

THE STRUGGLE OF A GENERATION AND BEYOND: "WE ARE ALL THE WALKING DEAD"

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- The beginnings of a struggle
- Achievements
- Unfinished agenda



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PNEUMOCYSTITIS CARINII PNEUMONIA AND MUCOSAL CANDIDIASIS IN PREVIOUSLY HEALTHY HOMOSEXUAL MEN

4 homosexual men presented with

- Fevers,
- Pneumocystis carinii pneumonia
- Mucosal candidiasis
- Multiple viral infections
- Kaposi sarcoma
- Low numbers of T helper cells

A NEW ILLNESS: SLIM DISEASE

- 1982: first described in 2 fish landing sites, Lukunyu and Kasensero in Rakai District
- Identified by the population and ascribed it to witchcraft
- It afflicted mainly people who had engaged in illicit trade across the border in Tanzania

Collaborative Science at work:

- A failed investigation, then A successful one
 - No research budget, but inquisitive minds
 - Universities of Makerere, London, Zambia
 - Ministry of Health
 - Public Health Lab, Porton Down, Salisbury, UK
- *** Heterosexual disease (males and females), not transmitted by mosquitoes

Why rural Rakai?

An HIV epicenter

“Slim disease” patients were first identified in Rakai in 1982.

The Lancet · Saturday 19 October 1985

SLIM DISEASE: A NEW DISEASE IN UGANDA AND ITS ASSOCIATION WITH HTLV-III INFECTION

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LEADERSHIP for a truly national response takes shape

- Leadership, leadership and more leadership.....

LEADERSHIP, leadership and more leadership!

- New Government in place

INITIAL RESPONSES

- **1986:** Start AIDS Control Program and **ABC prevention strategy**
- **1987:** Start of The Rakai Research project
: The AIDS Support Organization (TASO), a **home grown NGO** to support PLWA
- **1988:** A **National Sero-survey** conducted to assess the magnitude of the epidemic
- **1990:** Joint Clinical Research Center (JCRC), AIDS Information Center (AIC)
- **1992:** Uganda AIDS Commission started, to coordinate a multisectoral response
- **INTENSE AIDS PREVENTION CAMPAIGNS**

COMMUNITY RESPONSE

- Communities have wisdom, resilience and have offered so much to the HIV response.....Going from despair to hope
- “ This is a struggle for survival of our generation, our children and our grand children: Surely we must all be infected. We are just the walking dead”
- “Shall we ever marry, and why get children who will be born infected and die or who will look after them?”
- “What is the purpose of living”

Rakai STI control for HIV prevention trial



1994-1999

Annual participation rate:
94%

Provided

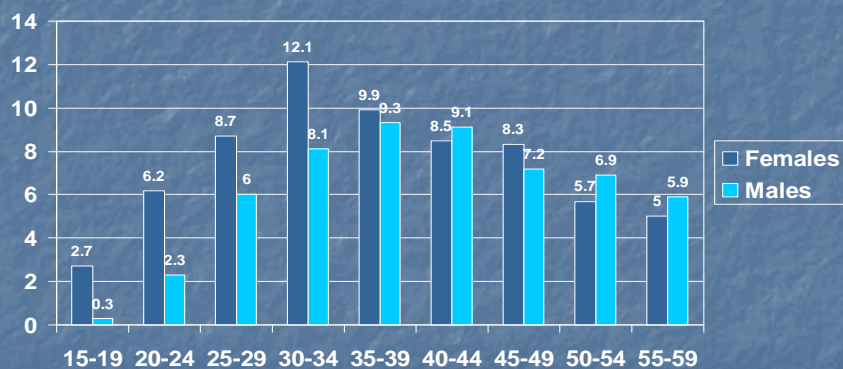
blood:	91%
urine:	94%
vag swabs:	93%

Accepted RX: 95%

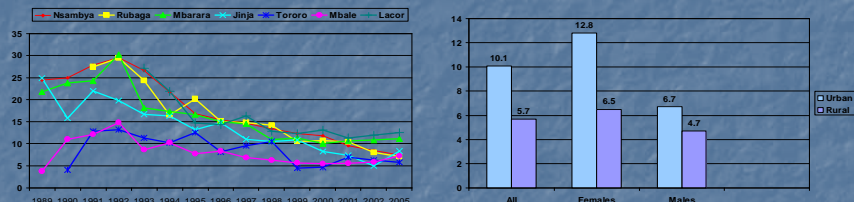
Free Access to Anti-retrovirals

- Announced 2004
 - Global fund
 - Multi-country AIDS program (MAP)
 - PEPFAR
 - Health system challenges towards scaling up

Adult HIV Prevalence by Age and Sex

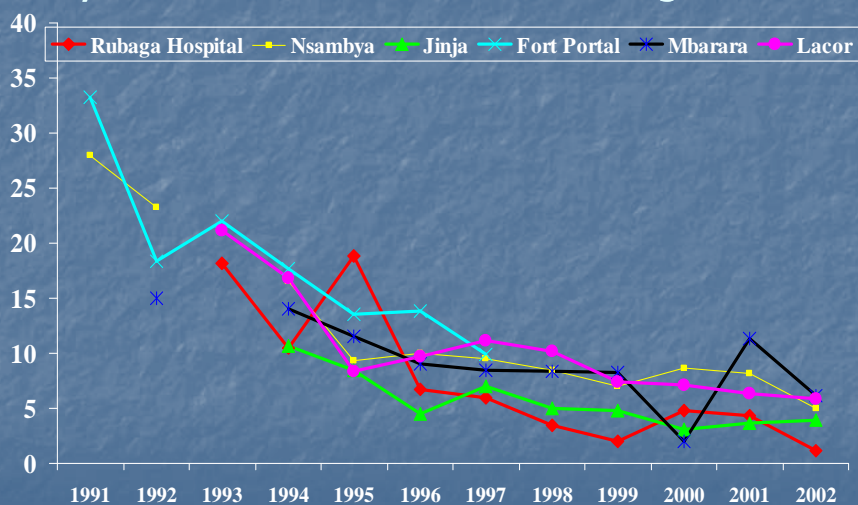


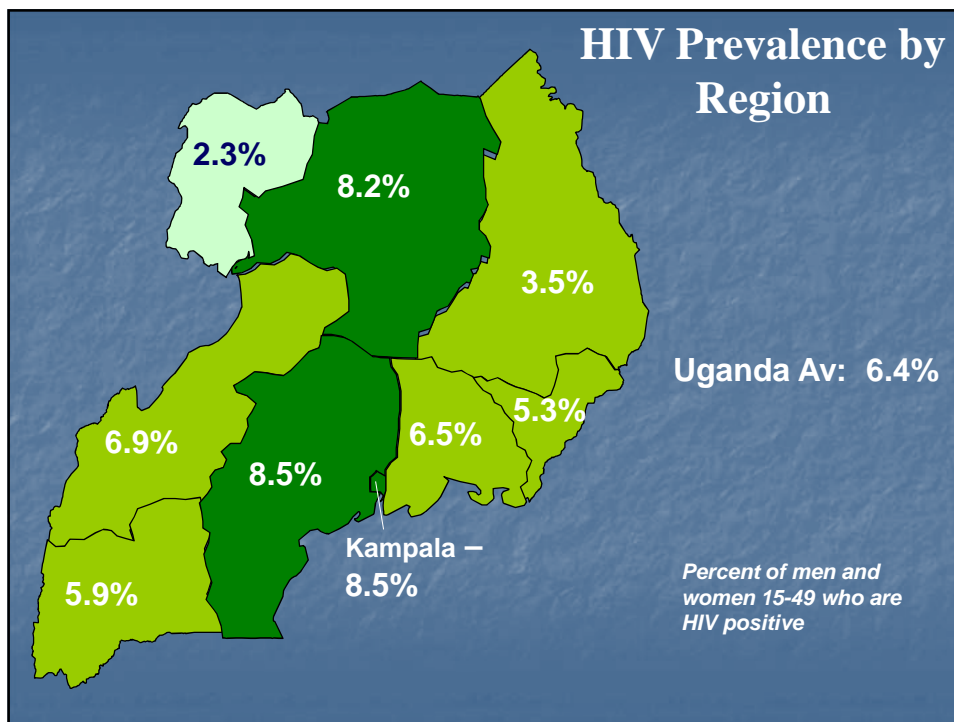
Trend of the Epidemic



- 3 distinct phases of the epidemic
 - Phase 1: 1989-1992; phase 2: 1992-2002; phase 3: 2002-2005
- Stabilization of prevalence btw 6.1 and 6.5
- Prevalence higher in women and urban areas

Trends in HIV Prevalence among 15-19 year old antenatal women in Uganda





Burden of HIV/AIDS in Uganda

- Number of adults and children live with HIV/AIDS – 980,000
- Number of AIDS deaths ~ 1 million
- Number of AIDS orphans ~ 1.5 million
- HIV prevalence at 6.4%
 - 10.1% of urban areas
 - 5.7% for rural areas

Drivers of the Epidemic

DRIVERS

- High risk sexual behaviour
 - Sex with multiple partners especially non-marital, non-consensual;
 - Inconsistent or no condom use;
 - Commercial, transactional and intergeneration sex including sex for survival;
 - Alcohol consumption and drug abuse before sex;
 - Unprotected sex with someone whose status one does not know; and without testing and disclosure.

Discordance and Non-disclosure

- HIV discordance among couples where at least one partner is infected is high
- Problems:
 - discordant couples not aware of their HIV status
 - married couples unlikely to use condoms consistently
 - couples who test individually disclose to persons other than their spouses
 - fear of domestic violence and marital disruption

Economic Factors

- Poverty leads to commercial, transactional and intergenerational sex
- Conversely, HIV/AIDS is a driver of poverty

Socio-Cultural Factors

- Some socio-cultural expectations with negative consequences
- Construction of male and female sexuality
- Increasing urbanization and exposure to foreign media may erode family values
- Cultural values and traditional gender roles increase vulnerability of women

Human Rights, Stigma and Discrimination

- Human rights:
 - The right to determine one's own sexual behaviour; sexual future; access to information and health care services; confidentiality
 - Need to balance individual rights vs community rights
- Stigma and discrimination
 - Affect access to health care services including HIV prevention
 - May lead to heroism and glorification

Concurrent STIs

- Biological and epidemiological evidence linking concurrent STIs to the risk of HIV transmission
- HSV-2 is widespread with close to 50% of Ugandans infected
- HIV increases severity and duration of herpes symptoms and may reduce efficacy of treatment

High Risk and Vulnerable Groups

- Include:
 - CSWs, widowed, divorced and separated, IDP camps, OVCs, uniformed forces and fishing communities
- OVCs:
 - more likely to have sex by age 15 than other youth
 - young female OVCs 1.5 times more likely to initiate sex before age 15 than other younger women
 - 14.6% of female orphans had had sex before age 15 while 18% of male orphans had had sex by age 15

Intense Research: a contributing factor to success

- Basic/ Lab Science
- Operational research
- Intervention research

e.g Nevirapine for PMTCT, prophylactic treatment of opportunistic infections, male circumcision

Male Circumcision

- Trial efficacies were:
 - Orange Farms South Africa 60%
 - Kisumu, Kenya 53%
 - Rakai Uganda 51%
- All 3 trials were stopped by DSMB after interim analyses
- Circumcision must be considered a proven intervention for prevention of HIV in men

ACTIONS REQUIRED

- Continued Leadership, leadership and more leadership
- An inclusive Health System that will reach into rural areas as well as hard to reach sites and fully embrace HIV+ as equal players and key catalysts for change
- Programs that reach out to and support marginalized and at risk communities
- Universal access to Antiretroviral and other treatments
- Far more investment in HIV prevention is needed – particularly to scale up **Combination Prevention**
- **Making use of HIV/AIDS programmes to enhance other health services**

Thank you for your attention

Trial Site Community Characteristics

	South Africa	Uganda	Kenya
Trial setting	Semi-urban	Rural	Urban
Study sites clinic	3 clinics	Community based	1
Circumcision (%)	~20%	16%	<10%
HIV incidence	2.7-5.2	1.1-2.1	2.5

The Three Trials: Study Characteristics

	South Africa	Uganda	Kenya
Age	18-24	15-49	18-24
Final N	3,520	4,996	2,784
Enrollment completed	Jan 2005	Jul 2005	Sept 2005
Completion date	Mar 2005	Jul 2007	Sept 2007