

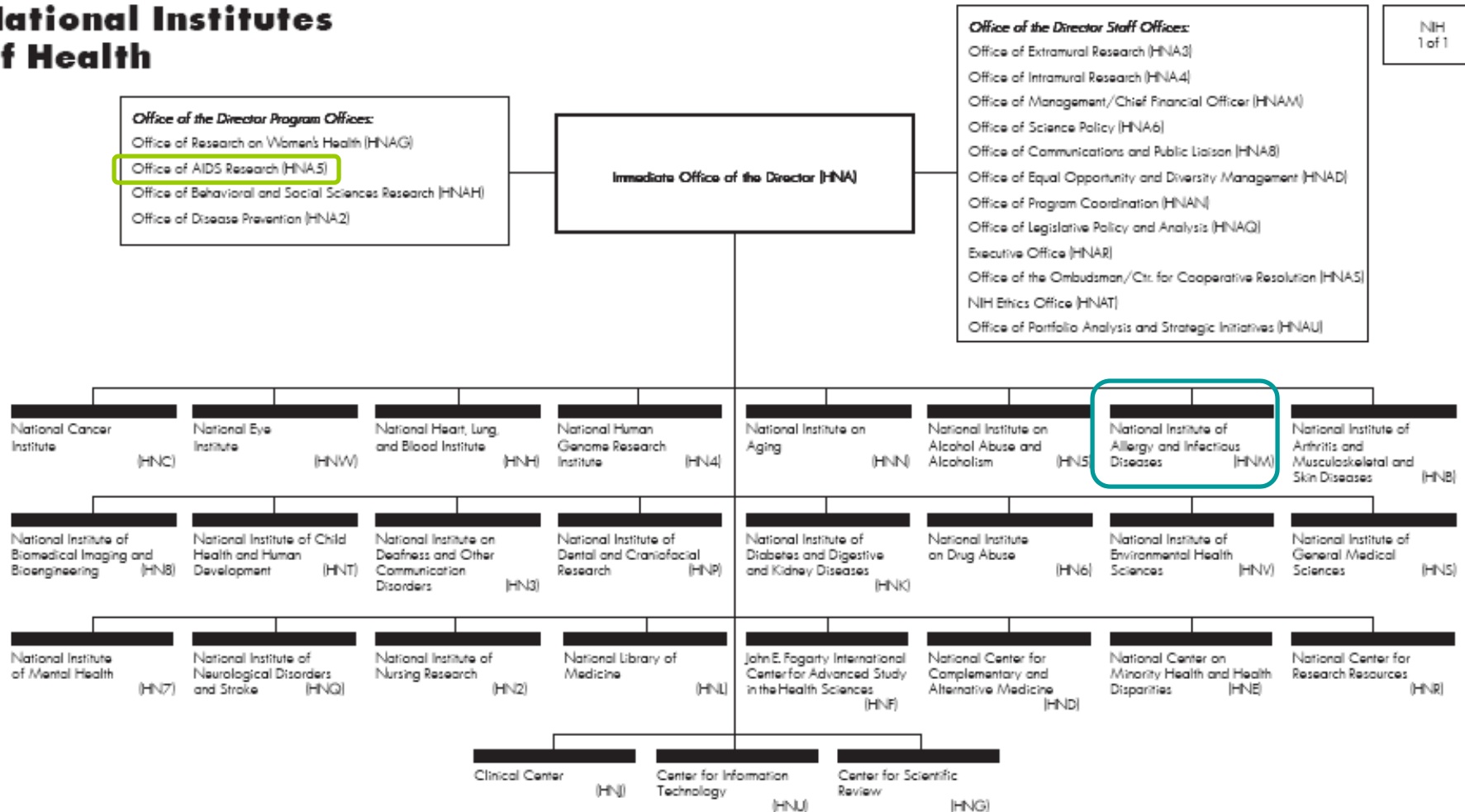
# Building and Maintaining Partnerships in HIV Vaccine Research

May 6, 2009

**Rona Siskind, MHS**  
**Division of AIDS, NIAID, NIH, HHS**



# National Institutes of Health



Web site: <http://www.nih.gov>

# NIAID's Clinical Research Priorities for HIV/AIDS

**Translational  
Research /  
Drug  
Development**

**Mother to Child  
Transmission**

**Microbicides**

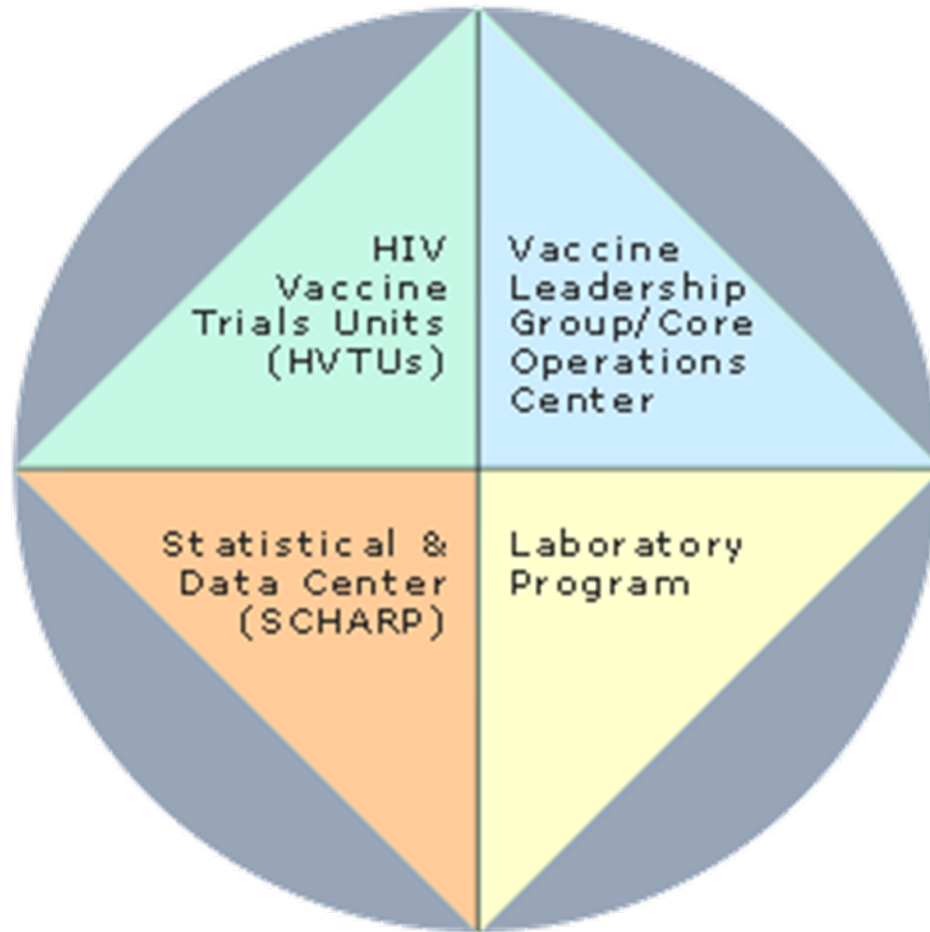
**HIV  
Vaccines**

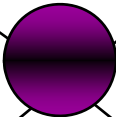
**Prevention of  
HIV  
Infection**

**Optimization of  
Clinical  
Management  
including  
Co-Morbidities**

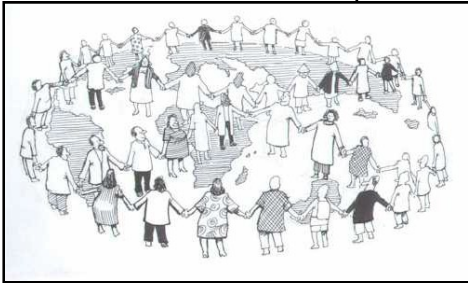
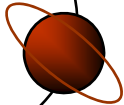
**Populations**

# HIV Vaccine Trials Network (HVTN)





# Our Universe





STOP AIDS!  
NO HEALTHCARE  
FOR LESBIAN,  
GAY, BISEXUAL  
PEOPLE'S ANTI...

ALZ1  
2  
WASTED  
YEARS

YOU  
ARE  
KILLING US

DR. FAUCI,  
YOU  
ARE  
KILLING US



FEDERAL AIDS TREATMENT RESEARCH, RUN BY THE NATIONAL INSTITUTES OF HEALTH (N.I.H.)...  
LET THE RECORD SHOW...TEN YEARS...ONE BILLION DOLLARS...ONE DRUG

# STORM THE N.I.H.



**MAY 21.** INFO: 212-989-1114

# Community

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- **NIAID/DAIDS** requires community involvement in all aspects of the research process and organization - site, network and cross-network level
- **Goals:**
  - Build trust
  - Information exchange - between NIAID, researchers and community
  - Voice for study participants and community
  - Facilitate dissemination of research results in the broader community

# Clinical Research Priorities

**Translational  
Research /  
Drug  
Development**

**Mother to Child  
Transmission**

**Microbicides**

**HIV  
Vaccines**

**Prevention of  
HIV  
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**Optimization of  
Clinical  
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including  
Co-Morbidities**

**Community Partners**  
**Populations**

# HVTN – Community Engagement

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- **The HVTN:**
  - **Commits human resources at every level of scientific development and governance to ensure communities are engaged and have input**
  - **Believes that well-informed communities contribute to better science, helping to foster trust and mutual understanding of research issues**

# Community Education Unit

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## **Provides Staff support for**

- ☑ Community educators and recruiters at sites
- ☑ Local Community Advisory Boards (CABs)
- ☑ Global CAB (GCAB) and its working groups on Scientific issues and Ethics



## **Trains/educates on relevant topics**

- ☑ Vaccine science
- ☑ Ethics
- ☑ How to read a protocol



## **Develops and distributes**

- ☑ The CAB Bulletin

# HVTN Legacy Activities

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- ✓ **Build partnerships**
- ✓ **Conduct primary research**
- ✓ **Implement pilot projects at sites to increase priority population involvement in HIV vaccine trials**
- ✓ **Conduct targeted community education**
- ✓ **Develop a cultural competency program**
- ✓ **Policy development for vaccine trial conduct**



published online August, 2005

# JAIDS

## **Assessing the Attitudes, Knowledge, and Awareness of HIV Vaccine Research Among Adults in the United States**

M. Allen et al.

**Telephone Survey by NIAID's HIV Vaccine Communications Campaign of 2,000 members of the general population and 500 each of African Americans, Hispanics, and MSM in selected U.S. cities.**

# Results of NIAID Survey

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- **Majority of respondents across groups believe an HIV vaccine is the best way to control and end the global AIDS epidemic.**
- **People believe that an HIV vaccine already exists and is being kept a secret**
  - **47.1% African-Americans**
  - **26.5% Hispanics**
  - **13.4% MSM**
- **Many incorrectly believed that the HIV vaccines being tested could cause HIV or they didn't know if they could**
  - **78% African-Americans**
  - **57.5% Hispanics**
  - **68% MSM**

# Study participation that reflects demographics of the epidemic would be optimal

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- **US HVTN trials 2004-06**  
(incl STEP all US sites)
  - 37% Female  
63% Male
  - 60% White  
26% Black  
9% Hispanic/Latino  
5% Asian/Pacific Islander  
Native American,  
multiracial and other
- **New infections, 2006 †**
  - 27% Female  
73% Male
  - 35% White (11.5\*)  
44% Black (84\*)  
17% Hispanic/Latino (29\*)  
2% Asian/Pacific Islander  
1% Native American  
1% other

\*rate per 100,000

# NIAID HIV Vaccine Research Education Initiative (NHVREI)

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- **Increase awareness of need for an HIV vaccine**
- **Improve public's knowledge of and attitudes toward HIV vaccine research**
- **Enhance partnership between community and researchers**
- **Create support for current and future HIV vaccine trials**
- **Project implemented by AED/GYMR**

# NHVREI Activities

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- **Research and Consultation**
- **Materials and Message Development and Dissemination**
- **Media-related Activities**
- **Partnership Development and Outreach**

# NHVREI Plans for 2009

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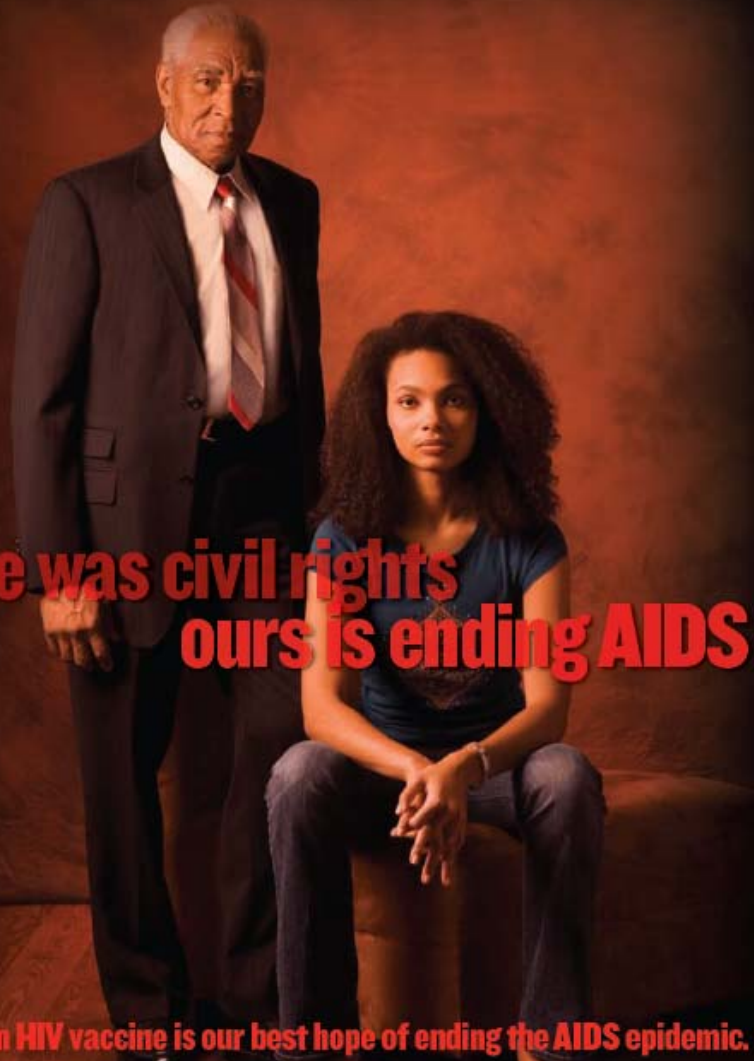
- **Launch the NHVREI Network**
  - Plans for up to 25 national or regional organizations/coalitions
- **Renewal and Expansion of Local Partnership Program**
- **Formative Research & New Materials**
  - Stakeholder interviews, focus groups, concept testing for new materials
- **Subject Matter Expert Consultation**
  - Focus on engaging African-Americans in HIV vaccine research
- **Ongoing Conference Outreach, Community Engagement & Media Relations**

# Summary

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- **Trust is essential for individuals and communities to support and participate in HIV vaccine research.**
- **By providing accurate information and engaging in conversations about HIV vaccine research we hope to strengthen our partnerships and continue to build trust.**

**Every generation has its great cause.**



**mine was civil rights  
ours is ending AIDS**

**An HIV vaccine is our best hope of ending the AIDS epidemic.**

Right now, there is no vaccine to prevent HIV infection. But scientists are working to find one. To succeed, they will need people from all walks of life to support HIV vaccine studies and encourage those who volunteer. Learn more about how you can do your part. Visit <http://betheneration.nih.gov>. Together, we can be the generation that ends the AIDS epidemic. E-mail [betheneration@nih.gov](mailto:betheneration@nih.gov) for more information.

HIV VACCINE RESEARCH  
The Road to a Cure Starts Here



**be the generation.nih.gov**

Recommendations for Community Involvement  
in National Institute of Allergy and Infectious Diseases  
HIV/AIDS Clinical Trials Research



February 2009

**NIAID**

[www.niaid.nih.gov](http://www.niaid.nih.gov)

**Division of AIDS (Organization)**

<http://www3.niaid.nih.gov/about/organization/daids/>

**Community Partners (Network Coordination)**

<http://www3.niaid.nih.gov/about/organization/daids/Networks/daidsnetcoord.htm>