

# Questions TO ASK YOUR DOCTOR

Be prepared before you go see your doctor. Here are some helpful suggestions.

- Plan ahead!
- Write down questions to ask
- Ask a friend or relative to come with you to talk to the doctor
- Listen carefully to what the doctor says to your questions
- If you have questions or concerns, ask how to get in touch with the institutional review board. Protect your rights!

If you are thinking about participating in a preventive HIV vaccine clinical trial, here is a list of questions you might consider asking your doctor:

- What kinds of tests and treatments are involved?
- Will the study change my daily life?
- How long will the study last?
- Will I need to stay in the hospital?
- Who will pay for the study? Will I be paid?
- Who will take care of my health during and after the research study?
- How will I know the treatment worked? Will I be told the results of the study?



# Key Facts ABOUT HIV VACCINE RESEARCH

- There is no HIV vaccine available.
- It is impossible to get HIV from an HIV vaccine. People can only get HIV from their own behaviors.
- Volunteers for a preventive HIV vaccine trial must be HIV negative.
- In order for a preventive HIV vaccine to work for all people, all races, ethnicities and genders must be represented in clinical trials.
- Currently, not many African Americans are represented in clinical trials.
- The best long-term hope for controlling the spread of HIV is developing a preventive HIV vaccine.
- A complete approach to controlling AIDS includes prevention, care, treatment, and HIV vaccine research.

# Resources IN WASHINGTON D.C.

## FOR MORE INFORMATION ABOUT PREVENTIVE HIV VACCINE RESEARCH CONTACT:

Community Education Group  
729 8th St SE; Washington, DC 20003  
<http://www.communityeducationgroup.org>  
(202) 543-2376



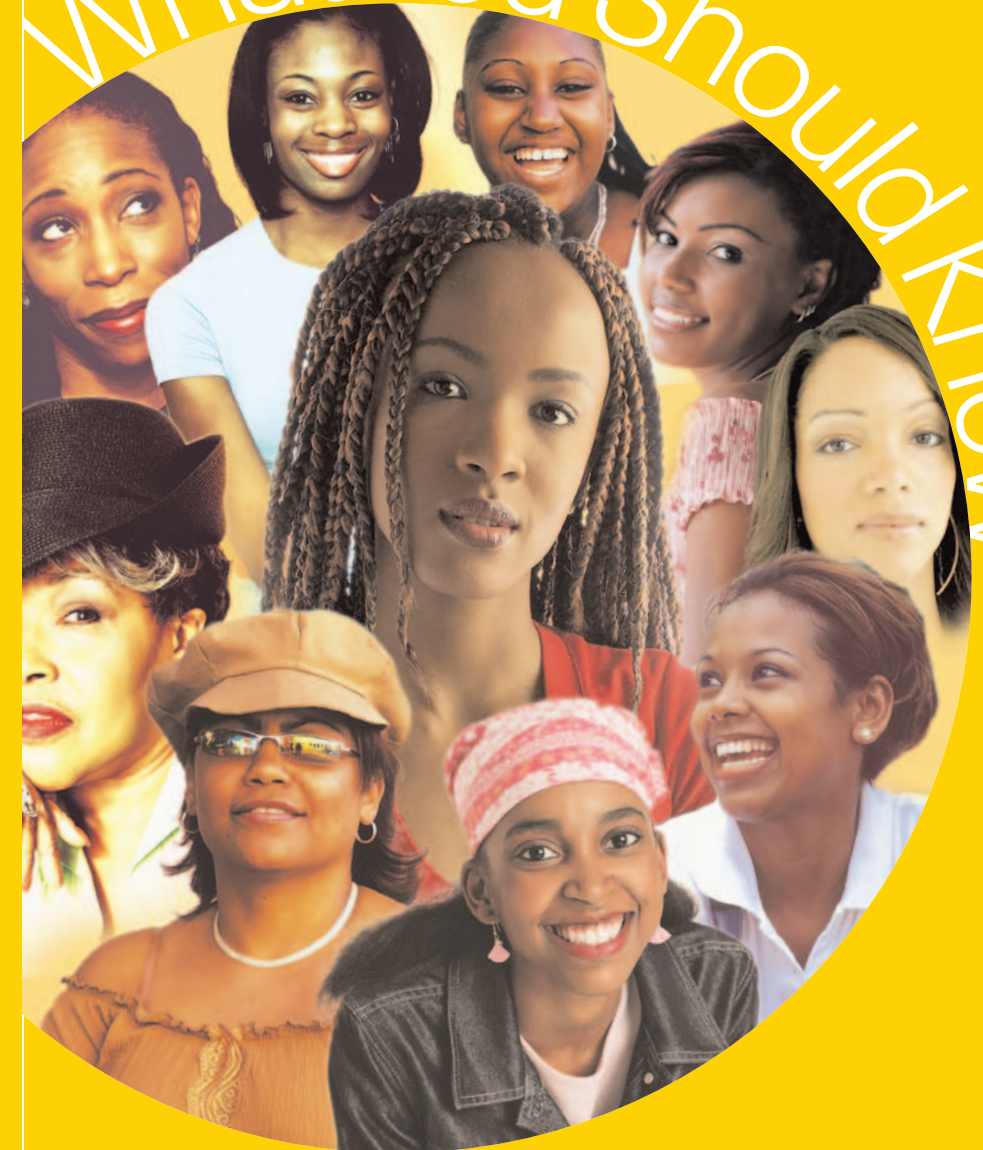
Vaccine Research Center: <http://vrc.nih.gov>

National Institute of Allergy and Infections Disease,  
National Institutes of Health  
<http://www.niaid.nih.gov/daids/vaccine>

AIDS Info Hotline: 1-800-448-0440

INTERESTED IN VOLUNTEERING: 1-866-833-LIFE (5433)

# What You Should Know



Preventive HIV Vaccines

# Be Informed

GETTING IT RIGHT

# Myths to Truths

# Research

TO FIND A PREVENTIVE HIV VACCINE: COMMON QUESTIONS

## WHY SHOULD AFRICAN AMERICAN WOMEN LEARN MORE ABOUT PREVENTIVE HIV VACCINES?

African American women are one of the groups most affected by HIV and AIDS in the United States. Many African Americans do not know much about HIV and HIV vaccine clinical trials. If we want to stop this disease from affecting our community, we have to understand HIV and all the ways to stop it. Here are a few reasons why women — and all African Americans — should learn more about HIV vaccine research:

- In the U.S., African Americans make up about 46% of all new HIV infections each year
- In the U.S., African-American women make up about 67% of new AIDS cases among women.
- Certain drugs might not work the same in all racial or ethnic groups, so everyone needs to be represented in the trials
- A vaccine is our best hope for stopping the spread of HIV

## A FEW DEFINITIONS

To start, here are some words that we should all know about HIV, AIDS, and HIV vaccines.

### HIV (Human Immunodeficiency Virus)

- HIV is the virus that causes AIDS
- HIV weakens the body's defense system (called the immune system) so that it cannot fight illness
- HIV is spread by unprotected sex, injection drug use, and mother to child
- HIV is in blood, semen, vaginal secretions, and breast milk
- Nobody can tell just by looking whether or not a person has HIV; the only way to know for sure is through a blood test

### AIDS (Acquired Immune Deficiency Syndrome)

- AIDS is the late stage of HIV infection
- At this point, a person might have many symptoms like fever, weight loss, infections, diarrhea, herpes, and cancer
- Without medical help, a person with AIDS will die

### HIV Vaccine

An HIV vaccine teaches the body's immune system to recognize and fight HIV.

Scientists are working on two types:

- Preventive HIV vaccines: Made to stop the virus from infecting people who are HIV negative
- Therapeutic HIV vaccines: Made to treat people who are HIV positive to keep them from getting sick

There are many myths about HIV and preventive HIV vaccine clinical trials. These myths are very harmful to the health of the African American community.

### MYTH

Magic Johnson has beat HIV / AIDS, so no one has to worry it.

### TRUTH

There is no cure for HIV. Medical research has made it possible for many, like Magic Johnson, to live longer, healthier lives.

### MYTH

People can have more unprotected sex while participating in preventive HIV vaccine trials.

### TRUTH

Research study participants do not know if the vaccine will work. They are always encouraged to protect themselves from HIV through:

- Condoms
- Clean syringes
- Treatment of sexually transmitted diseases

### MYTH

HIV is man-made.

### TRUTH

HIV is not man-made. No matter where HIV started, we must act to prevent it from spreading in our community.

### MYTH

You can't trust researchers or doctors. They will allow terrible things to happen to you, like in the Tuskegee Syphilis study.

### TRUTH

While the Tuskegee Syphilis Study was a tragedy, many laws have been created to protect people who participate in clinical trials. Today, all research must be reviewed by groups of people who are there to protect the rights and health of participants.

### MYTH

You can get HIV from a preventive HIV vaccine trial.

### TRUTH

HIV vaccines do not contain the actual virus. Instead, they contain something that looks like HIV, so that the body will make cells that destroy real HIV or anything that looks like it.

### MYTH

Anyone can enroll in preventive HIV vaccine trials.

### TRUTH

There are strict guidelines for volunteers. Rules require that volunteers be:

- Healthy
- HIV-negative
- Between 18 and 50 years old

## IS THERE A PREVENTIVE HIV VACCINE ALREADY AVAILABLE?

No. It took many years for scientists to discover the vaccines that work for other diseases (see chart below). People are still working very hard today to find one for HIV.

## IF I VOLUNTEER, WHAT SHOULD I EXPECT?

A preventive HIV vaccine trial site will provide you with information and answer any questions you may have. After learning more, if you think you want to participate, you will follow these steps:

### (1) Informed Consent

- Interview
- Hear more details about the study and ask questions
- Read and sign a consent form

### (2) Eligibility Screening

- Complete a health questionnaire
- Get blood tests and physical exam

### (3) Vaccination

- Get a vaccine or series of vaccines over the next months
- Keep a record of any physical reactions
- Get more blood tests and physical exams while you participate

## ARE PEOPLE TREATED ANY DIFFERENTLY THAN ANIMALS IN THESE TRIALS?

Yes. Clinical trial volunteers are treated with much care and respect, and their health and rights are a priority. When drugs and vaccines are developed, they are first tested on animals. Only after they are found safe, they are approved by the U.S. Food and Drug Administration (FDA) for human tests. Vaccines then go through three phases:

### PHASE 1

12 to 18 months, 100 to 200 participants, testing safety

### PHASE 2

Up to 2 years, hundreds of participants, testing safety and immune response

### PHASE 3

3 to 4 years, thousands of participants, testing safety and immune response

