Partnering with AIDS Service Organizations to Improve Clinical Trials Participation
Workshop Objectives

• Understand which cancers are prevalent among Women living with HIV/AIDS (WLHA)

• Learn about clinical trials and strategies to educate and refer WLHA clients to AIDS Malignancy Consortium (AMC) clinical trials

• Learn how to access information about AMC clinical trials

• Access referral resources
About the Collaboration

HIV/AIDS and Cancer Community Research Collaboration
Memorial Sloan-Kettering Cancer Center
Gay Men’s Health Crisis
The City College of New York

Cancer Prevention
Cancer Screening
Cancer Treatment/Clinical Trials
Cancer Survivorship

Intervention:
Increasing the Capacity of ASOs to Educate and Refer
(INCASO)
Why have this workshop?

- ↑ cancer incidence among People Living with HIV/AIDS (PLWHA)
- 79% of WLHA are women of color
- Women and minorities are underrepresented among enrollees to cancer clinical trials
- ASOs are on the frontlines of HIV care
- ASOs need capacity-building to address PLWHA cancer concerns
Cancer Risk among PLWHA

- Women with HIV are 6 times more likely to be diagnosed with cervical cancer than are HIV-negative women of the same age.
- Ethnic, racial, and sexual minorities experience:
  - worse cancer outcomes
  - higher overall death rates
- Cancer is a threat to PLWHA who are living longer due to improved HIV/AIDS treatment.
Cancer Risk among PLWHA

- **HIV+ women** smoke at **greater rates** than do women in the **overall U.S. population**.
- The risks for most **smoking-related cancers** (lung, kidney, laryngeal, and stomach cancers) appear to be **greater** among **women** than men.
- **HIV-infected women** have **1.8 times the risk** of anal HPV infection as **HIV-uninfected women**.
Overview of HIV/AIDS and Cancer

Tobacco
Alcohol
Immune System deficits
AIDS-defining cancers
HPV infection
Hepatitis C infection
Chronic diseases
Care continuum
Research: An Overview

- What is Research?
  - Understanding processes in health and disease
  - Discovery and interpretation of facts

- Ethical Problems with Past Studies
  - Willowbrook Hepatitis Study
  - San Antonio Contraception Study
  - PHS Tuskegee Study

- Belmont Principles

- Federal Office of Human Research & Protection
**What are Clinical Trials?**

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<th>What are clinical trials?</th>
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<td>– Research studies that test new prevention strategies, therapies, and treatments in humans</td>
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<th>Why are clinical trials important?</th>
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<td>– Help develop new treatments equal to or better than current ones</td>
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<td>– Increase knowledge and ensure progress against disease</td>
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Phases of Clinical Trials

**Phase 1**
(15-30 people)
To find a safe dose and how treatment should be given
To see how treatment affects the human body

**Phase 2**
(Less than 100 people)
To determine if the new treatment has an effect on a certain cancer
To see how the new treatment affects the human body

**Phase 3**
(From 100 to several thousand people)
To compare the new treatment (or new use of a treatment) with the current standard treatment

**Phase 4**
(Several hundred to several thousand people)
To further assess the long-term safety and effectiveness of a new treatment
Different Types of Clinical Trials

- Prevention
- Screening
- Treatment
- Other types of clinical trials
  - looking at ways to improve comfort and quality of life
  - look at the link between risk factors and disease
Clinical Trials & WLHA: Barriers

**Trust**
- Suspicion about research practices
- Risk of Negligence/Harm
- Guinea Pig

**Culture**
- Language Barrier
- Tuskegee Syphilis Study
- Discrimination (Race, Gender, Sexual Orientation)

**Access to Healthcare**
- Inconvenient (work schedule, child care, transportation)
- Complex consent forms and procedures
- Busy clinical staff

**Knowledge & Attitudes**
- Unclear about what is involved in clinical trials
- Unfamiliar with research terminology
- Belief that their life isn’t valued by clinical staff
Benefits of Clinical Trial Participation to WLHA

- Access to new treatment methods
- One-to-one contact and support
- Play an active role in one’s own health care
- Improving and increasing treatment options for others (Altruism)
Role of the AIDS Service Organization: Many Influences on a WLHA

ASO Staff

Community

Newspapers, Magazines

TV, Radio

Internet

Healthcare provider

Family

Co-workers

Friends

Public Health Policy
Why Should ASOs Recruit and Refer WLHA to AMC trials?

- Dedication to the well-being of PLWHA
- Source of education and prevention resources
- Understand the culture and beliefs of the population
- ASOs can address many barriers to trial participation
Teachable Moments

• Health Fairs and Expos
• Resource personnel (Social Workers, Community workers, Health Educators, etc.)
• Elevators, Hallways, and Waiting areas
• Appointment desks
• Support group sessions
• Social Networking
Clinical Trial Recruitment Process

ASO Community Outreach

ASO Client Pre-Screening

ASO Client Referred to AMC

AMC Eligibility Process

AMC Recruitment (Informed Consent)
Current AMC Trial Opportunities
Resources

• National Cancer Institute (NCI) website
  www.nci.org

• Office of HIV/AIDS Malignancies (OHAM) of the National Cancer Institute http://oham.cancer.gov/

• AIDS Malignancy Consortium Clinical Trials http://pub.emmes.com/study/amc/public/index.htm

• INCASO Resource Guide