

# PROJECT INFORM



# ANNUAL REPORT

2002-2003

# our mission

**P**roject Inform is a national, non-profit, community-based organization dedicated to improving the lives of people living with HIV disease and their loved ones. Our mission is to:

provide  
vital information on the diagnosis  
and treatment of HIV disease to HIV-  
infected individuals, their caregivers,  
and their healthcare and service  
providers;

advocate  
for enlightened regulatory, research  
and funding policies affecting the  
development and delivery of effective  
treatments; and

inspire  
people to make informed choices and  
to choose hope over despair.

## COVER CREDIT

Partial view of "Faith, Love, Hope and Charity," by local muralist, Catalina Gonzales, recently installed in Project Inform's office.

## A Message from the Executive Director and Board President



**Ellen LaPointe**  
*Executive Director*



**Alonzo Reese**  
*President,  
Board of Directors*

**Dear Friends,**

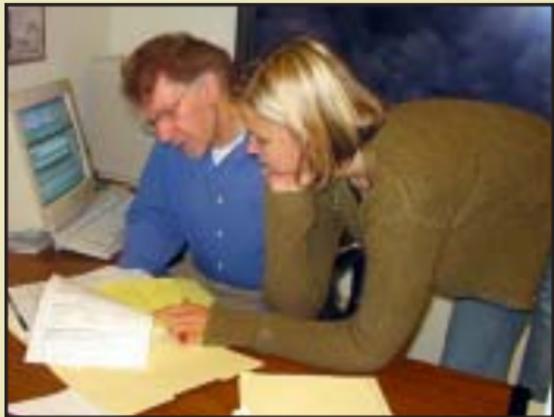
This past year has brought enormous challenges in the fight against AIDS. Grim reports of the expanding epidemic underscored the need for research to identify a safe and effective cure; for advocacy to ensure access to care and treatment; and for government leaders to be assertively shown that the needs of people with HIV warrant their attention. As well, people with HIV continued to demand accurate, timely information to help them make informed decisions about their health. All of this occurred against the backdrop of an economic recession and a political landscape in which our message was not always heard or readily embraced.

Project Inform rose to these challenges, taking leadership roles in preserving funding for the AIDS Drug Assistance Program (ADAP), protecting Medicaid programs, and freezing prices for HIV-related treatments. The call volume of our national hotline increased 20 percent, and we also helped develop a training program for minority educators working in communities hardest hit by AIDS. Throughout, we continued to offer a message of hope.

As HIV/AIDS tightens its grip on communities already challenged by poverty, racism, homophobia, and gender inequality, will government and the private sector make the kind of sustained commitment necessary to overcome the disparities this epidemic exploits? While this history is yet unwritten, please know that lives are made better every day because of your continued support of Project Inform. Thank you for helping us inform, inspire, and advocate on behalf of people living with HIV.

We simply couldn't do it without you.

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Hotline Manager Kris Starr, reviewing caller data sheet with volunteer hotline operator Gerry Hill.

**P**roject Inform is committed to providing free, confidential information about HIV/AIDS to anyone who asks. By helping people with HIV/AIDS understand their care and treatment options, Project Inform enables them to take control of their health and well-being.

## hotline

In 2002, volunteers on our toll-free **National HIV/AIDS Treatment Hotline** helped over 17,000 callers from across the U.S. and around the world to make informed decisions about their HIV-related treatment and care. Hotline operators, many of whom are HIV positive themselves, receive intensive training and ongoing education. This past year, calls were up more than 20%, with operators answering questions ranging from “Should I be tested?” to complex inquiries about new developments in treatment. Project Inform’s Hotline is a critical resource for people seeking confidential information about HIV treatments and related diseases.

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## website

**Available in English and Spanish 24 hours a day, 7 days a week, 365 days a year**, Project Inform's website features up-to-date treatment information, action alerts and organizational facts about Project Inform. The site—[www.projectinform.org](http://www.projectinform.org)—averages more than 200,000 page requests each month. Hundreds of other HIV/AIDS and health information organizations link to our site, a testament to the trust and respect Project Inform has earned within diverse communities confronting the challenges of HIV/AIDS.

[www.projectinform.org](http://www.projectinform.org)

“

*Your drug treatment information has saved my life. I thank you for keeping us informed in a rural area where knowledge is limited and being informed is the key to survival.*

”

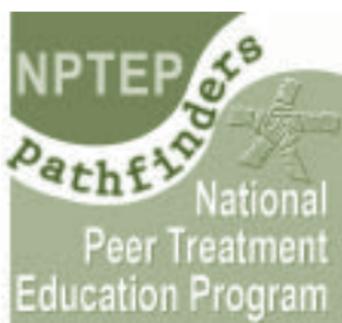
— ROBERT

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## outreach and education

In partnership with other leading organizations, Project Inform directly **trained over 500 people how to teach vital skills and information to individuals living with HIV and AIDS** in 2002.

In workshops held throughout the nation, people who care for those with HIV learn how to teach skills such as monitoring disease progression, evaluating treatment options, managing medications and side effects, and improving nutrition. In turn, people with HIV/AIDS apply these skills to better manage their disease and maintain healthy and positive lives. By training people how to pass on information and skills to their clients and loved ones, **these trainings create a ripple effect of positive change.**



Project Inform is proud to have partnered with Howard University, the Hyacinth AIDS Foundation, the Latino Commission on AIDS and the University of Maryland to develop and implement the National Peer Treatment Education Program (NPTEP).

Targeting educators who work in communities of color highly impacted by HIV/AIDS, the program focused on increasing and improving community access to HIV care and treatment.

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As part of our commitment to community education, Project Inform held Update Town Meetings throughout California and the United States, including in Atlanta, Chicago, Nashville, Oakland, Palm Springs, Philadelphia, and San Diego. These meetings provided a wide range of information from basic facts about HIV infection to advanced reports on current issues and evolving treatment options.



Following the **International Conference on AIDS in Barcelona**, Project Inform conducted four **community meetings** to report on the topics presented, including funding issues and vaccine development. These meetings were held in collaboration with several Bay Area community-based organizations, including the AIDS Research Institute, the Conant Foundation, the African American AIDS Policy Institute in Oakland, and WORLD (Women Organized to Respond to Life-Threatening Disease).

“

*Your help to me when my son's disease was identified was invaluable. Likewise the training that I received from your staff helped not only me, but my entire family in our awareness of the function and treatment responses to this virus. Sincere thanks to you all.*

”

— MARILYN

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Program Manager Shalini Eddens, MPH, reviews a groundbreaking issue of *Wise Words* that focused entirely on the unique care and treatment issues affecting HIV-positive women over 50, one of the fastest growing segments of people living with HIV.

“

*My partner has suffered with AIDS for 20 years and I simply cannot tell you how wonderfully helpful you have been to me. I call and it seems like I get my answers in the mail just 5 minutes later. I love all of you from the bottom of my heart.*

”

— CLIFFORD

## publications

**Our treatment publications provide potentially life-saving information to more than 61,000 people in need.**

In 2002, Project Inform produced and updated over 80 fact sheets and discussion papers covering topics such as anti-HIV therapies, immune restoration, and pregnancy and HIV. We also produced *PI Perspective*, our comprehensive treatment journal, and *Wise Words*, a newsletter devoted to the specific concerns of women living with HIV. All Project Inform publications are available free of charge in English and Spanish. Publications can be obtained online at [www.projectinform.org](http://www.projectinform.org) and through our Treatment Hotline at 1-800-822-7422.

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**T**hrough its public policy and treatment and research advocacy efforts, Project Inform works to accelerate the pace of discovery in HIV/AIDS, provide a community voice to the research process, and ensure access to and adequate funding for treatment and quality healthcare.

## treatment and research advocacy

Project Inform partnered with the National Minority AIDS Council to develop and facilitate the 2002 **North American AIDS Treatment Action Forum**. This forum brought together more than 400 treatment professionals from the United States, Canada, Mexico and Eastern Europe to ensure the continuity and success of the treatment advocacy movement.

Project Inform played a leading role in securing a **two-year price freeze on many HIV/AIDS drugs**.

In 2002, Project Inform led the fight to ensure that critical research of **Interleukin-2** as an immune-based treatment for HIV disease is completed and evaluated.

advocacy

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## public policy

Project Inform increased **advocacy for AIDS Drug Assistance Program (ADAP) funding**—resulting in the U.S. Senate asking for a \$100 million increase

for ADAP in 2003. We also took a **leadership role in securing sufficient funding from the California State Legislature** to make up for the lack of adequate funding at the federal level, ensuring that all eligible ADAP clients will continue to receive life-prolonging anti-HIV drugs.

Members of Project Inform's Public Policy department participated in a **protest against U.S. HIV/AIDS policy and took part in a subsequent meeting with U.S. Department of Health and Human Services Secretary Tommy Thompson**. These activities were instrumental in furthering the Secretary's understanding of Project Inform's perspective on international and domestic HIV issues and expanding access to and dialogue with the Secretary and his staff.

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Through the **Treatment Action Network (TAN)**, Project Inform brings a constituent-based perspective to its public policy work and drug access efforts. TAN is the largest national grassroots network of individuals advocating on HIV/AIDS research, treatment and healthcare issues. Over 2,000 volunteer members of TAN write, email and call their Members of Congress, the President and federal administrative officials about HIV/AIDS legislation and funding issues. TAN members also have contacted pharmaceutical companies to ask for faster access to promising treatments and lower drug prices. In the past year, TAN members have advocated for increased funding of HIV/AIDS programs; reauthorization of the Ryan White CARE Act, the Early Treatment for HIV Act, the Patients' Bill of Rights; and strong medical privacy regulations.

“

*Project Inform's advocacy work has kept the need for AIDS funding on the radar screen of our nation's legislators. As the number of people living with HIV continues to grow, the need for increased funding for care and treatment depends on Project Inform's leadership.”*

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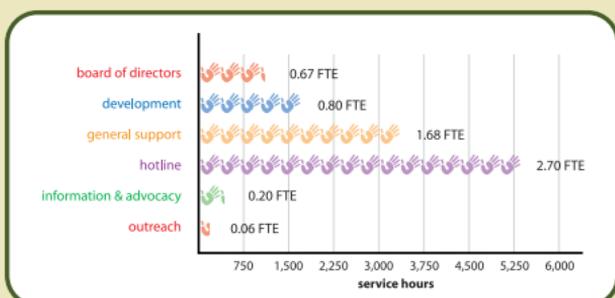
— LEI CHOU  
DIRECTOR,  
THE ACCESS  
PROJECT AIDS  
TREATMENT  
DATA NETWORK

All of Project Inform’s work aims to bring a message of empowerment and hope to people living with HIV. Our staff and volunteers are deeply committed to the fight against AIDS, and many have been a part of this struggle since the beginning. Our determined efforts—and the enormous generosity of our private donors—allow us to fulfill our mission and inspire people to choose hope over despair.

## volunteer services

Volunteers are at the heart of Project Inform, initiating projects and supporting vital programs. **In 2002, more than 160 volunteers worked a total of 12,000 hours** on programs, projects and special events—**equivalent to six full-time employees**. Project Inform also benefits from our Board of Directors and National Board of Governors, all of whom generously volunteer their time and efforts. We could not accomplish all that we do without our volunteers, and we are tremendously grateful for their spirit, talents and shared commitment to our mission.

**Volunteer and Intern Service Hours per Department (6.10 FTEs)**



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## special events

Essential to Project Inform's fundraising efforts are the special events organized by staff, volunteers and community partners. Highlights from 2002 include Macy\*s Passport, an annual fashion event to benefit HIV/AIDS organizations in San Francisco and Los Angeles, and Academy of Friends, an Oscar night gala that distributes proceeds to a number of Bay Area HIV/AIDS service organizations. Together these events raised nearly \$100,000 to support critical services at Project Inform. We thank all those who helped make these events a success.

## ron wilmot bike ride

Founded by Ron Wilmot, an HIV/AIDS activist and avid cyclist, this annual event has raised over \$550,000 for Project Inform programs since its inception in 1995. Before he died of AIDS in 1997, Ron challenged family, friends and the community to continue organizing a local ride for people of all ages and abilities, with an emphasis on encouraging people with HIV/AIDS to participate. Project Inform is grateful for the hundreds of individual and team cyclists who have completed the 7-mile course through Golden Gate Park each year since then. We are also proud that more than 95% of the funds raised by the Wilmot Ride go directly to supporting our programs and services.



A few of the fast-moving wOrldware team, who have been the top fundraising group at the Ron Wilmot Bike Ride since 1999. Thanks, wOrldware!

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## evening of hope

Our signature annual event raised over \$235,000 in 2002—a tremendous boost to our work bringing information, advocacy and inspiration to those living with HIV and the people who love them. Evening of Hope brings together new and longtime Project Inform supporters and friends for an evening of camaraderie and renewed commitment to the fight against AIDS. The evening also features the presentation of the Thomas M. Kelley Fundraising Activist Award, which honors an individual who has demonstrated a commitment to furthering the goals of Project Inform through fund-raising and public relations.



Former Board President Joseph Garrett (left) proudly accepts the Thomas M. Kelley Fundraising Activist Award from Tom Kelley.

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## donors

Project Inform relies significantly on the generosity of private donors. Nearly 95% of our budget is derived from non-governmental sources. The enclosed materials acknowledge the individuals, foundations and corporations whose financial contributions allow us to continue our life-saving work. We are enormously grateful for their support.

## partners in hope

Especially important to our fundraising efforts is Partners in Hope, the leading circle of individual donors who make significant annual contributions in support of our programs. In 2002, Partners in Hope contributed \$132,251 to support programs at Project Inform.

## workplace giving

Workplace giving programs contributed more than \$100,000 to Project Inform in 2002. These programs include all donations made by employees through payroll deductions at their workplace. We received these deductions through many sources, including the United Way of the Bay Area, Local Independent Charities, and Health Charities of America.

## retail

Project Inform is very appreciative of the efforts of Under One Roof, a San Francisco store that sells merchandise to benefit Project Inform and other AIDS service organizations. We are also grateful to Community Thrift Store in San Francisco, which resells donated goods and distributes the proceeds to the organization of the donor's choice.

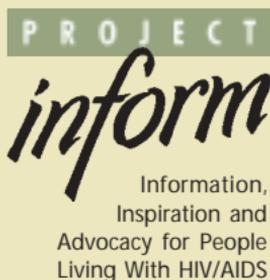
thank you

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Kaiser Permanente recognizes Project Inform for developing and communicating the evidence base for a wide range of treatments available for populations affected by HIV/AIDS. As our community benefit goals include addressing the healthcare needs of vulnerable populations and helping consumers make knowledgeable decisions, we are pleased to provide continuing support to Project Inform's Integrated Treatment Education Program through our KP Cares for Communities National Grant Program.

Raymond J. Baxter, PhD  
Senior Vice President  
Kaiser Permanente  
Community Benefit Program

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WEBSITE  
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