



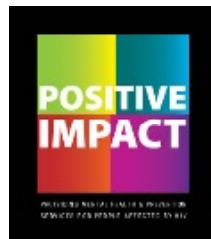
# RESEARCH ADVOCACY FOR HIV PREVENTION:

Setting a Prevention Justice Research Agenda

Sunday, Dec 2<sup>nd</sup>, 2007

9:00 am to 4:00 pm

The Cairo Room at the Hyatt Regency  
265 Peachtree Street NE, Atlanta, GA



This Training is organized by the Community HIV/AIDS Mobilization Project (CHAMP) and the AIDS Vaccine Advocacy Coalition (AVAC) in collaboration with AIDS Research Consortium of Atlanta, amfAR, Gay Men's Health Crisis (GMHC), Global Campaign for Microbicides, LA Gay & Lesbian Center, Positive Impact, and The Michael Palm Basic Science, Vaccines & Prevention Project of Treatment Action Group (TAG).

## Welcome and Introductions

### **Julie Davids, Executive Director, CHAMP**

Welcome participants. This training is an affiliated event of the Prevention Justice Mobilization (PJM). PJM was initiated by CHAMP & several partners & has over 350 organizational and individual endorsers for our principles – we need more RESOURCES for HIV prevention; we need more RESEARCH for better options; and we need REALITY-BASED prevention policies that would include the social and structural factors that create greater vulnerabilities to HIV for so many people in this country.

See <http://preventionjustice.org> for more information.

### **Waheedah Shabazz-el, ACT UP Philadelphia & CHAMP**

Thank you to all the cosponsors of this day-long training.

Before we begin, I just wanted to say something about HIV prevention research advocacy, and why it is so dear to me. I am a PWA and I sit on several community advisory boards (CABs) in Philadelphia. I could not grasp what it was that I was suppose to do in those meetings, other than eat a lot of chicken! The only substantial thing we did was to go over informed consent documents. But even this did not feel like offering much input, because we gave our comments after they were already written.

Julie Davids and CHAMP had the idea to go to meetings and conferences where these scientists are, get on working groups, and give input on the ground floor when they are developing concepts. So we started doing that. We were invited by the director of the HIV Prevention Trials Network (HPTN) to attend their meetings. Yet, folks did not know why we were there. They would come right out and ask us: “Why are you here?” We would respond: “We are community representatives.” Then they would respond “You don’t belong here, Are you in the right place? Do you know where you are?” And I would respond, “Yes, I’m in the right place because you are talking about HIV!” After a while, they got used to us being around and started looking forward to us being around. Once the scientists understand why we were there — not to challenge them, but to actually enhance the process and give the point of view from the community — they really welcomed it.

The lack of community participation in AIDS research is dangerous for our communities and us. I didn’t know who was speaking “for me”, I didn’t understand what they were saying “about me”, I thought that I should be there speaking for myself and for people living with AIDS. This is why it is important for me to be in that space and participate in the process.

So I want to encourage people who sit on community advisory boards: “Don’t be fooled by the chicken!” There is more to this thing than some chicken. We need to get into those meetings and conference, sit in the working groups, raise our hands and volunteer. When they started putting me on the agenda, and I actually have a space to talk, then I know I’m an important part of the process. We need to make sure that we get into these spaces as people working in the community. This is why I’m involved in prevention research advocacy, because who knows better about what is going on in my community than me?

We have a lot of experts here, and it’s going to be an exciting day. Thanks.

# AGENDA

## **Moderators:**

Waheedah Shabazz-El, Community HIV/AIDS Mobilization Project  
Mark McLaurin, New York State Black Gay Network

### **1. What is prevention research?**

This session will provide a general overview of the complex field of HIV prevention research, including discussions on three major areas under investigation:

1. Bio-medical – such as vaccines, microbicides, and pre-exposure prophylaxis;
2. Behavioral/Social – such as condom use and harm reduction; and
3. Structural – such as affordable housing, prison reform, and access to healthcare.

## **Presenters:**

Judy Auerbach, San Francisco AIDS Foundation  
Monica Ruiz, amfAR  
Walt Senterfitt, Community HIV/AIDS Mobilization Project

### **2. How does prevention research happen?**

This session will examine the process researchers use to find out if a particular intervention can prevent HIV in the real world, and the key role of community participation in providing this answer. Presenters will use examples from recent prevention research studies to:

1. Explore research challenges of HIV prevention in the real world;
2. Discuss the relationship between research institutions and communities throughout the clinical trial process, from preparation to follow up;
3. Address key considerations for ensuring safety of trial participants; and
4. Identify potential emerging issues during the research process.

## **Presenters:**

Paula Frew, The Hope Clinic, Emory University Vaccine Center  
Melanie Thompson, AIDS Research Consortium of Atlanta  
Anna Forbes, Global Campaign for Microbicides

### **3. Where do prevention research happen, and who sets the agenda?**

This session will provide a broad overview of existing research infrastructures (NIH, CDC, etc.), current prevention research agendas (domestic and international), and opportunities for community participation.

## **Presenters:**

Judy Auerbach, San Francisco AIDS Foundation  
Julie Davids, Community HIV/AIDS Mobilization Project  
Emily Bass, AIDS Vaccine Advocacy Coalition

### **4. Why do we need prevention research advocacy?**

This activist and researcher panel will engage participants in a dialogue on critical perspectives on HIV prevention research, using current issues to provide context for important advocacy questions that must be answered.

## **Panelists:**

Greg Millett, Centers for Disease Control and Prevention  
Waheedah Shabazz-El, Community HIV/AIDS Mobilization Project  
Emily Bass, AIDS Vaccine Advocacy Coalition  
Walt Senterfitt, Community HIV/AIDS Mobilization Project

# RESEARCH ADVOCACY FOR HIV PREVENTION: Setting a Prevention Justice Research Agenda

## Presenter Biosketch

**Judith D. Auerbach, Ph.D.** is the Deputy Executive Director for Science and Public Policy at the San Francisco AIDS Foundation (SFAF), where she is responsible for developing, leading, and managing SFAF's local, state, national, and international science and policy agenda. Prior to joining SFAF, Dr. Auerbach served as Vice President, Public Policy and Program Development, at amfAR (The Foundation for AIDS Research), where she headed amfAR's Public Policy Office in Washington, D.C. Dr. Auerbach came to amfAR in 2003, after serving from 1995 to 2003 as Director of the Behavioral and Social Science Program and HIV Prevention Science Coordinator in the Office of AIDS Research at the National Institutes of Health (NIH).

Dr. Auerbach received her Ph.D. in sociology from the University of California, Berkeley, in 1986, and taught sociology at Widener University and the University of California, Los Angeles. She has published and presented in the fields of AIDS, health research and science policy, and family policy and gender. Dr. Auerbach's current research interests focus on developing basic and intervention approaches to health promotion and disease prevention, taking into account the interplay of biological, behavioral, and social factors; and the social organization of scientific knowledge. Dr. Auerbach received the 2004 Feminist Activist Award from Sociologists for Women in Society in recognition of her work on women and HIV/AIDS, the 2005 Mentor Award from the Public Leadership Education Network (a consortium of women's colleges) for service as a role model and mentor to PLEN students, and a 2006 Research in Action Award from the Treatment Action Group for her career in AIDS research and policy.

**Emily Bass** has worked as an AIDS advocate, activist and scientific writer for the last ten years. She is currently at the AIDS Vaccine Advocacy Coalition in New York City, where she works on publications and program activities focused on the well-designed, ethical prevention trials and rapid implementation of existing prevention strategies. She has spent the past seven years traveling to and working in Uganda, and is writing a book about AIDS treatment roll out there.

**Julie Davids** is the Executive Director of CHAMP (Community HIV/AIDS Mobilization Project), a national HIV/AIDS policy, organizing and training organization with offices in New York City, Los Angeles and Providence, RI. CHAMP is dedicated to recruiting, training and mobilizing an independent and powerful HIV/AIDS movement in the United States, and ensuring the development of a broad and effective range of HIV prevention options and improved policies worldwide. She is a founding member and former community organizer with Health GAP, which has successfully organized efforts to change U.S. trade and pharmaceutical industry policies that have blocked access to low-cost medication for people with HIV in poor nations and regions. She is the former Director of Leadership Development and Advocacy for Philadelphia FIGHT, the largest comprehensive HIV/AIDS organization in Pennsylvania, where she co-founded Project TEACH (Treatment Education Activist Combating HIV), an innovative training and community education program for people living with HIV. As an active member of ACT UP Philadelphia since 1990, Ms. Davids focused on HIV treatment research advocacy and served on the Community Constituency Group of the AIDS Clinical Trials Group. For two years, Ms. Davids served as Director of the Critical Path AIDS Project, founded by Kiyoshi Kuromiya, which provides Internet services to low-income people living with HIV and leads advocacy efforts on HIV/AIDS treatment and research issues. Ms. Davids earned a B.A. from Temple University and was a 2002-03 Charles H. Revson Fellow at Columbia University.

**Anna Forbes**, a widely published writer, community organizer and activist, has worked in HIV/AIDS since 1985 and in women's health care and human rights advocacy since 1977. A public advocate for the development of non-condom HIV prevention tools since 1992, she now serves as Deputy Director for the Global Campaign for Microbicides. Anna's writing has appeared in the *AIDS and Public Policy Journal*, *AIDS Policy and Law*, *Harvard Health Policy Review*, *PLOS/Medicine*, the *New York Times*, *Newsweek* and other journals and periodicals. She has also contributed to anthologies including *Our Bodies Ourselves* and is the author of eight children's books on HIV/AIDS.

**Dr. Paula Frew** is currently the Director of Health Communication and Applied Community Research at The Hope Clinic of the Emory Vaccine Research Center, Emory University School of Medicine. She is responsible for the development and oversight of the clinic's communication and community education practices, and for overseeing its behavioral research agenda. She also leads an evaluation team for the Project LINK initiative—a project developed in collaboration with partner agencies and community—to reduce HIV incidence among minority women living in one of Atlanta's high risk zones.

She has been with Emory University for over 10 years, previously working as Asst. Director of Educational Programs in the School of Medicine and as Project Director/Senior Editor for the CDC HealthComm Key project – Center for Public Health Communication and on “Project X” – Club Drugs and HIV Risk in Young Adults at the Rollins School of Public Health.

She holds an undergraduate degree from the University of California at San Diego, an MA degree in Liberal Arts: Health, Culture, and Society from San Diego State University, an MPH degree in Prevention Science from Emory University, Rollins School of Public Health, and a PhD in Health Promotion and Behavior from the University of Georgia (College of Public Health).

She is an active investigator and has authored several published papers in peer reviewed journals on health communication practices, HIV/AIDS vaccine trial and vaccine acceptability issues, and the role of community engagement in prevention research. She has produced a number of community education projects while at the Hope Clinic, notably the award-winning “Hope for Humanity” exhibit at Fernbank Museum, and co-produced the “Hope in Our Soul” faith-based HIV vaccine program with community partner organizations. She has been an organizer of several community events such as the Hope Springs Eternal 5K fun run/walk each spring, HIV vaccine awareness day, and the annual volunteer appreciation day at the Hope Clinic. She also serves as a faculty mentor and advisor to several undergraduate and graduate students each year from Emory University, Agnes Scott College, and other local colleges.

**Robert E. Fullilove, EdD** is the Associate Dean for Community and Minority Affairs and Professor of Clinical Sociomedical Sciences at the Mailman School of Public Health of Columbia University. He currently co-directs the Community Research Group at the New York State Psychiatric Institute and Columbia University along with his wife, Mindy Thompson Fullilove, MD. They are also co-directors of a newly formed degree program in Urbanism and the Built Environment in the Department of Sociomedical Sciences at the Mailman School of Public Health.

Dr Fullilove has published numerous articles on minority health with a particular focus on HIV/AIDS and sexually transmitted diseases, as well as papers on such topics as mathematics and science education. From 1995 to 2001, he served on the Board of Health Promotion and Disease Prevention at the Institute of Medicine (IOM) at the National Academy of Sciences. Since 1996, he has served on five IOM study committees that have produced reports on a variety of topics including substance abuse and addiction, HIV/AIDS, tuberculosis, and damp

indoor spaces and health. In 2003 he was designated a National Associate of the National Academies of Science, an honor bestowed by the Academies for those who have made “significant contributions” to its work. In 1998 he was appointed to the Advisory Committee on HIV and STD Prevention (ACHSP) at the Centers for Disease Control, and in July 2000, he became the committee’s chair, serving in that capacity until fall 2004. Finally, in 2004, he was appointed to the National Advisory Council for the National Center for Complementary and Alternative Medicine at the National Institutes of Health [NIH].

Dr Fullilove serves on the editorial boards of the journals Sexually Transmitted Diseases, and the Journal of Public Health Policy. He is fluent in French and is a frequent lecturer at the Conservatoire National des Arts et Métiers [The National Conservatory of Arts and Trades] in Paris. He has twice been awarded the Distinguished Teaching Award from the graduating class at the Mailman School of Public Health, and in May 2002, he was awarded an honorary doctorate from Bank Street College of Education.

**Mark Jason McLaurin** is the Executive Director of the New York State Black Gay Network, the nation’s only staffed statewide policy and advocacy coalition dedicated to improving the overall health and wellbeing of black gay men. Mark has been working in the field of HIV/AIDS Prevention Policy for nearly ten years and serves on the Board of Directors of CHAMP (Community HIV/AIDS Mobilization Project), is a board officer of the National Black Gay Mens Advocacy Coalition and serves as Chairman of the Board of the House of Manolo Blahnik (an entity which seeks to target the ballroom community with effective HIV prevention messaging). Mark is a graduate of the Catholic University of America, Human Rights Campaign’s Youth College for Campaign Training and the Black AIDS Institute’s African American HIV University. Previous stints include service as Policy Advisor to United States Senator Barbara A. Mikulski (D-MD), Midwest Regional Director for National AIDS Education and Services for Minorities and Director of HIV Prevention Policy for Gay Mens Health Crisis. Mark dedicates his work to the memory of countless loved ones gone much too soon.

**Gregorio Millett, M.P.H.** is a behavioral scientist at the Division of HIV/AIDS Prevention (DHAP) at the U.S. Centers for Disease Control and Prevention (CDC). He is the lead scientist for Brothers y Hermanos, a large multisite study investigating social and cultural factors associated with the high rates of HIV infection among Latino MSM and black MSM. Mr. Millett is also the lead scientist on an exploratory study that employs respondent driven sampling to target black bisexual men. He has published in the American Journal of Public Health, American Journal of Preventive Medicine, AIDS, Sexually Transmitted Diseases, Journal of Acquired Immune Deficiency Syndromes, Archives of Sexual Behavior as well as other medical and public health journals, and has presented at numerous professional conferences about HIV and minority MSM. Mr. Millett was among the team of CDC scientists who investigated the 2003 HIV outbreak among young Black MSM in North Carolina. Mr. Millett earned a B.A. from Dartmouth College, received his Masters of Public Health from the University of North Carolina, Chapel Hill, and is a doctoral candidate at the University of Alabama, Birmingham.

**Monica S. Ruiz, Ph.D., M.P.H.** is the Acting Director for Public Policy at amfAR, The Foundation for AIDS Research. Prior to joining amfAR, she was the sole behavioral scientist and the Acting Chief of the Prevention Sciences Branch, Division of AIDS, at the National Institutes of Allergy and Infectious Diseases, National Institutes of Health. In this capacity, she worked primarily with the HIV Prevention Trials Network, a worldwide collaborative clinical trials network that develops and tests the safety and efficacy of primarily non-vaccine interventions designed to prevent HIV transmission.

Dr. Ruiz received her doctorate in Preventive Medicine from the University of Southern California School of Medicine and her Masters degree in Public Health from the University of

California, Berkeley. Dr. Ruiz' current interests include addressing behavioral and policy issues pertaining to the development and implementation of non-vaccine HIV prevention strategies and strengthening the advocacy and community constituency bases for HIV prevention.

**Walt Senterfitt, Ph.D.**, a gay man living with AIDS, is an epidemiologist who served as a Visiting Scientist at the CDC's Division of HIV/AIDS Prevention, coordinating demonstration projects of HIV prevention interventions with HIV positive people. He currently serves as the Chair and Administrator of the Institutional Review Board for the Los Angeles County Department of Public Health. His special focus as a public health official has been to increase the active collaboration of researchers and policy makers with the community constituencies that are the targets and intended beneficiaries of the research and policy. He can speak on prevention with positives, and a broad range of prevention research and prevention policies. Walt also serves as the Chair of the Community HIV/AIDS Mobilization Project (CHAMP), and is involved with Being Alive/Los Angeles and the Southern California HIV/AIDS Coalition.

**Waheedah Shabazz-el** is the community organizer & trainer at the Community HIV/AIDS Mobilization Project. She is a 54 year old African American Muslim female who was diagnosed with AIDS in 2003. She is a retired Postal Worker with 20 years of service to the United States Government. Waheedah is a Peer Educator/Consultant for Philadelphia Fight, is certified by the Philadelphia Department of Health in HIV Prevention, serves as an organizer for the Philadelphia County Coalition for Prison Health-Care and is a member of the PRHCN (Prison Re-Entry Health-Care Network). She also works with ACT-UP Philadelphia, works as Co-coordinator Prevention Justice Partnership with CHAMP and sits on the Positive Committee for The Office of HIV Planning in Philadelphia.

**Dr. Melanie Thompson** has been involved in HIV research as Principal Investigator of the AIDS Research Consortium of Atlanta (ARCA) since 1988. ARCA is a community-based research center involving over 50 private doctors and 5 public clinics in Atlanta. She has served as principal investigator on over 275 clinical trials of therapies to treat HIV and its complications and has served on national HIV guidelines panels since 1989, including the IAS-USA Antiretroviral Guidelines Panel since its inception. She is a former chair and current member of the National Institutes of Health, Office of AIDS Research Therapeutics Research Working Group.

She has become increasingly involved in HIV prevention research over the last few years and currently is one of three principal investigators for the CDC-sponsored US study of tenofovir for HIV prevention in HIV-negative men who have sex with men. She also has conducted two large studies of HIV prevention with persons who are HIV-positive. Currently she is principal investigator of a CDC-sponsored study testing strategies for African-American men who have sex with men. Dr. Thompson oversees ARCA's Metro Atlanta Women of Color Initiative (MAWOCI) and Synergy Atlanta projects. Both are mobile community outreach programs offering free HIV rapid testing and/or STD testing, prevention education and linkage to care. Dr. Thompson has recently been an advisor to the AIDS Personal Public Service Announcement Project, a joint venture of the New Media Institute of the University of Georgia and Verizon Communications.

Most importantly, she is actively involved in the primary care of persons with HIV infection in Atlanta, from whom she derives the passion and inspiration for her ongoing work in HIV research.