DC 20515-0546
<http://rohrbacher.house.gov>
Phone: (202) 225-2415
Fax: (202) 225-0145

• **Representative Linda Sanchez (D, 39th)**
District including Artesia, Cerritos, Hawaiian Gardens, Lakewood, La Mirada, Lynwood, Paramount, and South Gate, a large part of Whittier, small parts of Long Beach and Los Angeles, and parts of unincorporated Los Angeles County.)
1222 Longworth Building
Washington, DC 20515
Phone (202) 225-6676
Fax (202) 226-1012
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Cerritos, CA 90703
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Fax (562) 924-2914

• **Representative Laura Richardson (D, 37th)**
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1725 Longworth House Office Washington, DC 20515
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100 W. Broadway □
West Tower, Suite 600
Long Beach, CA 90802
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• **Representative Jan Harman (D, 36th)**
District including Lomita, West Carson, Harborside Beach, Redondo Beach, Manhattan Beach, El Segundo, San Pedro, Venice, Torrance, Wilmington)
2400 Rayburn House Office Bldg.
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Phone: (202) 225 8220
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The State of California

• **Governor Arnold Schwarzenegger (R)**
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Sacramento, CA 95814
Phone: (916) 445-2841
Fax: (916) 558-3160
<http://gov.ca.gov/>
Local Office:

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Los Angeles, CA 90013
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• **Senator Alan Lowenthal (D, 27th)**
2032 State Capitol
Sacramento, CA 95814
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115 Pine Ave., Suite 430
Long Beach, CA 90802
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The City of Long Beach

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<http://www.longbeach.gov>

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Phone: (562) 570-6801

• **Vice Mayor Val Lerch (District 9)**
district9@longbeach.gov
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Legend

D=Democrat
R=Republican

The Health Care Reform Act: How Will It Affect People Living With HIV/AIDS?

By Project Inform, April 5, 2010

President Obama has signed the Patient Protection and Affordable Care Act (PPACA) and the Health Care Education and Reconciliation Act of 2010 into law. Together they enact an historic health care reform plan, the first major overhaul of the health care system since 1965, when Medicaid and Medicare were put in place. Americans have been debating broad health care reform, of both the public and private sectors, since 1914. The passage of the PPACA is a hard-won victory for the millions of Americans who are uninsured or underinsured, including many living with HIV.

The PPACA is far from perfect and doesn't include all the provisions we fought for to best serve people living with HIV. However, there are some significant victories contained in this law. It also represents a major step forward in broadly expanding affordable and comprehensive health care. Finally this reform begins to create a more coherent system of health care for Americans that we can continue to build upon and further improve through ongoing advocacy efforts.

Following is an initial outline of some of the important provisions of health care reform for people with HIV and other chronic conditions:

Public Insurance (Medicaid and Medicare) Improvements:

- In 2011, states will have the option to expand their Medicaid programs to all people under a certain income (133% Federal Poverty Level (FPL) – FPL increases every year, in 2010 it is \$14,403 for one person and \$29,324 for a family of four). In 2014, Medicaid will be expanded by federal mandate and will cover everyone under 133% FPL, ending the requirement that

people with HIV must get sick before they can qualify for Medicaid.

- In 2010, people who depend on Medicare Part D for their prescription drugs will receive a \$250.00 rebate when they reach the coverage gap (the coverage gap is the time during which people essentially lose coverage and must pay the full cost of their drugs until they have paid several thousand dollars out of their own pocket - most people with HIV reach the gap in the second or third month of the plan year). In 2011, the pharmaceutical industry has to provide a 50% discount on brand name drugs while people are in the coverage gap. By 2020, the coverage gap for Medicare Part D is eliminated.

- In 2011, AIDS Drug Assistance Program (ADAP) payments that are made to Medicare Part D on behalf of HIV positive people who are in the coverage gap will count toward the amount of out-of-pocket spending they must reach to get meaningful prescription coverage under Medicare Part D. This will save money for ADAPs and allow Medicare beneficiaries to gain access to a much more comprehensive formulary of necessary drugs.

Reforms to private health care:

- Within six months, children cannot be denied insurance due to pre-existing conditions. By 2014, adults will no longer be able to be denied for pre-existing conditions. Within six months, adults with pre-existing conditions will be allowed to buy into a temporary national "high-risk" plan that will stay in effect until 2014. Out of pocket costs will be capped under the temporary plan.

- Within six months, young adults can stay on their family plans until age 26.

In 2010, lifetime caps on benefits will be prohibited.

(See Health Care on page 5)



People Who CARE

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All C.A.R.E. clients and staff are invited to send us comments, artwork, poetry, photographs, essays or other writing. Include your name, address, and phone number. All submissions are printed at the discretion of the editor.

People Who CARE is published by the C.A.R.E. Client Advisory Panel. The panel meets from 12pm-1pm on the 2nd Tuesday of each month at St. Mary in the Parr Health Enhancement Center, Bonzer Room. All are welcome.

Letter Writing Tips

By Fred Maldeis,
CARE Client Advisory Committee Member

The CARE Program needs our help to advocate for funds from the State of California. You can help. Short, hand written letters are most likely to be read. Emails are a distant second. You may want to include statements like these:

- 1.) CARE enrolls ADAP recipients and helps clients navigate through benefit systems such as Medicare and Medi-Cal to help us pay for these life saving but expensive medications.
- 2.) CARE has physicians who specialize in HIV/AIDS treatment. They treat many HIV-related illnesses and prescribe complex mixes of medications necessary to keep us alive.
- 3.) St. Mary Medical Center CARE Program is a leader in the fight against the HIV/AIDS epidemic in Long Beach. HIV is an infectious disease and management of the epidemic is good for everyone in our community. Long Beach has among the highest "at risk" populations in the nation.

(Health Care from page 3)

In 2010, insurance companies will no longer be able to take away coverage when someone gets sick.

In 2010, some health plans will be required to cover some preventive services free of cost to their participants.

Improvements to private insurance:

- In 2014, state "exchanges" will be established, allowing individuals and small businesses to purchase coverage; this will effectively end "job-lock", when people can't leave their current job to start a business or new venture because they or a family member won't be able to get insurance.
- In 2014, plans operating in the exchanges will be required to offer several levels of defined benefit packages.

Affordability for individuals and small businesses in the exchanges:

- Individuals who can't afford insurance will get financial help through government subsidies up to 400% of FPL (currently \$43,320 for a single person and \$88,200 for a family of four).
- Expenditures on insurance premiums and out-of-pocket expenses will be capped.
- Small businesses will be helped to purchase and offer insurance through tax credits.
- There are exemptions for individuals and small businesses who still can't afford insurance or who may not qualify.

(Source: Project Inform; projectinform.org)

Other Upcoming Events



**PEER
SUPPORT GROUP**

Wellness education & support
for people living with HIV

3RD TUESDAY OF EACH MONTH

PARR HEALTH ENHANCEMENT CENTER AT ST. MARY
1055 LINDEN AVE, LONG BEACH
GLENN ROOM , 2ND FLOOR

11:00 AM - 1:00 PM

2010 SCHEDULE: JAN. 19, FEB. 16, MAR. 16, APR. 20, MAY 18,
JUN 15, JUL. 20, AUG. 17, SEP. 21, OCT. 19, NOV. 16, DEC. 21

FOR MORE INFO, CALL (562) 624.4963

*SPECIAL THANKS TO LONG BEACH PRIDE AND
MOM'S PHARMACY FOR THEIR GENEROUS SUPPORT*

CARE Client Picnic

Saturday, August 7, 2010

11:00am-2:00pm, Recreation Park
7th St. and Park in Long Beach
Food * Games * Prizes * Fun

Orange County/Long Beach

Strength For The Journey

A Retreat for People Living With HIV/AIDS
Camp Sky Meadows—August 9-13, 2010
For registration information, call or email Ralph
Mayo: (562) 612-0045, ralphmayo2005@yahoo.com

Heterosexual Support Group

Now Forming

For more information, call Sal (714) 715-5645

Beyond Coping Support Group

Meets Tuesdays, 6-7:30pm

For more info, call John Blasco (562) 624-4915

(AIDS Action from page 1)

offered a crisis counseling hot-line, legal aid volunteers, food, transportation, and a “buddy system” to help care for the ill. It was the first to offer services to all people regardless of age, gender, race or sexual orientation.

1982: AIDS Project Los Angeles

AIDS Project Los Angeles (APLA) and San Francisco AIDS Foundation were founded by volunteers, and were similar in scope and function to GMHC. Some services varied, but they offered referrals to community services they could not provide. All three operated outreach programs designed to educate the public as to the known facts about AIDS transmission, and to help prevent, or at least curb, further transmissions by promoting the use of condoms. Through their brochures, billboards (such as Zelda Rubenstein’s famous “Mama cares...Wear your Rubbers!” campaign) and workshops, they helped answer the public’s questions about AIDS transmission. Their efforts helped calm the fears and backlash against Gay men in those early days of panic and misinformation.

1984: Ryan White

Ryan White was in Middle School in Kokomo, Indiana. He was a hemophiliac who contracted AIDS from an HIV-contaminated blood product, Factor VIII. At that time, much of the supply was contaminated because doctors did not know how to test for the disease, and donors didn’t know they were infected. Of hemophiliacs treated with blood-clotting factors between 1979 and 1984, nearly 90% became infected with HIV. After the diagnosis, Ryan presented with 25 T-cells, and doctors gave him six months to live. When his health began to rebound he tried to return to school, but the school refused him admittance. The disease was still little understood as to transmission factors, and the school officials and a vocal group of parents who, fearing that AIDS could be spread by casual contact, kept him away. Ryan worked part-time as a paper-boy, and people cancelled their subscriptions, believing they could get HIV from the newsprint. His parents engaged in a protracted legal battle that garnered national attention. Ultimately, after the intervention of the Indiana State Health Commissioner, White was readmitted in April of 1986. Families of fellow students took their children out of school, still fearful, though by that time the causes of transmission were much better understood. The Kokomo Tribune Newspaper editorially supported the White family. They were called homosexuals, and received death threats for their efforts to educate people. According to White’s mother Jeanne, people on the street would often harass Ryan, calling out “We know you’re Queer,” and other epithets. Ryan, however, never blamed gays, or anyone else for his infection. Ryan did finish the eighth grade in Kokomo, though he was forced to accept many restrictions, such as requiring him to eat with disposable utensils, and use separate restrooms.

The publicity of the trial had focused much attention on Ryan. He appeared frequently on Phil Donohue’s talk show, as well as many appearances on national TV, and countless articles in

newspapers and magazines. He eventually became known as the “poster boy” for AIDS. Many celebrities such as Michael Jackson, Greg Louganis, and Elton John appeared with White during the trial and for the rest of his life. In 1988, Ryan spoke before President Reagan’s AIDS Commission, relating his tale of hate, fear and discrimination he had faced in Kokomo. The family had moved to Cicero, Indiana, and he emphasized the different experience there, where he was greeted by school officials and students who had been educated as to the “non-risk” of casual contact. He used this as an example of the power and importance of AIDS education.

By spring of 1990, Ryan’s health was deteriorating rapidly. His last public appearance was with the Reagans, where he spoke hopefully about attending college and his date for the prom. Sadly, he passed away several months before his high school graduation, and the prom. His funeral was attended by over 1500 people. His high-visibility had made him one of the earliest “Public Faces” of AIDS. Larry Kramer, a co-founder of both GMHC and ACT UP said: “I think little Ryan White probably did more to move people than anyone.”

He then praised Ryan’s mother, Jeanne, for her continued involvement through her non-profit Ryan White Foundation. Many in the media had sought to portray Ryan as an “innocent victim” of the epidemic. The White family rejected the phrase because it implied that Gay men with AIDS were somehow “guilty”. Jeanne White credited her Gay contacts in New York and LA for helping to keep Ryan alive, as they kept them posted on the latest treatments and information.

In 1990, four months after Ryan’s death, Congress enacted the Ryan White Comprehensive AIDS Resources Emergency Act. It is the largest federally funded program for people living with HIV/AIDS. It funds programs to improve availability of care for low-income, uninsured and under-insured AIDS patients and their families. It provides care for around 500,000 people a year and provided funds to over 2000 organizations, as of 2009. President Obama recently signed an extension to this life-saving program.

1985: Rock Hudson and the Reagan Presidency

Rock Hudson had been out of the public’s eye for a while when he began appearing on “Dynasty” (one of TV’s most popular shows) in 1984. The world was shocked by the ravages shown in the face of the one time Hollywood He-Man. Though rumors that the actor was homosexual had occasionally surfaced throughout his career, he had dodged the “bullet” and had enjoyed a long career as one of Hollywood’s most famous hunks. The reaction of the public to the Oscar-nominated actor’s death later that year was one of shock and disbelief. If Rock Hudson could die from this strange new disease, was anyone safe? But his death had accomplished something that no amount of factual news could. His was a well-known face and it suddenly humanized the AIDS epidemic for the public at large.

(See AIDS Action on page 8)

News Briefs

Medicare expands coverage for treating facial lipodystrophy syndrome in people living with HIV

The Centers for Medicare & Medicaid Services (CMS) announced on March 23, 2010 its decision to cover facial injections for Medicare beneficiaries who experience symptoms of depression due to the stigmatizing appearance of severely hollowed cheeks resulting from the drug treatment for Human Immunodeficiency Virus (HIV). The decision is effective immediately.

Facial lipodystrophy (LDS) is a localized loss of fat from the face, causing an excessively thin appearance in the cheeks. In some cases, facial LDS may be a side effect of certain kinds of medications (antiretroviral therapies) that HIV positive individuals receive as part of their HIV infection treatment regimen.

The facial LDS can leave people living with HIV looking gaunt and seriously ill, which may stigmatize them as part of their HIV status. Individuals who take these medications and experience facial LDS side effects may suffer psychological effects related to a negative self-image. These effects may lead people living with HIV to discontinue their antiretroviral therapies. The new decision allows for treatment of individuals who experience symptoms of depression due to the appearance changes from facial LDS.

The injections included in the coverage decision are “fillers” that have been approved by the U.S. Food & Drug Administration (FDA) to be injected under the skin in the face to help fill out its appearance specifically for treatment of facial LDS. Data show that these injections can improve patient self-image, relieve symptoms of depression, and may lead to improved compliance with anti-HIV treatment.

“Today’s decision marks an important milestone in Medicare’s coverage for HIV-infection therapies,” said Barry M. Straube, M.D., CMS Chief Medical Officer and Director of the Agency’s Office of Clinical Standards & Quality. “Helping people living with HIV improve their self-image and comply with anti-HIV treatment can lead to better quality of life and, ultimately, improve the quality of care that beneficiaries receive.”

New heat-stable form of Norvir approved

On February 10, 2010, the FDA approved a new heat-stable form of Norvir (ritonavir) 100mg tablets, which do not need to be refrigerated. The daily dose is 600mg taken twice a day. When used with other protease inhibitors, its dose should be reduced. The tablets are white and oval in shape, with “A NK” on the pill. The soft gel capsule and liquid forms of Norvir are still available.

This new tablet must be taken with meals, unlike the soft gel capsule. It should be swallowed whole to maximize its effectiveness and not chewed, broken or crushed. The prescription label warns that people who switch from the capsule to the tablet may experience more stomach and abdominal side effects, such as nausea, vomiting, pain or diarrhea. These side effects may decrease over time.

CARE Hours of Operation

C.A.R.E. CLINIC

(562) 624-4999

Monday—Friday 8:30am—12:00noon 1:15pm—4

LAB HOURS

Monday—Friday 8:30am—11:30am 1:15pm—3:30pm

Clinic and Lab are closed on the 2nd Wednesday and the 1st Thursday of the month from 8:30am until 9:30am for Staff Meetings.

Remember to bring your insurance card every time you have lab work done.

C.A.R.E. PROGRAM OFFICES

(562) 624-4900

Monday—Friday 8:30am—12:00noon 1:15pm—4:30pm

Program offices are closed on the 2nd Wednesday of the month from 8:30am until 1:15pm for Staff Meetings.

C.A.R.E. DENTAL CLINIC

(562) 624-4949

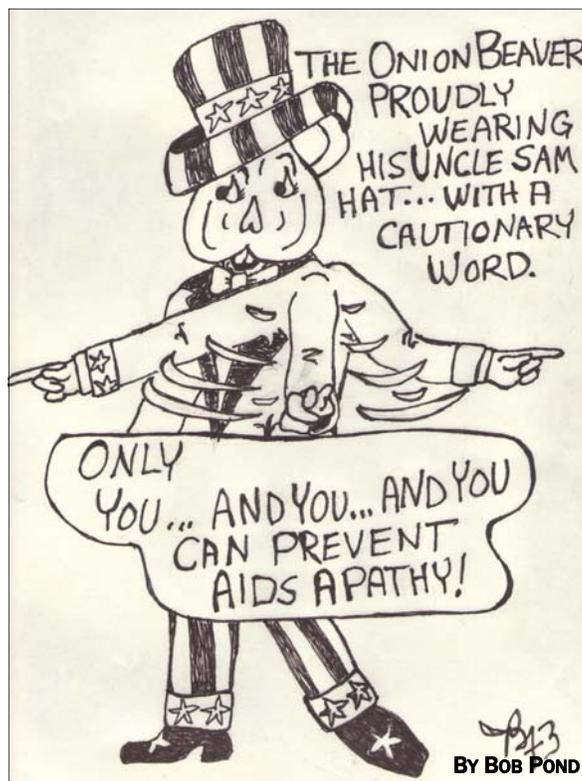
Monday—Friday 8:00am—12:00noon 1:00pm—4:30pm

Dental Clinic is closed on the 2nd Wednesday of the month from 8:00am until 10:00am for Staff Meetings.

www.careprogram.org

Services offered include HIV testing, outpatient medical care, dental care, ADAP registration, nutritional counseling, mental health services, case management, benefits assistance, food bank and HIV treatment counseling and education.

The Onion Beaver



President Reagan and his wife Nancy had been friends of Hudson's since their acting days. It was only after Hudson's death that Reagan finally uttered the word "AIDS" in a speech to the public. Throughout his years in office, he never expressed much sympathy for people with AIDS, perhaps fearing backlash from his conservative, faith-based constituents. Despite the advice of Dr. Everett Koop, his Surgeon General, he never endorsed, or mentioned safe-sex or condom usage. Without the endorsement of the President, America was the only western industrialized nation without a government-sponsored education and prevention program. Koop went before Congress to advocate safer sex and AIDS education and to lift a ban on condom advertising. He was attacked by Congressman William Dannemeyer of California who wanted the names of everyone with AIDS, "to wipe them off the face of the earth". Koop was quoted as saying "some of these people seem more concerned with homosexual genocide than with human tragedy."

1986: The CARE Program

Jennifer Andrews, as an emergency room social worker at St. Mary Medical Center, saw that many people infected or affected by HIV/AIDS had very limited resources for education and access to care and services. With a vision of an all-inclusive facility, and a generous grant from the Sisters of Charity of the Incarnate Word, Ms. Andrews founded the Comprehensive AIDS Resource and Education (CARE) Program. Long Beach had great numbers of underserved People With AIDS (PWA's) at the time. Through almost 25 years of both good and bad times of public and private funding, The CARE Program and Clinics continues to address the medical, dental, and psychosocial needs of people infected or affected by HIV/AIDS.

1987: "And The Band Played On"

In 1981, Randy Shilts was the first openly Gay reporter hired by a mainstream US newspaper, The *San Francisco Chronicle*. He began just weeks after the new "Gay disease" was detected and the rumors began to fly. So he was basically at "Ground Zero" for the start of the epidemic. His many articles and much research yielded his book "And The Band Played On." The book was the first widely read bestseller on the subject, and he became a prominent spokesperson on HIV/AIDS. The book traced the history of AIDS and showed his readers the sometimes hidden human toll of the disease. Though widely considered to be the best history of the epidemic, it was criticized for subjectivity and the overdramatization of alleged "Patient Zero" Gaetan Dugas. Shilts himself was diagnosed HIV-positive in 1985, which eventually led to his death. In 1993 HBO produced an award-winning film of the book. The movie was a star-studded affair, in which most of the performers worked for little or no salary. Their appearances in minor roles and cameos showed their support for the cause.

1987: ACT UP

As early as 1983, Larry Kramer was beginning to be disenchanted with the methods and machinations of the GMHC, and resigned from its Board of Directors. The Reagan Administration's fumbling and ineffectual dealings with the AIDS crisis were viewed by Kramer, Vito Russo, and others of his friends as verging on genocidal. As a result, a meeting was called at the NY Lesbian and Gay Services Center, and they founded the AIDS Coalition to Unleash Power (ACT UP). They defined themselves as "a diverse, nonpartisan group united in anger and committed to direct action to end the AIDS crisis." Whereas earlier organizations tried to work within established frameworks, ACT UP employed theatrical and "in your face" tactics. They used highly visible "sit-ins" and "die-ins" to attract media attention and provoke actions through confrontations.

Some highlights of their actions:

On March 24, 1987, ACT UP members demonstrated at Wall Street and Broadway in New York, to demand greater access to experimental drugs and to establish a coordinated national policy to fight the disease. Kramer had an op/ed piece published the day before, describing some of their concerns and actions.

On April 15, they held a protest at the New York City General Post Office to a captive audience of people filing last minute tax returns.

ACT UP proved its media savvy at this protest, because TV stations routinely do stories about down-to-the-wire tax filings, thereby guaranteeing media attention.

In January 1988, *Cosmopolitan* magazine published an article by Robert E. Gould, a psychiatrist, entitled "Reassuring News About AIDS: A Doctor Tells You Why You May Not Be At Risk." The main point was that in unprotected vaginal sex between a man and a woman who both had "healthy genitals," the risk was negligible, even if the male partner was infected. Women of ACT UP met with the doctor in person, calling him on medically misleading facts, and demanding a retraction and apology. When he refused, the women decided they had to take action. It was significant that this time it was the women who organized separately from the main group. 150 activists protested in front of the Hearst Building (Cosmo's parent company). Chanting "Say No to Cosmo!" and carrying signs saying "Yes, The Cosmo Girl Can Get AIDS!" the protest garnered national attention, and Cosmo eventually issued a partial retraction of the article's misleading content.

In May of 1988, ACT UP Boston held its first protest at the Department of Health and Human Services regarding delays and red tape surrounding approval of AIDS treatment drugs. Their demands included a National Emergency AIDS Project, a compassionate and comprehensive national policy on AIDS, intensified drug testing, research and treatment efforts and a

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full scale national education program for everyone in the country. Their efforts were largely effective in rushing approval of the newest drugs, which could have been mired in years of clinical trials. Even though some of those drugs were later proven to have damaging side effects, there's no doubt many, many people are alive today, thanks to the drugs' early approval.

In March 24, 1988, ACT UP members infiltrated the NY Stock Exchange and chained themselves to the VIP balcony to protest the high price of AZT. They displayed a sign reading "SELL WELLCOME!" referring to the pharmaceutical sponsor of AZT, which had set a price of \$10,000 per patient per year. The price placed the drug well out of reach for nearly all PWA's. Several days after the protest, Burroughs Wellcome lowered the price to \$6,400 per year. This event also allied ACT UP with the Silence=Death Project. They created the famous poster of a pink triangle (which was used to mark Gays in Nazi death camps) on a black background with the text "SILENCE=DEATH."

In December, 1989, approximately 4,500 protesters arrived at St. Patrick's Cathedral in NYC during mass. This demonstration was directed toward the Roman Catholic Archdiocese's public stand against AIDS education and condom distribution.

1987: The Names Project

Perhaps one of the quietest, but most powerful statements of advocacy is The Names Project Memorial Quilt. The idea was conceived when Cleve Jones attended a candlelight march in remembrance of Harvey Milk and George Moscone. People taped signs bearing the names of loved ones lost to AIDS on the Federal Building in San Francisco. He observed how much the signs resembled a patchwork quilt. Formally begun in 1987, the Project collects the 3'X6' panels (the size of an average grave), assembles them into 12'X12' sections, and arranges for their display and storage. In the early days many AIDS casualties did not have funerals or memorial services. Fearing the stigma, many of the families hushed up the passages, and many funeral homes refused to handle the remains. Each panel was designed to honor and memorialize the individuals. Some are simply names and dates, while others are personalized with clothing, stuffed animals, photos, records, ashes, and one even with a bowling ball. The Quilt has twice been nominated for the Nobel Prize. Actress Elizabeth Taylor has said, "The Quilt is a masterpiece created out of love. It is a rare and intense experience of what it means to be human." The massive piece of folk art was first displayed in 1987 with fewer than 2,000 panels. When shown on Washington D.C.'s National Mall in 1992, it had grown to 26,000 panels. It currently consists of more than 46,000 panels, and its estimated that only 20% of AIDS deaths are represented.

In 1989 the Quilt was the subject of a Peabody and Academy

Award winning documentary, "Common Threads: Stories from the Quilt."

1988: Surgeon General Everett C. Koop

Surgeon General Everett C. Koop took a courageous stand when he published a brochure: "Understanding AIDS." The explicit text with its graphic details of oral and anal sex, explaining high-risk behaviors, along with the encouragement of condom usage as a prevention measure, enraged conservatives. 107 million copies were mailed to every residence in the country, the largest mailing in history at that time.

1988: Elizabeth Glaser

Elizabeth Glaser (wife of actor Paul Michael Glaser) received a blood transfusion containing HIV during the birth of her daughter. She unknowingly passed the infection through breast milk. Not

knowing she was infected, she also passed the virus to her second child. All three were diagnosed in 1986. Meeting with President Reagan to ask for funds to research and treat the different needs of children with HIV, and seeing no results, she and two friends formed the Pediatric Aids Foundation (PAF). They concentrated their funding on research into the transmission from mother to child, and the care and treatment of those children already infected. The PAF also worked to educate about the disease. Today, the PAF is an international organization helping children and families all over the world.



1991: The Ribbon Project

The Ribbon Project, created by Visual AIDS and promoted by Broadway Fights AIDS and Equity Cares, was introduced in June of 1991, at the Tony Awards. The simple design of a single loop of red ribbon became one of the most widely recognized symbols of AIDS. The project urges everyone to wear the Ribbon in support of AIDS service organizations as well as people living with HIV. For years the ribbons were worn as a gentle reminder that the fight against AIDS still goes on.

So this has been a "highlight" reel of the earliest actions taken by both public and private activists. There was much more to cover...the films and songs and other artistic reactions to the epidemic...and far too many courageous (and villainous) people who affected our lives while dealing with the early terror, fears, and stigma connected to the disease.

But it is important to remember that many of those who began the fight against the discrimination, lack of funding and public support, information and research, and ignorance and fear of the AIDS epidemic did not live to see the results of their bravery and courage against insurmountable odds. All of us who have lived to see the death sentence that once was an AIDS diagnosis become the manageable disease of HIV owe them a huge debt of gratitude. Now it is up to us to continue the struggle that they began, and to carry on until the battle is won.

(for help with research...my thanks to Paul Hugli and my trusty AIDS Awareness Trading Card Set).

Bone Problems And HIV Disease

(From AIDS Infonet, www.aidsinfonet.org)

WHAT IS BONE?

Bone is a living, growing material. It has a framework of protein. Calcium strengthens the bone framework. The outer layer of bone has nerves and a network of small blood vessels.

Old bone is removed and new bone is added all the time. In young people, more bone is added than is removed. Our bones get heavier and stronger. After age 30, more bone is removed than is added. Bones become lighter and more brittle.

People with HIV have unusually high rates of two bone disorders: osteoporosis and osteonecrosis. This may be caused by HIV or by the medications used to treat it.

WHAT IS OSTEOPOROSIS?

Osteoporosis, or porous bone, occurs when too much mineral is removed from the bone framework. The bones become brittle and fracture more easily. The most common fractures are in the hip, the spine (vertebrae) and the wrist.

Osteopenia is a less severe loss of bone minerals.

WHAT CAUSES OSTEOPOROSIS?

As we age, our bones lose their mineral content. You may lose bone mineral faster if you are over age 50, a woman after menopause, Caucasian or Asian, or are slender and lightweight. Osteoporosis is also linked to a lack of calcium or vitamin D in your diet, smoking, heavy use of caffeine or alcohol, and lack of physical activity. A recent study found that people who had 5 or more alcoholic drinks a day had a fracture rate 3 times higher than average. Also, people with hepatitis C infection had a 3.6 times higher fracture rate. Advanced kidney disease can also cause loss of bone mineral content.

We don't yet understand why people with HIV have higher rates of osteoporosis. However, a recent study found greater bone loss among people infected with HIV over time.

Use of tenofovir can also result in a loss of bone mineral.

HOW DO I KNOW IF I HAVE OSTEOPOROSIS?

Unfortunately, many people find out they have osteoporosis by fracturing a bone. The only way to tell how fast your bones are losing mineral content is through tests. A DEXA scan, or Dual Energy X-ray Absorptiometry, is the most common test to measure bone mineral density.

Bone mineral density is reported in grams. This is compared to the "peak" mineral density for a healthy 30-year-old of the same sex. A "T-score" measures how far your bone mineral content is below the peak value. A T-score between 0 and -1 is considered normal bone density. T-scores between -1.0 and 2.5 indicate osteopenia. Osteoporosis is defined as a T-score of -2.5 or lower.

Bone density results can also be reported as a "Z-score." This compares your bone mineral content to people of your same age and sex. A Z-score of less than -1.5 may indicate abnormal bone loss.

WHAT CAN I DO ABOUT OSTEOPOROSIS?

To prevent osteoporosis, get plenty of calcium while you are building bone (up to age 30). The higher your peak bone density, the better.

If you have osteopenia or osteoporosis, you can reduce your

risk of fractures:

- Take calcium supplements, especially calcium carbonate or calcium citrate. Vitamin D can help with calcium absorption. Talk to your health care provider about the right amounts of supplements to take.
- Do more weight-bearing exercise. This seems to signal the bones to retain more mineral content.
- Stop smoking and reduce your intake of caffeine and alcohol. Reduce your risk of falling. Clear your walkways at home. Be careful on stairs or steep slopes.

WHAT IS OSTEONECROSIS?

Osteonecrosis means bone death. It is also called avascular necrosis. It usually affects the femur, which connects the leg to the hip.

Osteonecrosis is caused by a loss of blood supply to the bone. Injuries, excessive use of alcohol, and long-term use of corticosteroid drugs (to reduce inflammation) can cause osteonecrosis. Fat can clog blood vessels in the bone.

Osteonecrosis causes pain in the joints. Pain in the hip area could be a sign of osteonecrosis. At first the pain might only occur when you put weight on the joint. In more severe cases the pain could be constant.

A magnetic resonance imaging (MRI) scan can detect early stages of osteonecrosis. X-rays and other scans can detect advanced cases. Some health care providers use surgery to test for osteonecrosis.

A healthy person can sometimes recover from osteonecrosis, especially if it was caused by an accident. The body can repair damaged blood vessels and rebuild damaged bone.

If osteonecrosis is caused by alcohol or steroid use, you should stop using them. You can also reduce the weight you put on your joints. This is the opposite of treatment for osteoporosis.

Serious cases require surgery to repair the affected bone, or to replace a damaged joint, usually the hip.

Lactose Free Dietary Sources of Calcium, Vitamin D, and Protein

- Yogurt/Greek yogurt (not lactose free, but low in lactose and usually tolerated by lactose intolerant individuals)
- Soy milk
- Green vegetables (spinach)
- Meat/fish (especially salmon and sardines)
- Fortified orange juice
- Egg (white high in protein, yolk high in vitamin D)
- Yolk should be eaten 3x/wk if high cholesterol
- Baked beans

(As supplements, 1000mg of calcium and 1000-2000 IU of Vitamin D3 per day are generally recommended, but talk to your doctor or Registered Dietician about what is best for you.)

Elton John's Letter to Ryan White, 20 Years After His Death From AIDS

From The Washington Post

By Elton John

Sunday, April 25, 2010

Twenty years ago this month, you died of AIDS. I would gladly give my fame and fortune if only I could have one more conversation with you, the friend who changed my life as well as the lives of millions living with HIV. Instead, I have written you this letter.

I remember so well when we first met. A young boy with a terrible disease, you were the epitome of grace. You never blamed anyone for the illness that ravaged your body or the torment and stigma you endured.

When students, parents and teachers in your community shunned you, threatened you and expelled you from school, you responded not with words of hate but with understanding beyond your years. You said they were simply afraid of what they did not know.

When the media heralded you as an "innocent victim" because you had contracted AIDS through a blood transfusion, you rejected that label and stood in solidarity with thousands of HIV-positive women and men. You reminded America that all victims of AIDS are innocent.

When you became a celebrity, you embraced the opportunity to educate the nation about the AIDS epidemic, even though your only wish was to live an ordinary life.

Ryan, I wish you could know how much the world has changed since 1990, and how much you changed it.

Young boys and girls with HIV attend school and take medicine that allows them to lead normal lives. Children in America are seldom born with the virus, and they no longer contract it through transfusions. The insults and injustices you suffered are not tolerated by society.

Most important, Ryan, you inspired awareness, which helped lead to lifesaving treatments. In 1990, four months after you died, Congress passed the Ryan White Care Act, which now provides more than \$2 billion each year for AIDS medicine and treatment for half a million Americans. Today, countless people with HIV live long, productive lives.

It breaks my heart that you are not one of them. You were 18 when you died, and you would be 38 this year, if only the current

treatments existed when you were sick. I think about this every day, because America needs your message of compassion as never before.

Ryan, when you were alive, your story sparked a national conversation about AIDS. But despite all the progress in the past 20 years, the dialogue has waned. I know you would be trying to revive it if you were here today, when the epidemic continues to strike nearly every demographic group, with more than 50,000 new infections in the United States each year. I know you would be loudly calling for the National HIV/AIDS

Strategy that was promised by President Obama but has not yet been delivered. I know you would reach out to young people. I know you would work tirelessly to help everyone suffering from HIV, including those who live on the margins of society.

It would sadden you that today, in certain parts of the United States, some poor people with AIDS are still placed on waiting lists to receive treatment. It would anger you that your government is still not doing enough to help vulnerable people with HIV and populations that are at high risk of contracting the virus, including sexually active teenagers. It would upset you that AIDS is a leading cause of death among African Americans.

It would frustrate you that even though hundreds of thousands of HIV-positive

Americans are receiving treatment in your name, more than 200,000 don't know their HIV-positive status, largely because a lingering stigma surrounding the disease prevents them from being tested. It would disappoint you that many teenagers do not have access to science-based HIV-prevention programs in school, at a time when half of new infections are believed to be among people under 25.

I miss you so very much, Ryan. I was by your side when you died at Riley Hospital. You've been with me every day since. You inspired me to change my life and carry on your work. Because of you, I'm still in the struggle against AIDS, 20 years later. I pledge to not rest until we achieve the compassion for which you so bravely and beautifully fought.

Your friend,
Elton

Sir Elton John, a Grammy- and Academy Award-winning artist, is the founder and chairman of the [Elton John AIDS Foundation](#).



"You must be the change you wish to see in the world"—Mahatma Gandhi

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