

14 DAYS OF HIV AWARENESS TOOLKIT

2021 Theme: "Ending the HIV Epidemic with Holistic Healing"

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About the 14 Days of HIV Awareness Toolkit

This toolkit was created by the Gilead COMPASS Initiative® Faith Coordinating Center at Wake Forest University School of Divinity for faith and community leaders and to utilize from World AIDS Day (December 1) to HIV Cure Research Day (December 14). These 14 Days of HIV Awareness have a central focus on holistic approaches to supporting and loving people living with HIV/AIDS. We also hope this resource will equip communities with various tools that build their capacity to address HIV/AIDS. It is our sincerest wish to continue to expand this toolkit in the future.

About the Gilead COMPASS Initiative® Faith Coordinating Center

The Gilead COMPASS Initiative® Faith Coordinating Center at Wake Forest University focuses on preparing ministry and nonprofit leaders to address the needs of vulnerable populations such as African Americans and LGBTQ individuals. These groups, particularly in the South, often experience a higher number of cases of HIV/AIDS with access to fewer support and prevention resources. At our center we offer grant funding, training sessions, cohorts, and resources to better equip leaders and communities to transform the story of HIV in the South.

About the COMPASS Initiative

The Gilead COMPASS (COMmitment to Partnership in Addressing HIV/AIDS in Southern States) Initiative® is an unprecedented more than \$100 million commitment over 10 years to support organizations working to address the HIV/AIDS epidemic in the Southern United States. The South is most affected by the HIV epidemic, accounting for 54% of all new HIV diagnoses in the U.S. In response to the Southern HIV epidemic, COMPASS focuses on providing concentrated investments in the region to reduce HIV-related health disparities, build awareness, advance education, and reduce stigma.

About Wake Forest University School of Divinity

Wake Forest University School of Divinity is a graduate, professional school that is Christian by tradition, Baptist in heritage, and ecumenical in outlook. Consistent with Wake Forest's commitment to academic excellence and in the spirit of the University motto, Pro Humanitate, the School of Divinity prepares leaders informed by a theological understanding of vocation. Through imaginative courses and diverse programs of community engagement, students are equipped to be agents of justice, reconciliation, and compassion in Christian churches and other ministries.

About World AIDS Day

The theme for the 2021 observance is "Ending the HIV Epidemic: Equitable Access, Everyone's Voice" ("El tema de este año para WAD se confirma como: Poner fin a la epidemia de VIH: acceso equitativo, la voz de todos").

World AIDS Day was first observed in 1988. Each year, organizations and individuals across the world bring attention to the HIV epidemic, endeavor to increase HIV awareness and knowledge, speak out against HIV stigma, and call for an increased response to move toward *Ending the HIV Epidemic: A Plan for America*.

For more information about national World AIDS Day activities, visit https://www.hiv.gov/events/awareness-days/world-aids-day

About HIV Cure Research Day

Marginalized communities have the collective power to help shape how medical innovation and research impact their health-care access and treatment and how they choose to heal their communities. On December 14, 2015, Dr. Allison Mathews launched the 2BeatHIV research project funded by an R01 NIH NIAID grant (PIs Tucker/Rennie) and housed at UNC Chapel Hill. The 2BeatHIV project used crowdsourcing to identify and develop community-sourced ideas to improve community engagement for HIV cure research. As a result, 2BeatHIV initiated the development of several community engagement projects, including a campaign about HIV cure research, a campaign to



reduce stigma associated with HIV testing, stakeholder video interviews about the challenges and opportunities for HIV cure research, and a series of HIV cure capacity building workshops with community-based organizations. In 2016, Dr. Allison Mathews and Kimberly Knight co-founded HIV Cure Research Day (December 14) in the state of North Carolina to promote collective ownership over finding a cure for HIV and ending the epidemic. The original slogan for the day, "Own the Cure," highlights the power that collective advocacy can have in shaping how a medical cure is developed and distributed to those most marginalized and affected by the epidemic. This idea is a powerful tool toward eradicating health

disparities in access and treatment across multiple disciplines and fields of study. HIV Cure Research Day was officially proclaimed by the Durham County Board of Commissioners on December 14, 2016, and from 2017-2019 was proclaimed by Roy Cooper, Governor of North Carolina. In 2018, Governor Cooper and the Office of Public Engagement invited Dr. Mathews to host the inaugural World AIDS Day in the Executive Mansion in collaboration with the Office of the First Lady of North Carolina, the NC Department of Health and Human Services, and the UNC Institute for Global Health and Infectious Disease. The goal of the event was to start the conversation about ways we could leverage the resources available in North Carolina to address the HIV/AIDS epidemic. Dr. Mathews delivered a talk at TEDxCaryWomen entitled, "Fight HIV Stigma through Access, Mobilization, and Equity," which chronicles the inspiration for the founding and the impact of HIV Cure Research Day in the state of North Carolina.

While an HIV cure is the ultimate goal, it is important to also address access and equity issues, so that marginalized communities no longer have to struggle to receive adequate and equal access to health care. Historically, marginalized groups have been exploited in research studies and rarely benefited from medical innovations, due to disparate education and access. This history has created mistrust of clinical scientists within the affected groups. The current research structure expects participants to voluntarily contribute their data to scientific studies without any expectation of benefit or ownership over the medical advancements developed from the studies. This structure leaves participants from marginalized communities disadvantaged. They are bearing the risk of research participation but often are not benefiting from therapeutic discoveries because of their marginalized status in society and limited access to healthcare. HIV Cure Research Day seeks bold strategies to empower community members to transform the way that scientists, government entities, and businesses engage with low-income and marginalized people about research and healthcare access. The day celebrates the life of Timothy Ray Brown, the first man cured of HIV; highlights advancements in HIV cure science; and facilitates community involvement in identifying novel ways to end the epidemic through research, technology, policy and social justice.

To date, HIV Cure Research Day and the activities of the 2BeatHIV project have hosted more than 25 community events with over 1000 attendees and 75 community partners; generated 450 crowdsourced ideas; helped create 6 new companies; reached 450,000 people online; won several state and national awards; and has been recognized by the NIH and international scholars. In 2021, the Gilead COMPASS Faith Coordinating Center at Wake Forest University adopted responsibility for planning HIV Cure Research Day and leading efforts to promote activities for the 14 Days of HIV Awareness from World AIDS Day (December 1) to HIV Cure Research Day (December 14).



Wake Forest University Activations

The Faith Coordinating Center is collaborating with several centers and academic departments on the campus of Wake Forest University to promote HIV awareness.

<u>Subscribe to our calendar</u> to stay up to date on our events (virtual and in-person)!

OCT 29 - NOV 10

We are proud to partner with the Department of Theatre & Dance on the production of "The Normal Heart" by Larry Kramer and **directed by Brook Davis.**

Evening Shows: Oct 29-30 & Nov. 4-6, 2021 at 7:30pm

Matinees: Oct 31, Nov 7, and Nov 10 at 2:00pm

Location: The Tedford Stage

In the early 1980s, one man rose up and helped lead an army to fight an ignored plague. Larry Kramer's largely-autobiographical play, *The Normal Heart*, explores the politics, fear, anger, and frustration he experienced during the early years of the AIDS crisis in New York. This year, 2021, marks the 40th anniversary of the first cases of the disease later to be known as AIDS. Kramer's *The Normal Heart* is a profound, tragic history lesson for audience members too young to remember this dark time in America, as well as those old enough to see the parallels between then and now.

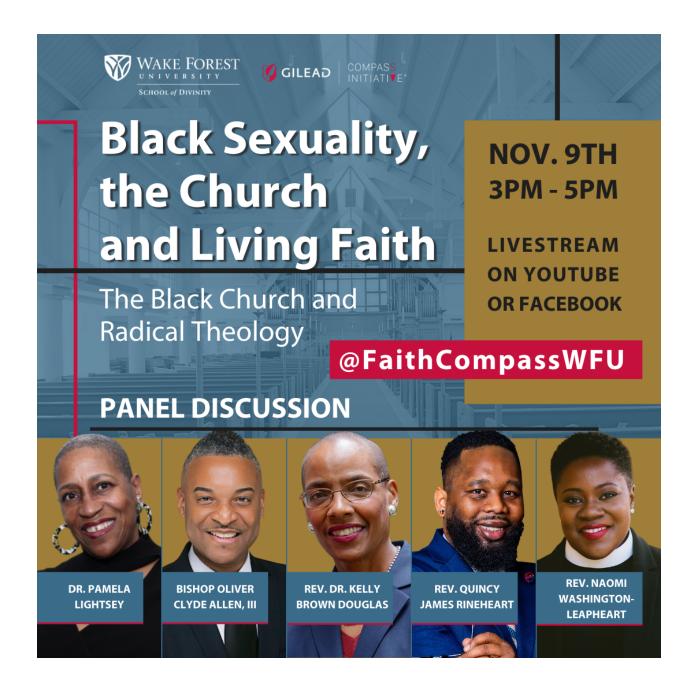
The Normal Heart is presented by special arrangement with Samuel French, Inc.

There will be a special activation of HIV awareness information and art produced by the Faith Coordinating Center in the lobby of SCALES Performing Arts Center.

A Talk Back with Dean Jonathan Walton, Dr. Allison Mathews, and Lead Actor, Chris Cates, will be hosted after the performance on November 5, 2021.

NOV9

The Faith Coordinating Center will be hosting a panel discussion on **Black Sexuality, the Church and Living Faith**. This panel discussion is part of our Virtual Training Series which is free and open to the public. You can <u>register for panel discussion and other sessions here</u>. This event will also be live streamed on Youtube and Facebook @FaithCompassWFU



NOV 30

In honor of World AIDS Day

11AM - 12PM Host Hour of Prayer with Wake Forest School of Divinity in Davis Chapel Register for the event here.

DEC 1 - DEC 14

December 1 - 14, 2021

Faculty, staff and students can visit the HIV Awareness Art Installation on WFU's campus. We invite your thoughts on how we can work together to end the HIV epidemic by adding your creative contribution to the art installation.

DEC 1

Dr. Shonda Jones, our Principal Investigator for the Gilead COMPASS Faith Coordinating Center, will be participating in a panel discussion at 11AM EST with Gilead Sciences entitled, "The Impact of AIDS on the Black Community"



DEC 14

Join us for our panel discussion on December 14! The event will be live streamed on Facebook and Youtube at 3PM EST

"Curing HIV: Healing the Mind, Body and Spirit" Register to attend here.



What are 14 ways that community members can participate in 14 days of HIV Awareness from World AIDS Day (December 1) to HIV Cure Research Day (December 14)?

- 1. **Post the HIV Cure Research Day graphic** on your social media profile.
- 2. **Use the "14 Days of HIV Awareness" toolkit** to distribute educational materials through your networks (e.g., email listservs, social media, town hall discussion, etc.)

- 3. Host a watch party and discussion about the "Power Within Reach" video produced by the Gilead COMPASS Faith Coordinating Center to raise awareness about the intersections between HIV and faith. <u>Download the discussion guide here.</u> Access multiple <u>versions of the video</u> for use on your media platforms here.
- 4. Post your reason for fighting HIV stigma on social media
- 5. **14 mins of mindfulness meditation:** Honor those we have lost during the HIV/AIDS epidemic, offer thoughts of gratitude for how much progress we have made to support people affected by and living with HIV, and imagine a future where the HIV epidemic has ended.
- 6. **Join the online** Faith and HIV capacity building workshops hosted by the Faith Coordinating Center at Wake Forest University.
- 7. **Volunteer to join a community advisory board** about a local issue important to you and your community. All issues impact the HIV epidemic, so you can start with your passion!
- 8. **Share inspirational quotes** by leaders who talk about HIV (provided on last page of this toolkit).
- 9. **Join the <u>HIV Cure Research Day Panel</u>** discussion on December 14 at 3PM on Facebook and YouTube
- 10. **Visit AIDSVu.org** to download the HIV Cure Research Day social media toolkit and share facts with your community. You can also learn about where you can find testing and prevention resources in your community
- 11. **Encourage your faith leaders to talk about healing HIV** and loving all of God's children. Download the "HIV and Faith Leader Toolkit" here.
- 12. **Share your status with loved ones.** Here are some <u>tips on how to disclose</u> to loved ones.
- 13. **Support your loved ones** who are experiencing any type of rejection, especially those experiencing stigma because of their sexuality. Here is a resource on how to have conversations about the Bible and sexuality.
- 14. <u>Learn about the HIV policy issues happening in your state</u> and talk to your legislatures about supporting measures to protect people living with HIV.

Note: You can use these facts to post as captions on social media, email listservs, and organizational websites.

Facts about HIV

- 1. **HIV Is a Social Justice and Racial Justice Issue:** Black Americans account for more HIV diagnoses (43%) and people living with HIV (42%) than any other racial and ethnic group in the U.S. Black Americans are vulnerable to HIV because of structural barriers, steeped in racist and anti-Black policies and practices, to resources like healthcare, education, employment and housing. The three groups most affected by HIV are Black gay men, Black cisgender women and transgender women of color.
- 2. **HIV Treatment Works, U=U:** People diagnosed with HIV don't "die in two or three weeks." People living with HIV, when on effective treatment, live long and healthy lives and cannot sexually transmit HIV. When someone living with HIV receives effective treatment and follows regimens prescribed by their HIV providers, HIV becomes undetectable when tested. **When HIV is undetectable, it is untransmittable: U=U (#UequalsU)**
- 3. **HIV Prevention Works:** HIV testing should be a part of regular medical screenings. The CDC recommends that every person ages 13-64 receive an HIV test. When a person takes a test and receives an HIV diagnosis, they can be linked to care immediately to protect and improve their own health and prevent passing on HIV to others. When a person takes a test and learns they are HIV negative, they can then make decisions that can protect them from HIV. Medications like PrEP (a daily pill to prevent HIV) are 99% effective at preventing HIV when taken as prescribed for people who do not have HIV.
- 4. **HIV Is a Chronic Health Condition, Not a Death Sentence:** HIV can be prevented, tested, and treated like any chronic disease such as diabetes. It is not a death sentence. People living with HIV and on treatment can be healthy, have children, and not pass on the virus (Undetectable = Untransmittable). In most cases, HIV treatment means taking just one pill a day.
- 5. **Faith-based HIV Stigma Hurts, and Spreads the Disease:** With more than 10,000 US congregations having members living with HIV, it is important for faith communities to take leadership in addressing HIV stigma. Shaming people living with HIV or for being on medication to prevent HIV stops people from seeking the care they need and lets undiagnosed people pass on the virus.

Historical Facts About Those Who Have Been Cured of HIV:

 Berlin Patient - Timothy Ray Brown - Cured of HIV in 2008, Brown was diagnosed with Leukemia and underwent chemotherapy treatment, 2 stem cell transplants, and total body radiation. He was in remission from cancer and HIV for 12 years, but died from leukemia in 2020.

https://www.avert.org/news/5-times-hiv-was-cured

- London Patient Adam Castillejo Cured of HIV in 2019 from a bone marrow transplant for lymphoma. After a decade of clinical trials he revealed his identity in the NY Times in March 2020 at the height of the Covid-19 pandemic.
 - https://www.nytimes.com/2020/03/09/health/hiv-aids-london-patient-castillejo.html
- **Loreen Willenburg** First person declared cured of HIV without medical intervention After testing positive in 1992, she is among a group of 64 so-called elite controllers <u>enrolled in a study</u> who seem to have a genetic ability to sequester or suppress the virus. She uniquely has shown no evidence of HIV using the most powerful of gene probing techniques. https://www.poz.com/article/first-woman-may-cured-hiv-without-bone-marrow-transplant

There are other cases of people thought to have been cured, but they eventually experienced HIV recurrence. They were important cases that have helped HIV cure scientists better understand how HIV affects the body and what medical interventions may work. Excerpt from https://www.avert.org/news/5-times-hiv-was-cured

- Mississippi Baby (2013)
 - At the CROI conference in 2013, it was announced that a baby born with HIV in Mississippi, USA was functionally cured of HIV, meaning no HIV virus was detected off HIV treatment. The baby was given a strong dose of three antiretroviral drugs soon after birth, but their treatment stopped abruptly at 18 months when the mother was lost from care. When mother and baby returned to care five months later, the baby's viral load was undetectable.
 - But just over two years later, the landmark case took a significant blow when detectable levels of HIV were found again in the baby. Hence why, in cases such as the London patient, scientists are hesitant to declare a cure.
 - Even so, the case is important for research as it indicates that early, aggressive ART can result in short-term remission in children. We now also have a better understanding of how ART can control viral replication and limit the establishment of viral reservoirs. This is where groups of immune system cells may be infected with HIV, but where the virus is dormant and not being actively reproduced, and so also not causing any further damage. Understanding these will help us to find the key to long term viral suppression.
- French Teenager (2015)
 - More recently, in July 2015, researchers announced that a French teenager who was infected with HIV at birth was still in good health 12 years after she last took ART. It is the longest known paediatric HIV remission case so far.

 However, it is not yet known why she has fared better than the Mississippi baby – was there a biological reason? Would she have fared the same in the absence of treatment in the first place? Researchers cannot draw conclusions.

• Visconti group (2012)

- In a 2012 study, 14 French people with HIV known as the 'Visconti cohort', started taking ART within 10 weeks of infection. After three years of medication, they stopped taking treatment, which would normally result in HIV re-emerging. Remarkably, they maintained low levels of HIV in their systems for an average of seven years before a recurrence of the virus emerged.
- Another study, the 2018 'Control of HIV After Antiretroviral Medication Pause' (CHAMP) study, also yielded similar results – some 13% of those treated in early infection were considered post-treatment controllers.

Researching an HIV cure: the main approaches

There are several strategies that HIV cure scientists are using to achieve a functional cure of HIV that is safe and replicable in humans. Even though there have been three people cured of HIV, the strategies used to cure the Berlin and London patients were extreme cases where the patients had both cancer and HIV. They required stem cell transplant for their cancers, and consented to a experimental intervention that involved using a stem cell donor that had a genetic mutation to their CCR5 receptor (the receptor that HIV latches on to infect immune cells) that made the donor naturally resistant to HIV infection. Treatment for their cancer required both patients to undergo chemotherapy and a bone marrow transplant, which is dangerous for the individual, and thus not an option for curing HIV in the absence of life-threatening cancer.

See the excerpt from https://www.avert.org/about-hiv-aids/cure on the four most common ways scientists are using to develop an HIV cure:

- 1. 'Activate and eradicate' (sometimes known as 'Shock and kill') aims to flush the virus out of its reservoirs and then kill any cells it infects.
- 2. Gene editing changing immune cells so they can't be infected by HIV.
- 3. 'Immune modulation' permanently changing the immune system to better fight HIV.
- 4. Stem cell transplants replacing a person's infected immune system with a donor immune system.

Although the stem cell approach has had some success in the past, it's very dangerous for the patient. It would only be considered a viable option, if the person needed a stem cell transplant to treat another more deadly condition, such as very advanced leukaemia – which, unlike HIV, doesn't have as many other safe and effective treatment options available.

While there is promising research being carried out in these areas, there is no viable cure on the horizon.

There are 6 Martin Delaney HIV Cure Collaboratory Research Sites in the United States, including:

- 1. defeatHIV
- 2. CARE (Collaboratory of AIDS Researchers for Eradication)
- 3. Delaney AIDS Research Enterprise (DARE)
- 4. BELIEVE
- 5. BEAT-HIV
- 6. Immunotherapy for HIV Cure

9 HIV Cure Myths Debunked

Myths about HIV cure are fairly common around the world, including the United States. Indeed, there is a belief among some African Americans living with HIV (PLWH) that the government is purposefully withholding an HIV vaccine or cure from the public. Some PLWH also believe that dietary supplements and alternative medicine will cure HIV. Given the pervasive nature of HIV cure myths, it is important to know the facts about the current state of HIV cure research and try to address some of the most common myths.

Here are the 9 most common questions and myths we have encountered through our work and in US popular culture.

Myth 1: There is a cure for HIV.

There is no cure for HIV. There are three documented cases of people being declared in HIV remission (i.e., cured), but we do not know how to safely replicate those findings in other humans yet.

Myth 2: Scientists have never used Timothy Brown as a research case to find a cure.

Scientists are currently examining multiple strategies to cure HIV based on findings from Timothy Brown. This short video describes one of the strategies being explored at the HIV Cure Center at UNC Chapel Hill:

UNC Science Short: Can 'kick and kill' cure HIV?

Myth 3: If they can develop a vaccine for COVID-19 so fast, they can do it for HIV too.

Scientists have been working to develop a vaccine for HIV for nearly 40 years. The HIV virus is more complex than COVID-19 because it mutates much more rapidly inside the body, making it difficult to

develop a vaccine that responds to all variants. The science used to develop the COVID-19 vaccine was borrowed from what we have learned from HIV and cancer research and decades of research on coronaviruses. You can learn about all of the clinical trials being done to develop an HIV cure that can be used on a mass scale:

AVAC – Cure - http://www.avac.org/prevention-option/cure
The Body's HIV/AIDS Cure Research Resource Page

Myth 4: Magic Johnson is cured of HIV.

Magic Johnson is not cured of HIV. He has repeatedly said he still has HIV and is taking medication to manage the disease. He is taking the same medication as other people living with HIV are taking. His viral load is "undetectable" because he consistently takes his medication.

Check this article to learn more:

Why Do People Still Think Magic Johnson Doesn't Have HIV?

Myth 5: Having an "undetectable" viral load means someone is cured of HIV.

An HIV-positive person can achieve undetectable levels by consistently taking antiretroviral therapy (ART). However, there is still HIV virus that "sleeps" in hiding places throughout the body. Once a person stops medication, they will experience a rebound of HIV viral replication. Scientists are trying to find a way to eliminate the remaining dormant virus so people will no longer have to take medication.

Check this article to learn more:

HIV-Positive and 'Undetectable': What Does It Really Mean?

Myth 6: Pharmaceutical companies are withholding a cure from the public to make money on treatment medication.

Pharmaceutical companies are investing millions of dollars into research to find a cure for HIV. They are currently investing millions of dollars into providing "HIV treatment as prevention." This means that people living with HIV who consistently take their medication are over 90% protected from passing the virus to HIV negative partners. Pharmaceutical companies also provide an HIV prevention pill called PrEP, which can protect HIV negative people from getting HIV more than 90% of the time, when taken as directed.

There will continue to be a market for HIV prevention, treatment, and cure as long as the possibility of infection exists.

Check this article that explains the role of pharmaceutical companies in HIV cure research:

The For-Profit HIV Cure Research Crunch

Myth 7: The government is using HIV to control the population.

The United States federal, state, and local governments have dedicated billions of dollars to HIV prevention and treatment over the past 30 years. Governments can, and often do, choose to partner with nonprofits to do HIV-related work.

Check this site for a timeline of HIV/AIDS and the role of the US government in helping fight the epidemic:

https://www.aids.gov/hiv-aids-basics/hiv-aids-101/aids-timeline/

Myth 8. A holistic diet and lifestyle alone can cure HIV.

While holistic medicine, spirituality, and a healthy diet can supplement HIV treatment, it is NOT enough to cure HIV. The virus attacks the immune system and needs anti-retroviral drugs to fight off the infection.

Read an explanation here:

Alternative (Complementary) Therapies for HIV/AIDS: Entire Lesson http://tinyurl.com/zh9d35k

Myth 9: Black doctors have already found a cure but it is being suppressed.

No one has found a cure for HIV yet. There is a diversity of doctors and scientists, including Black doctors from countries in Africa and those in the United States, who are examining multiple strategies to cure HIV across the world. Racial/ethnic diversity is welcome because people with different perspectives can help address the myriad issues related to finding a cure for HIV.

To learn more about how you can be involved in finding a cure for HIV, visit these websites:

amfAR.org AVAC.org

https://www.thebody.com/category/curing-hiv

Here are the 6 Martin Delaney Collaboratory Research Sites funded by the National Institutes of Health (NIH) working to cure HIV:

- 1. defeatHIV Fred Hutchinson Cancer Research Center, Seattle, WA
- 2. <u>CARE UNC Chapel Hill, Chapel Hill, NC</u>
- 3. <u>Delaney AIDS Research Enterprise (DARE) University of California, San Francisco, San</u> Francisco, CA
- 4. <u>BELIEVE Cornell University, New York, NY</u>
- 5. BEAT-HIV University of Pennsylvania, Philadelphia, PA
- 6. Immunotherapy for HIV Cure Beth Israel Deaconess Medical Center, Boston, MA

Historical Quotes of Inspiration From Influential People:

- 1. Like no other illness, AIDS tests our ability to put ourselves in someone else's shoes to empathize with the plight of our fellow man. While most would agree that the AIDS orphan or the transfusion victim or the wronged wife contracted the disease through no fault of their own, it has too often been easy for some to point to the unfaithful husband or the promiscuous youth or the gay man and say This is your fault. You have sinned. I don't think that's a satisfactory response. My faith reminds me that we all are sinners.
 - Barack Obama
- 2. It is bad enough that people are dying of AIDS, but no one should die of ignorance.
 - Elizabeth Taylor
- 3. The greatest grand challenge for any scientist is discovering how to prevent the spread of HIV and finding the cure or an effective vaccine for AIDS. -
 - Philip Emeagwali
- 4. Let us give publicity to H.I.V./AIDS and not hide it, because the only way to make it appear like a normal illness like TB, like cancer, is always to come out and say somebody has died because of H.I.V./AIDS, and people will stop regarding it as something extraordinary.
 - Nelson Mandela
- 5. I enjoy being the messenger for God in terms of letting people know about HIV and AIDS.
 - Magic Johnson