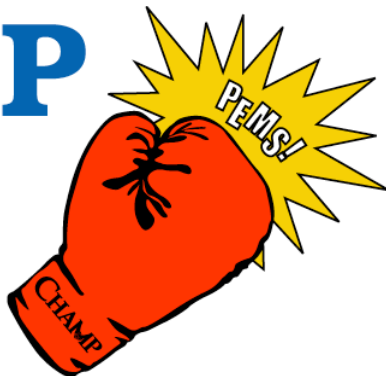


# CHAMP vs. CDC



## Community Pressure Forces CDC to Halt Dangerous HIV Prevention Reporting System

***CHAMP and allies help put the brakes on PEMS; CDC must open the doors to community collaboration to fix it, or nix it for good!***

As a part of their Advancing HIV Prevention program (launched in 2003), CDC has been developing mandatory reporting requirements for all of the HIV prevention programs they fund. They have said that PEMS (Program Evaluation and Monitoring System) would provide better documentation of how prevention programs work.

But providers were appalled to see that PEMS mandated that each person accessing testing or counseling would have to answer hundreds of questions – including invasive questions about sex and drug use -- even from the first visit or in a brief educational session. In addition, staff would be burdened with drastically-increased data entry and security requirements for a program that many would consider research -- without research-level funding or ethical protections.

CHAMP recommends that CDC fix PEMS by limiting it to basic monitoring, funding well-planned evaluation research informed by community participation, convening an ongoing consultative process for redesigning the system, and eliminating privacy risks without burdening community programs. **Cont. p2**

### CHAMP Launches Pilot Program for Community Organizing & Mobilization Building a Grassroots HIV Prevention Movement: The Prevention Justice Partnership

The history of AIDS activism was paved with brave individuals who organized to fight for survival. Important victories were won on domestic and global access to treatment and care in the first quarter century of this pandemic. Much remains to be done, not the least of which the search for a vaccine and a cure. But one urgent question can and must be answered: What can we do to stop the persistent rates of new infections worldwide.

While the current U.S. domestic and global HIV prevention policies seem stuck in the 1950s, driven by radical right-wing ideology instead of sound scientific research, the impact of these policies will have negative and costly consequences lasting decades after this President leaves office. Since community-based AIDS organizations are already struggling to provide vital services after years of under funding, a new generation of activists is sorely needed in order to turn the path of the epidemic. **Cont. p4**

## **CHAMP VS. CDC (Cont. p1)**

CHAMP has been leading the community charge for drastic PEMS reform since our Strategy Lab and HIV Prevention Network allies first alerted us to the threat it posed to HIV prevention programs. Even though introduction of PEMS has been repeatedly delayed since 2004, there has been no systematic or representative input into the design and piloting of the new system, and frustrations have been boiling over during trainings and within our hardworking community organizations.

**PEMS implementation has been fraught with problems, and CHAMP is glad to announce that CDC has now agreed to our demand to suspend implementation of PEMS to allow time for a review of concerns being expressed about the system.**

CDC announced this decision on March 2 in a letter sent to CHAMP as well as the directly-funded HIV prevention agencies and health departments around the country who have been struggling with a poorly designed system, unrealistic timelines, insufficient training, and unaddressed concerns about program impact and privacy for clients.

In addition to creating an opportunity for more meaningful participation in the re-design of the system, this indicates a willingness by CDC to respond to community concerns, and we applaud CDC for taking this important step. We are now urging CDC Project Officers, PEMS Regional Leads and health departments to provide a clear explanation of the letter to ensure that providers recognize that PEMS data collection can be put on hold, and for CDC to agree to full community participation in PEMS reform.

CHAMP seeks to improve HIV prevention monitoring through an inclusive and genuine review process that involves providers and people living with HIV, and goes beyond addressing the cosmetic and technical flaws with PEMS and the deployment process. On March 6, CHAMP submitted recommendations developed through extensive collaboration with front-line prevention providers and people living with HIV, in order to assist with the re-design of PEMS. (This document, and other useful information, is available on our PEMS campaign online headquarters: <http://www.champnetwork.org/index.php?name=PEMS>)

## **CHAMP Opens CDC's Eyes to the Problems, Still Fighting to Open the Doors to Collaboration:**

CHAMP sent out a call for community feedback regarding PEMS in November 2005 and the responses informed two public briefing papers we released. Our December issue of *HHS Watch*, titled "Rube Goldberg Meets Big Brother," highlighted some of the concerns people expressed: PEMS sucked up too much staff time and resources, created new barriers to accessing prevention services, interfered with effective program delivery, and ultimately would produce unusable, poor quality data that would do nothing to help evaluate prevention efforts. During this time, CDC postponed the deadline for implementation from January 1<sup>st</sup> to April 1<sup>st</sup>, 2006.

In January, CHAMP circulated an organizational sign-on letter insisting on a community meeting with senior CDC decision-makers to address the concerns providers, people with HIV, and others accessing prevention services have with the system. Additional pressure was generated by action alerts, which increased grassroots calls and letters to Dr. Rob Janssen, head of CDC's HIV prevention division.

**But CDC has still not agreed to a request for a face-to-face, solutions-oriented meeting with people living with HIV, the directly-funded community prevention organizations charged with implementing PEMS, and national advocacy organizations** – despite a request for such a meeting submitted by CHAMP on behalf of nearly 50 such groups. *We call upon all people who care about HIV prevention to demand that CDC open their doors to true collaboration by hosting this important meeting, and agreeing to ongoing consultation with community members.*

Every provider wants to know how well their prevention programs are doing, whether they're targeting and meeting the needs of those most at risk for HIV, and wants to be able to do so through a well-run database that could simplify reporting. But at a time when President Bush and Congress have cut federal funding for HIV prevention programs to 1998 levels, CBOs are in no position to implement a poorly designed, time-consuming, and insufficiently-piloted data reporting system.

Community mobilization around PEMS has helped turn back the growing power imbalance between CDC and front-line service providers, who have been marginalized in HIV prevention policy-setting. CHAMP is honored to help amplify the voices of those who give and use prevention services around the country, and we will ensure that we *all* have a meaningful role in designing the programs that affect our work and our lives.

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**What's Up @ CHAMP** – We have been gearing up for the Prevention Justice Partnership and working on curricula for the first quarter trainings, but we've still hit the road and opened our doors in the past three months. Here's some highlights:

**December 22, 2005, Providence** – CHAMP opened our Rhode Island office with a community forum entitled “**A Reality Check on HIV Prevention.**” Distinguished panelists provided a balanced and accurate view of the epidemic and prevention efforts during “World AIDS week.” CHAMP board member **Mark McLauren, David Holtgrave** of Johns Hopkins, and **Ethan Zahn** of Grassroots Soccer and *Survivor* fame presented.

**January 1, 2006** – Julie Davids wrote “**A Community Perspective: Six Things to Watch and Four Things to Try in 2006**” for the National Alliance of State & Territorial AIDS Directors' (NASTAD) HIV Prevention Bulletin. Read it at <http://www.champnetwork.org/index.php?name=nastad>

**February 5-8, 2006, Denver** – Julie Davids and Sean Barry attended the **2006 Conference on Retroviruses and Opportunistic Infections (CROI)**, where we released a **Statement of Support for HIV Prevention Research on Pre-Exposure Prophylaxis** with AIDS Vaccine Advocacy Coalition (AVAC), Gay Men's Health Crisis (GMHC) and Treatment Action Group (TAG). Read it at <http://www.champnetwork.org/index.php?name=press>

**February 8, 2006, DC** – Lei Chou helped organized hill visits with the **HIV Medicaid & Medicare Workgroup**, bringin constituents from Rhode Island & Pennsylvania to educate law makers onthe impact of drastic Medicaid cuts on people living with HIV/AIDS.

**February 18, 2006, Philadelphia** – Julie Davids & Sean Barry presented a day-long community organizing institute: “**Getting Ready to Win**” at the 13th annual Ryan White Youth Conference, sponsored by the **National Associated of People With AIDS (NAPWA.)** Sarah Howell presented lessons learned from CHAMP's Find the Condoms campaign.

**Prevention Justice Partnership** from p1 - Recognizing that a successful movement depends on a strong, well informed, and organized constituency, the CHAMP Academy is launching a unique pilot program - The **Prevention Justice Partnership (PJP)**. This twelve-month program is designed to provide a new generation of leaders with tools and resources to advocate for HIV prevention policies based on science. Central to the program are the two-day intensive on-site training and strategy sessions every quarter, coupled with ongoing mentorship and support. For our pilot year, we have invited a diverse group of grassroots organizations from around the country to partner with CHAMP. Following are brief descriptions of our six partners:

**ACT UP Austin** – Formed as a response to the call to action made by the Campaign to End AIDS in 2005, a group of diverse individuals decided to take the next step and reactivate the Austin chapter of ACT UP. This young and enthusiastic group recognized the negative impact current HIV prevention policies are having on their communities, and they are organized and ready to change them for the better. CHAMP will utilize the rich resources and build upon the skills of group members to develop and launch a strategic HIV prevention advocacy campaign.

**ACT UP Philadelphia** – A veteran of the AIDS activist movement, this powerful group has grown along with the ever-changing AIDS crisis for eighteen years. Addressing both the domestic and global AIDS crisis, ACT UP Philly has been extremely effective in using direct action and the media to change the public dialog and policy. Recognizing sustainability as one of the many challenges facing a diverse, community based, and all volunteer organization, ACT UP Philly is partnering with CHAMP to focus on fundraising, leadership development, and infrastructure building for the long haul.

**Allies Linked for the Prevention of HIV and AIDS/ALPHA** - Founded by an HIV positive young man in 2003, this all-volunteer organization provides HIV prevention counseling and testing services in a community setting in Boise, Idaho. While these services are vital, ALPHA also realizes that more must be done to stem the growing HIV epidemic. From local opposition to harm reduction/needle exchange, to proliferation of abstinence-only-until-marriage programs, there is no shortage of issues to address. CHAMP will work with this partner to incorporate a policy advocacy campaign.

**Proyecto Lucha & BAY Positive** – Based in San Francisco, Proyecto Lucha was formed out of the ashes of recent federal and local prevention program cuts, especially in the gay, lesbian, and transgender immigrant Latina/o community. BAY Positive is a drop-in center and support group for young HIV positive people in the Bay area. CHAMP will work to recruit participants from both of these overlapping communities to identify and train a new generation of AIDS activists, building a new voice to revitalize the AIDS movement in San Francisco.

**North Carolina Harm Reduction Coalition** – A diverse statewide coalition of PLWHAs, IDUs, sex workers, service-organizations, religious leaders, researchers, students, and community allies, the NCHRC was created in response to the HIV epidemic among people of color and injecting drug users in the state. NCHRC works to "encourage and motivate the acceptance of harm reduction strategies in North Carolina through education, advocacy, and resource development." CHAMP will work with the NCHRC to strengthen their coalition structure, translate platform items into concrete and winnable campaigns, and provide training for their members who are new to advocacy.

**C2EA Rhode Island** –CHAMP is working with a group of Rhode Island HIV/AIDS activists to start up a state chapter of the Campaign to End AIDS (C2EA). We are partnering with C2EA RI through a two-month training program, the Prevention Justice Seminar. This seminar is an in-depth immersion course on the history of AIDS activism and current policies impacting the epidemic. With a shared base of knowledge, we expect to advance towards campaign building and execution full steam ahead.

## CHAMP's NYC Activist Group Builds Momentum

**CHAMP NY** is the new identity of the NYC-based prevention activist group formerly known as H-POP, the HIV Prevention Organizing Project. The group has been recruiting new members, having weekly meetings, and strategizing to continue fighting for just HIV prevention policy in New York.

The popular **Find the Condoms in Your School Campaign** will continue to be a priority for the group in the coming months. Last fall, CHAMP initiated the Find the Condoms campaign to respond to the lack of availability of condoms in NYC public schools. As a part of the campaign, high school students from all five boroughs attempted to "find the condoms" in their own schools and reported their results to CHAMP.

The results from the surveys (as well as a Freedom of Information Act request that CHAMP made) showed that the majority of schools in the city do not have free condoms available for their students -- and that schools order only enough condoms to provide 1.4 condoms per sexually active student per year! CHAMP NY is hosting Saturday meetings with high school students, creating an organizing toolkit for youth, and **"Know Your Rights"** postcards to distribute in schools to educate and reach out to more students. And this summer, we'll host an intensive training for high school students on the fight for condom access.

CHAMP NY is also starting monthly forums on HIV prevention policy issues, co-sponsored by the Lesbian, Gay, Bisexual, and Transgender Community Center. This important collaboration will feature panel discussions on timely HIV prevention issues and explore their relationship with LGBT liberation and social justice. Our April forum will focus on pre-exposure prophylaxis, the experimental use of anti-HIV drugs as HIV prevention. Future forums will focus on issues such as the politics of emergency contraception and HIV prevention technologies; advocacy around HIV in prisons, and abstinence-only-until-marriage and comprehensive sexuality education.

To get involved or to find out more information about CHAMP NY, please contact Sonny Suchdev at [sonny@champnetwork.org](mailto:sonny@champnetwork.org) or 212-937-7955 x3. The group's weekly meetings take place at 'sNice café (45 8<sup>th</sup> Avenue in Manhattan) every Tuesday from 6:30 to 8:00PM.

## CHAMP IN THE NEWS

"(Correctional facilities) in the U.S. say the same things they say in Namibia -- that condoms will condone sex and increase prisoner rape,...But if they really wanted to prevent prison rape, there are a lot of things they can do and aren't."

— **Julie Davids** quoted in a story about condom distribution in Namibia, Planet Out, 1.9.06

"It's important to recognize that a panic-based approach was used to spread speculative information about something that has not materialized," said **Julie Davids**... With "no epidemic or a verified second case... I think the health department should have careful and detailed accounting of what we've learned and issue a retraction," — Quoted in an update on the "supervirus" story in Gay City News, 1.12.06

"This program is not going to give us the answers we need," said **Sean Barry**, director of prevention policy for the Community HIV/AIDS Mobilization Project. "Data collection that is too hard to do, and that conflicts with good and ethical prevention education will not happen in a thorough way." — Quoted in a Southern Voice story on PEMS, 1.13.06

## CHAMP OPENS 2006 WITH PUSH FOR NEXT-GENERATION PREVENTION OPTIONS

As prevention activists, CHAMP fights for greater access to current prevention technologies, such as needles and condoms. We also believe it is vital to expand our prevention options, and urge our members and allies to increase our collective work for well-designed, ethical and strategic research on options like social network strategies, microbicides, vaccines, STD treatment and the potential of antiretroviral medications in HIV prevention.

Last year, CHAMP joined **AIDS Foundation of Chicago** and the **Canadian AIDS Society** in founding the **Rectal Microbicide Working Group**. Many people believe that homophobia has hindered this effort. Ironically, women have up to 7 times as much anal sex as gay men in this world, as there are many more women than gay men, meaning that people of all genders need an effective microbicide that works *wherever* it's needed. As we entered the new year, the working group has hit its stride, linking top researchers and dedicated community activists through interactive teleconferences and gathering information on what it would take to develop an effective microbicide that could provide protection for men and women who have anal sex.

In February, CHAMP staff attended the **Conference on Retroviruses and Opportunistic Infections** (CROI, commonly known as the Retrovirus Conference), which is regarded as the top HIV/AIDS scientific conference in the United States. Reflecting the increasing recognition of the importance of integrating and expanding HIV prevention research, the conference had an expanded focus on HIV prevention research, with multiple workshops, plenary sessions and press conferences on prevention issues. The symposium called "*HIV Prevention Research: New Advances, Continued Challenges*" was so crowded that the fire marshal had to limit attendance, reminding some participants of the level of interest in sessions with data on combination anti-HIV drugs in the days when their effectiveness was first revealed. Please see our **March issue of the HHS Watch** for detailed discussions on some of the interesting data (<http://www.champnetwork.org/index.php?name=news>).

In the mid-1990s, people living with HIV and other AIDS activists demanded community access to the conference, resulting in the creation of a scholarship program for treatment educators and slots for community press, which has been expanded in recent years to include access for people outside the United States. During this conference, CHAMP delivered a letter to members of the CROI governing committee, asking for the addition of community scholarships, specifically for prevention educators and advocates. Our request was favorably received, and we look forward to working with the governing committee to ensure the greater participation of community prevention leaders in next year's gathering.

At the conference, CHAMP released a **statement in support of pre-exposure prophylaxis (PrEP) research** (<http://www.champnetwork.org/index.php?name=press>), which is evaluating if people could be protected from HIV infection if they take antiretroviral medication before acts of risk. Several PrEP trials have been shut down in other countries, over issues of access to treatment for people who may become infected, the provision of prevention equipment like needles in places where they are not currently legally available, and the involvement of community members in trial design and implementation. We support ethical trials for all people in need of prevention options.

Want to get more involved in research advocacy like this? CHAMP is going to train community members as research activists, and there's lots of ways to get started! Contact Julie Davids at [jdavids@champnetwork.org](mailto:jdavids@champnetwork.org) or 401-427-2302 x 10.

## A BIG Thank You to Our Generous Supporters!

In the very cold month of January, two very HOT house parties were held to raise money for CHAMP. Thank you to **Dr. Donna Futterman** and **Rudi Gaudio** for opening up their lovely homes for us, and also to the host committee for the Winter Fundraiser in Queens: **Jacqui Ambrosini, Towfiq Al-Awwal , K. Leonard Chung , Dana-Ain Davis , Sidney Donnell , Rudi Gaudio , Jeff Maskovsky , Roopali Mukherjee , Marvin Peguese , Elayne Tobin , Thomas Uldrick , & Jennie Uleman.** We Love You!

A special Thank You to **GMHC & MZA Events** for making CHAMP a beneficiary of December's **Move Against AIDS Dance-A-Thon**, a truly moving experience!

And to our amazing **individual donors**, we couldn't do it without you!

Judy Auerbach, Towfiq Awwal, Nilanjan Bhattaharya, Renee Blake, Frank Bove, James Braun, Michael P. Carfagna, Ray Cashma, Kasing Chung, Chris Collins, Marcia Collins, Gene Copello, Ted Cornwell, Keith Damsky, Dana-Ain Davis, Annet Davis-Vogel, William Dunmyer, Maria Fiesta, Judith Filc, Benjamin Garcia, Julia Greenberg, Howard Grossman, Mark Hayes, David Jones, Sonia Kandathil, Esther Kaplan, Aslam Karachiwala, Edward Kennelly, Ann Kleiman, Lola Maskovsky, Ben Maulbeck, Kenneth Mayer, Michael Mazier, Kelly McGowan, Moriah McGrath, Paul Meissner, Susan Mikula & Rachel Maddow, Akiko Mitsui, Kimii Mitsui, Kim Nichols, Judith Peters, George Phillips, Joey Reynolds, Bryan Roberts, Katie Romansky, Matthew Ruben, Robert Scarpa, Aleza Summit, Healy Thompson, Steven Tierney, Shawn Towey, Sasha Vodnick, Steven Weisman, Andrea Williams, Case Willoughby, Dan Wohlfeiler, Susan Wolfson, John Won, Barbara Zeller & Alan Berkman

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## CHAMP Staff

### Sean Barry

Director of Prevention Policy  
[sean@champnetwork.org](mailto:sean@champnetwork.org)

### Lei Chou

Director of Mobilization  
[leichou@champnetwork.org](mailto:leichou@champnetwork.org)

### Julie Davids

Executive Director  
[jdavids@champnetwork.org](mailto:jdavids@champnetwork.org)

### Sarah Howell

Program Coordinator  
[showell@champnetwork.org](mailto:showell@champnetwork.org)

### Sonny Suchdev

Community Organizer  
[sonny@champnetwork.org](mailto:sonny@champnetwork.org)

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594 Broadway, Suite 700  
New York, NY 10012

293 Oxford Street  
Providence, RI 02905

212.966.0466 x 1206  
[champ@champnetwork.org](mailto:champ@champnetwork.org)  
[www.champnetwork.org](http://www.champnetwork.org)