POZ's (Abbreviated) Encyclopedia of AIDS

Highlights of some of the juiciest subjects we've written about (with a little help from you) over the past 15 years.

May 1, 2009 By Regan Hofmann

We're not saying we know everything there is to know about HIV…but if we don't, we guarantee that you, our readers, do. For 15 years, we have honed our expertise by listening to you share the truth of what it's like to live with HIV.

For a decade and a half we have watched, peering over your shoulders and listening in, as tens of thousands of you have talked to each other—and to us—through your letters and online in our forums or via the comments sections of POZ.com. We have also taken your calls, heard your stories and questions and talked with you face-to-face. We are grateful to you for sharing your insight with us, and we gather our collective wisdom and in order to publish the best advice on preventing, treating and surviving AIDS.

Collectively, your voices, your stories and your experiences have made *POZ* the equivalent of one big 15-year Wikipedia entry. So, on the occasion of our anniversary, we thought it would be valuable to summarize some of the most topical insights so that those new to the disease can learn from our experiences—and we can be reminded of the hottest issues on our minds.

The following is an AIDS primer featuring some of the most salient aspects of life with HIV. It represents our collective thoughts on the topics and myths that have been discussed, debated and debunked over the years. Because this (abbreviated) encyclopedia only scratches the surface of all that we could cover, we once again turn to you for your infinite wisdom. Please help us by adding your own entries to this list in your comments below.

Activism

The AIDS activists who fought at the beginning of the epidemic for the rights and care of people living with HIV saved countless lives. There is no question that many of us would be much worse off—or dead—were it not for the relentless determination of those pioneering individuals. They wrote The Denver Principles, led the guerilla activism of ACT UP and publicly challenged politicians and presidents. They insisted on expanded drug access and inclusion in our health insurance policies. They created peer education inside prisons. And they secured federally funded programs

such as the Ryan White CARE Act and Housing Opportunities for Persons With AIDS (HOPWA). Now, more than ever, there is a dire need for vigorous advocacy from within and on behalf of the HIV community. It's our hope that this entire 15th anniversary issue of *POZ* inspires you to commit (or recommit) to the core principles of grassroots AIDS activism—The Denver Principles—and to join the National Association of People with AIDS (do so at napwa.org). Lend your voice to the collective cry for better and longer lives for all people living with HIV.

Africa

According to much of the U.S. media's coverage of HIV, Africa is the world's AIDS epicenter. Oprah has built a school there. Angelina and Madonna adopted children from AIDS-ravaged countries. It seems that the proceeds from each (Product) Red item we buy, and every dime we shell out at many AIDS benefits nowadays, get shipped overseas. Not to mention the $48 billion pledge the American government made to help fight AIDS around the world—but mostly, of course, in Africa—through the President's Emergency Plan for AIDS Relief (PEPFAR). But Africa is not the only place that the AIDS epidemic continues to thrive. Just ask any of the estimated 56,300 people who contracted HIV in America in 2006 according to data from the Centers for Disease Control and Prevention. It's not that Africans with AIDS don't desperately need our help; they do. *POZ* regularly covers the plight of our positive brothers and sisters there. It's just that we'd like to see more support for people living with HIV all over the world, including, Mr. President, a little love for those in your own backyard.

Blood, (Sweat and Tears)

From our hearts through our guts to our kidneys and livers and beyond, blood is the conduit of life. It carries the virus and some of our immune cells and allows us to tell how HIV is (or isn't) progressing in our bodies. Phlebotomists pull it into glass tubes to send to labs so our doctors can read our viral loads, CD4 counts and chemistry panels. Thanks to the oral swab HIV tests, a pin prick is no longer the only way to determine one's HIV status. So, if the sight of blood makes you faint, fear not; today, HIV can be diagnosed by swiping a small plastic instrument around the inside of your kisser. However, should the result be positive, you will have to give blood to confirm the result. Emptying this precious fluid into test tubes every several months helps determine whether antiretroviral medicines are suppressing your HIV viral load; analyzing it can also detect side effects or resistance to current treatments, thus signaling that it may be necessary to switch to a new regimen. Oh, and while blood can transmit HIV, sweat and tears cannot.

Brain Fog

Not to be confused with dementia—a much more serious, clinical state of brain malfunction—brain fog affects a great number of people with HIV. Also known as HIV-associated neurocognitive disorder (HAND), brain fog can be as irksome as depression, another mental disease oft-associated with HIV. Luckily, there are tactics for combating both. Now, where did we put that sudoku?

The Cure

As elusive as a vampire on a sunny day, the cure for AIDS continues to evade the world's brightest scientific minds. The cure has teasingly almost appeared more than once since we first discovered how the virus depletes the immune system. Notably, the advent of protease inhibitors in 1995

raised talk of total viral eradication and suggested that the virus could be banished from the bloodstream. Alas, the drugs were not the panacea some predicted: HIV hid in the lymph system and organ tissue, only to spring back to life when we thought it was dead for good. As we write this, hundreds of long-term nonprogressors (people with HIV who have not developed AIDS over many years though they are not on HIV meds) are being studied to determine whether their bodies hold the cure. And in 2008, we met The Berlin Patient, an HIV-positive man who was given a bone marrow transplant with HIV-resistant stem cells to fight his leukemia, resulting in the apparent eradication of the virus from his body. While a $200,000 bone marrow transplant—a complex, dangerous and often unsuccessful procedure—does not a cure make, the scientific community has new hope that we are getting ever closer to outsmarting our viral foe.

Death

Too many people have died from AIDS. To date, over 500,000 in the United States alone and more than 25 million worldwide. Even in recent months, we've seen the deaths of several of our heroes. From the days when funerals were a weekly event for many of us, to our 2001 cover featuring vials of the ashes of six friends who'd died of AIDS, to the very genesis of this magazine (*POZ* founder Sean Strub gave life to the magazine in part with funds collected from a viatical settlement with his life insurance company), death has always been a part of AIDS. We look forward to the day when (premature) death does not become us.

Doughnut Hole

No, not the center of your chocolate glazed. Rather, the gap in Medicare coverage that results in many positive people becoming destitute while trying to pay for the pills and other treatments that allow them to stay alive. No one should have to choose between food and treatment, especially not in one of the richest nations in the world.

Faith

As AIDS continues to spread in the African-American and Latino communities, faith-based organizations have stepped up to disseminate information, support and even, heaven help us, condoms to their faithful followers. Certain beliefs can be deadly. While we've seen some evangelical Christians willing to embrace some people with HIV, we wish that they'd open their minds and hearts to their gay brethren as well. Even if everyone at the pulpit would preach the gospel of acceptance, and if every congregation of every faith would accept the message, it would still take years to undo the damage done by labeling people with HIV as sinners. We won't be singing Hallelujah until people of all faiths embrace *all* people with HIV.

Harm Reduction

Needle exchange programs reduce the rate of HIV transmission among drug users. The scientific data are overwhelming. To stop the spread of AIDS, we must dispense clean needles and offer to substitute less harmful drugs for illicit uppers, downers and everything in between. Handing out needles doesn't make people do IV drugs; it helps prevent the spread of HIV among active drug users. Similarly, condoms do not make people (especially kids) have sex. Condoms allow people to do the inevitable, safely.

Hit Hard, Hit Early
Ever since the advent of AZT (retrovir) in the mid-'80s, there has been heated debate about when, and if, to start antiretroviral (ARV) treatment. When protease inhibitors brought many people with AIDS back from the brink of death, the "hit hard, hit early" chorus grew strong. But concerns about the still-unknown long-term effects of ARV therapy continue to fuel the debate over when it's best to begin treatment. The CD4 count at which experts recommend starting has risen steadily; today it suggests beginning when your CD4 count is at 350 or below (recent studies suggest that even this may be too late). Yet the real debate—preserving access to individualized therapy versus enforcing population-based treatment decisions—continues full force.

Kissing
Yes, you can. On the hand, the cheek, the mouth and…other parts of the body. Theoretical risks for different types of kissing depend on who's kissing whose what, when and how. But suffice it to say that the chance of HIV transmission from any kind of kissing is as likely as finding a snowflake in the Sahara. (For more info, see "How Is HIV Transmitted?" on aidmeds.com.)

Liver
The HIV epidemic didn't introduce us only to the wonders of the immune system. We also discovered some organs we'd always taken for granted—like our livers. Not only do livers become queasy from some HIV combos, but they also alert us to another virus: hepatitis. Whether B or C, it is a reality for many people living with HIV. What's more, HIV activism and research have helped the other H viruses find its way to treatment and awareness.

Microbicides
Though no microbicide has yet made it to market, there is a lot of hope—and a lot of Bill and Melinda Gates's money (including a recent $130 million grant) behind the idea—that a clear, odorless, tasteless, lubricating gel administered vaginally or anally can block HIV transmission. The birth control pill put the power to avoid unwanted pregnancy into women's hands—similarly, if they work, microbicides could radically alter the landscape of navigating safer sex.

Mosquito
No, they don't carry HIV. If a mosquito bites an HIV-positive person then dines on you, it will not give you the virus. Yes, they do carry malaria, as well as yellow fever. In many parts of the world, staying mosquito-free is a key to surviving HIV because a coinfection of malaria and HIV is more than twice as hard on a body. That's why many sub-Saharan African clinics dole out trifectas of HIV tests, antimalaria nets (treated with antimosquito spray) and vaccinations for TB and/or polio. The diseases are interrelated; when malaria (or malaria and TB together) taxes your body, you're less able to fight HIV or handle its treatment. A global trend is for preventive treatment and/or vaccination against several diseases concurrently. At *POZ*, we've always supported an integrated approach to health care. Viva la bug spray!

Orphans
By the end of 2007, more than 15 million children had been orphaned by AIDS, mostly in Africa. Many do not have HIV, but they are stigmatized and unwanted because their parents had AIDS.

Now, legions of tots—hungry, scared, desperate and impressionable—are being targeted by missionaries of various faiths looking for new recruits and by armies of various militant governments seeking new killers. Saving the children is not merely a humanitarian concern—it is essential if we want to save ourselves from religious extremists and terrorists, too.

Porn
POZ has featured its share of adult film stars. Our Miss June 1998 cover featured Rebekka Armstrong, and "The XXX Files" cover in April 1999 featured Tricia Devereaux. Gay male porn icon Aiden Shaw guest edited our August 1997 issue. And just last December, we profiled ex-porn star Darren James (who is straight). We don't do it to be salacious; rather, we wish to show that people with HIV can enjoy healthy, sexy lives. Unsafe sex has long been part of the adult film industry, largely because audiences prefer skin-on-skin sex and, as a result, porn stars are paid a premium to bareback. But as we have asked on our pages more than once: Why should porn stars risk their lives so we can have safe, virtual sex while watching them?

PEP/PrEP
Post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP) are two similar ways to possibly prevent HIV infection. PEP is administered to people who may have been exposed to the virus—think condom breaks and medical-setting needle sticks. Perhaps the 28-day course of drugs (they must be taken within 72 hours of exposure to HIV) could be standard fare in every home medical kit. PrEP is taken before a potential exposure; ongoing studies will prove whether it staves off infection. Another form of PEP/PrEP exists when HIV-positive mothers are given treatment before giving birth and their newborns receive meds post-birth. Given that, in certain cases, treatment can prevent infection, we ask: Could we already be in possession of a cure?

Racism
Today, about half of all new HIV cases are among African Americans and 18 percent are among Latinos; we've known for two decades that the disease was affecting communities of color. Now the epidemic is a crisis of unprecedented proportions in the Hispanic and black communities. In 2006, African Americans were 45 percent of new HIV infections, but 13 percent of the population. Those who could have allocated resources to prevent HIV infections in these communities are now wringing their hands. History shows that racism can spread HIV as effectively as sex without a condom.

Serosorting
Choosing only sexual partners who share your HIV status was once criticized as a viral apartheid. Today, safer-sex advocates encourage the practice and social networking sites facilitate it (and lessen disclosure trauma). Not that it is foolproof: Some people lie, are misinformed or make erroneous assumptions about their HIV status. And let's not forget the "window period" when a person is infectious but does not yet test positive.

Skittles
A slang term for some HIV meds administered (often sporadically) in jails and prisons. When will people realize that prisoners are our brothers and sisters? If we accept the denial of decent

medical care behind the walls (remember that HIV rates in prison are two and a half times those on the street, and that about a quarter of positive people pass through lockup some time in their lives), we erode our community's goal of human rights for all. And yesterday's prisoner may be your future husband, wife or neighbor. So let's not throw away the key to their health.

Spitting

May be punishable by a fine, but it should not be a felony—even if you are HIV positive. The trace amounts of HIV in spit and the mechanisms by which the enzymes in saliva interact with HIV prevent spitting from transmitting HIV. Just think: If someone brandished a rubber knife with the intent to harm, would that "threat" warrant life in prison? Criminalization of people with HIV is the ultimate stigma, but it also furthers the spread of HIV by discouraging those at risk from getting tested. A member of the highest court in South Africa, Edwin Cameron, who has HIV, put it eloquently: "HIV is a virus, not a crime." If nondisclosure of a potentially deadly, sexually transmitted virus can be grounds for criminalization, why not prosecute those who fail to disclose they carry human papillomavirus, which is a leading cause of cervical, anal and penile cancers?

Stigma

It's what stands between HIV and many of its solutions. Because people associate HIV with sex and drug use, they refuse to see that HIV is just like any other disease. Instead, HIV is enveloped in a haze of homophobia, fear, denial, disgust and indifference. Because of that, people living with HIV often fear rejection, feel shame and isolate themselves. They become afraid to disclose and seek medical care and the support of their loved ones and friends. Which, in turn, can lead to ill health—both physically and emotionally—for those living with the virus. Stigma also impedes preventing, testing and diagnosing HIV. People are afraid to talk about it and to find out their own status—which can lead them to unwittingly transmit the virus. And lots of people don't get tested because they fear being "witch hunted" by government agencies.

Swimming Pools

Yes, you may safely share them with HIV-positive people—as we reminded the world on our April 2008 cover featuring Caleb Glover, an HIV-positive toddler who was banned from a swimming pool because of his status. Come on people, it's 2009. Get it straight already. (And you may serve us on real dishes, not paper plates, if you please.)

Treatment

The hot talk lately is of treatment as prevention, or the notion of testing, identifying and administering meds to all people with HIV whether they want it or not; this, the argument goes, would render their viral loads undetectable and the people themselves virtually noninfectious regardless of whether they practice safe sex or safe injecting. Is it feasible to identify all positive people and pay for their treatments? And what about the ethics of making population-based treatment decisions for entire classes of people—regardless of their individual need, desire or benefit from it—as opposed to administering individualized treatment? Then there is the issue of adherence (poor adherence can spike the viral load of a person who was virtually noninfectious, which could lead to spreading drug-resistant virus). However, studies have shown the strategy can be effective, and Julio Montaner, head of the International AIDS Society, is red hot on the idea. The

notion of treatment as prevention is guaranteed to engender a hearty debate.

Wall Street

This tiny stretch of tarmac in downtown Manhattan is not only ground zero for all things financial, and terrorist, on American soil, but also the site of many a profound protest by AIDS activists lobbying for affordable treatment. Dying in—the staging of activists' faux deaths—was intended to get the attention of the pharmaceutical companies that price gouged people living with HIV (remember when the price of Norvir skyrocketted an unmitigated 400 percent?). The money that we, our employers, our health insurance companies and the government pay for AIDS medicines could have financed rebuilding the World Trade Center—in solid gold. And while the pharmaceutical companies get larger and richer, they become more risk adverse. They barely, and tentatively, pump money into the many small, independent biotech companies that lack the funds to do the research and development necessary to bring their products to clinical trials and, if they work, to market. Makes you wonder: Does it pay to cure AIDS? We hope and think so. And governments, relief organizations and foundations around the world would also like to see a change. They're burdened with the ever-rising costs of keeping people with AIDS alive—both for humanitarian and their own economic reasons. The price to not cure AIDS has always outweighed the profit to be made by failing to produce a cure.

(K)Y

Jelly. Lube. The slippery stuff. A good partner for condoms, helping them stay intact and in place. A necessity for the ever-increasing number of people older than 50—many of them armed with Viagra—who are getting more action than they did in college. Older people are inclined to have multiple partners and not use protection, which is contributing to a spike in HIV infection among eldersexuals (as some ASOs call them). It's time to turn around the safe-sex talk: Do preach to Papa.

Youth

From children born with HIV (though this number in the United States is fewer and fewer these days) to the increasing number of kids who only discover what HIV is after they are diagnosed, AIDS is rampant among America's youth. In 2006, 34 percent of all new HIV infections were among people younger than 30. This is largely due to the eight years of abstinence-only sex education that the federal government funded under the Bush (No. 2) administration. We have a dire need to reach our young ones with accurate and complete messages about sexual health. Given the cyber nature of their lives, we will need to wield well the new technology. Twitter, anyone?

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