30 Things to Know on the 30th Anniversary of AIDS

June 7, 2011 By Regan Hofmann

Sunday morning marked the 30th anniversary of the first reported cases of a terrible disease--a disease that came to be known as acquired immunodeficiency syndrome, or "AIDS." I woke with a strange feeling in my heart caused by a mix of three emotions: gratitude that I had survived to see this milestone, sadness for all the loss AIDS has brought to the world and more hope than I'd ever dared allowed myself.

I was torn from slumber by the sound of my Blackberry signaling an incoming email, ironically, from Timothy Brown, a.k.a. "The Berlin Patient"--the first person ever cured of HIV. (He sent a bunch of us an email saying he was ready to up his ante to fight for more funding for AIDS cure research. Which is great, because his face and story have been all over the media lately, including, on the POZ cover.)

I lay in bed, reflecting on the weird irony of that. Here I was, a woman who was told she'd be dead in a year 15 years ago, emailing a man who was told he'd be dead several times over, discussing our next steps fighting the disease that has so far failed to take us out.

It's more probable than ever that we might actually be able to end this bloody pandemic. There has been a lot of encouraging news lately, and I've noticed much cohesion within the global HIV community. It feels like evidence-based science is finally giving us the answers, and therefore the platform, we need to help the world understand that HIV is disease that we can treat--and cure.

I am asked often, by reporters, producers, friends, etc., "What's going on with AIDS? What essential things do I need to know?"
And I always struggle with where to start. HIV/AIDS is a gargantuan topic that impacts, and is impacted by, so many aspects of life from economics to religion, politics, art, migration, poverty, homelessness, global climate change, psychology and, of course, sexuality, to name merely a few.

But because I've always wanted and needed a short list of the issues, I'd thought I'd give it a try. (I'd love any of you to help me refine this list.)

At a time like this, remembrance is key. Much of the media coverage around the 30th anniversary has aimed to capture the history of the pandemic. And so, in order not to repeat others' brilliant retrospective takes, I decided on the occasion of the 30th anniversary of AIDS and on the eve of

the start of the United Nations' High Level Meeting on HIV/AIDS (I am a member of the U.S. delegation, for purposes of disclosure), to suggest 30 things we should keep in mind now, as we go forward and try to end HIV/AIDS once and for all.

If you have limited time, here's the elevator speech (assuming you're riding to the Top of the Rock; brevity is not my forte): There is enough scientific data to indicate that widespread administration of antiretroviral treatment (ARVs) will prevent death while preventing the spread of the disease. But, ultimately, because the cost is too high and because there are complications with delivering and taking treatment, we need to find the cure for AIDS ASAP. We are close. With the right adjustments to make AIDS drugs both more affordable and still profitable enough for those who manufacture them to want to stay in the game of making them, we can put enough people into care to stop death and slow the rate of new infections dramatically. The more people we put into care, the faster we'll beat AIDS. The cure is a real possibility and an investment of $100 million or so could accelerate cure research to a place where we could possibly start phasing people off drugs in as few as 5-10 years. We also need a vaccine.

We need new political capital, more cold hard cash, and the continued compassion of the world.

Finally, we need to normalize and destigmatize HIV (which requires decriminalizing it) so people are not afraid to know their status, connect to care, disclose and seek the support they need and deserve.

Thirty years in, if we remember one thing, it's that HIV--a terrifying triumvirate of letters that still strikes deep consternation in many--is merely an abbreviation for a retrovirus, one that we have scientifically demystified nearly to the point of rendering it harmless.

Three decades in could mark the historical turning point of one of the deadliest diseases of all time. It is a moment for nations, pharmaceutical companies, research science, religious and social leaders, celebrities, media, the global HIV community and the general public to come together to help each other in what could be the homestretch of a long and grisly battle. It's also a time to remember all the heroes we've lost, and an opportunity to make some new ones.

The right investments now will not only spare lives and dollars, but will rewrite history.

And who doesn't want "helped end AIDS" on their resume?

With that, 30 considerations as we soldier on.

HIV/AIDS is a winnable battle. Dr. Thomas Frieden, head of the Centers for Disease Control and Prevention, was the first to boldly label it thus and recent reports on our progress against the disease are backing him up. Yesterday, the Joint United Nations Programme on HIV/AIDS (UNAIDS) reported that the global rate of new HIV infections declined by nearly 25% between 2001 and 2009. In India, the rate of new HIV infections dropped by more than 50%; South Africa saw its rate decline by more than 35%. These two countries have the largest number of people of HIV on their

continents.

While fewer people today perceive themselves to be at risk, the truth is the opposite: more people are at higher risk for HIV than ever before. There have never been more people living with HIV on the planet than there are today--an estimated total of 33.3 million. While this is good news as it means fewer people are dying of HIV/AIDS, it's also a bad news as it points to our inability to stop the spread of a preventable disease. Due to the volume of people with HIV, an HIV-negative person's risk of contracting the virus is statistically higher than it was decades ago, when awareness and fear levels were at an all time high.

A whopping 20% of all Americans estimated to be living with HIV don't know it. That means there are about 240,000 people in the United States unaware that they are living with the virus who are potentially sexually active and/or sharing injection drug works with others.

Anyone who has ever had unprotected sex or shared injection drug equipment should be tested for HIV. Because of misconceptions around HIV risk, too few people are getting tested and too many people, especially women, are getting diagnosed too late. Many people and medical providers, believe that only "certain kinds of people who do certain kinds of things" are at risk for HIV. While certain types of sex, the number of partners, frequency and factors like having concurrent sexually transmitted infections can increase risk, a person can contract HIV from a single act of unprotected sex. We believe women can get pregnant this way; it's time we believed people can contract HIV this way. Those who are sexually active or using drugs should get tested regularly. Doctors should not profile people based on sexual orientation, self-reported life style factors, race, gender or sexual orientation.

A mere 6.6 million people with HIV/AIDS currently have access to life-saving antiretroviral medications. What's more, many of these 6.6 million people are on older regimens, many of which have debilitating side effects, making them difficult to take--a fact that can lead to drug resistance and people running out of available options.

27 million people (and counting as new infections occur daily) are on a fast track to death. The biggest, pinkest pachyderm in the room is that treatment can save lives, but that tens of millions of people will still die despite the fact that we have the medical ability to prevent this because we are not providing them with care and treatment.

Access to care is not just a challenge in the developing world. There are currently 8,300 Americans with HIV/AIDS on AIDS Drug Assistance Programs (ADAP) waiting lists. There are additional uncounted numbers who have been booted off the ADAP program but who aren't on waiting lists because some states have suddenly changed their eligibility requirements for ADAP to conceal the true size of their waiting lists. If entitlement programs like Medicaid and Medicare (that serve far more people with HIV than the Ryan White CARE Act/ADAP) are gutted, the current ADAP crisis may prove to be the tip of the iceberg. And we can't always count on government or pharmaceutical industry bailouts.

It is imperative that we dramatically increase access to care and treatment around the world. This week, at the United Nations High Level Meeting on HIV/AIDS, nations worldwide will make public their commitments to fighting the global pandemic. Advocates and activists, global leaders, public health experts and members from the worldwide HIV community will be on hand to push for 15 million people on care by 2015. But this is not enough. Almost all people living with HIV will eventually need care to survive.

There is no excuse for not connecting more people to care. A recently released study, known as "HPTN 052" showed that treatment can reduce the chance of transmission between a person living with HIV and one who is not by 96%. Not only does putting people on pills keep people alive, it stops the spread of the disease. Increasing access to care today is a moral imperative, good public health strategy and it will save billions of future health care dollars.

We must reconsider the pricing of AIDS meds--both internationally and in the United States. At some point, profit margins, even for for-profit companies must be reconsidered when not doing so means tens of millions of people will die.

Generic HIV drug pricing must be considered, even for the United States. Given the challenges of funding care in the U.S., the issue of generic pricing and length of patents may need to be examined to ensure better HIV/AIDS care and to prevent billions of tax payer dollars going to federally-funded AIDS Drug Assistance Programs.

It is time to consider taking HIV/AIDS out of its specialized health silo. The U.S.-based HIV community should consider moving beyond advocating for AIDS-specific funding to defend Medicaid and Medicare...and most importantly, the Affordable Patient Care Act. Globally, we need to fix broken health care delivery systems and address the crisis of the shortage of health care workers in order to be better positioned to deliver care to more people.

It is the not the sole responsibility of the United States government, or the governments of other nations that have stepped up historically and generously, to forever fund the global fight against HIV/AIDS. More nations must start taking better care of their own people and not depend on the United States or large, multinational health funds like the Global Fund to Fight TB, Malaria and HIV/AIDS to bail them out. Activists pushing for U.S. funding must simultaneously push nations that have historically cried poorer than they are.

The same treatment that saves peoples lives also endangers them. While we need to give more people living with HIV treatment to keep them alive until we develop a cure, we cannot overlook that HIV treatment is no picnic. The very drugs that can fend off AIDS can lead to other serious health conditions like malignancies, diabetes, premature aging, osteoporosis. An ever-increasing number of people who have been taking ARVs and living with HIV for a long time experience treatment failure, drug toxicities, debilitating side effects and drugs resistance. Treatment is not the best answer, long term.

Treating people with HIV is not, economically, a viable long-term solution. The price tag

to treat the current global caseload of all people currently living with HIV for the full course of their normal lifespans is in the trillions of dollars. The cure and a vaccine could prove cheaper.

We must invest immediately and much more significantly in AIDS cure research; we could see an AIDS cure in five years with a $100 million investment. Kevin Frost, CEO of the Foundation for AIDS Research (amfAR; I am a board member) claims an investment this substantial could radically alter the state of the AIDS cure. By comparison, the United States government alone spent $19 billion on HIV/AIDS prevention, care and treatment last year.

The science behind AIDS cure research is much further along and hopeful than many think. To wit, *Time* magazine named "PrEP" or "pre-exposure prophylaxis" (the practice of administering ARVs to HIV-negative people prior to HIV exposure to prevent infection) the number one scientific breakthrough of 2010--the same year in which the first person was officially proclaimed cured of AIDS. Researchers, government, investors and the media have focused too much for too long on treatment. We need to educate more people about the promising state of AIDS cure research.

We need to continue to invest significantly in vaccine development. Curing AIDS is key but we need a vaccine, too, or we may find ourselves curing AIDS over and over again.

We need to address the "Valley of Death." The delta between venture cap bio-tech investment and the big dollars needed to get promising treatment, prevention, vaccine and cure candidates through FDA-approval to market is huge and investors are looking for quick returns on their investment. We need to educate the investment community that ROI on HIV/AIDS research may no longer be decades away so they get some skin in our game.

Administering antiretroviral drugs to HIV-negative people when so many living with HIV cannot get them presents a moral dilemma. Treatment-as-prevention" as PrEP and "PEP" (or, "post-exposure prophylaxis" or the practice of administering ARVs within 72-hours after a potential incidence of exposure to HIV is called) are critical tools in the prevention tool kit. But can we really discuss nations paying to give drugs to high-risk people who are HIV-negative to prevent HIV when we aren't giving HIV-positive people drugs to stay alive? Especially when we can kill two birds with one stone by giving people living with HIV treatment...because that same treatment doubles as prevention. If we do this, do we really need PrEP? And why can't people just use a condom instead of taking drugs with side effects? And, if our global health programs balk at giving out condoms to sex workers and substitution therapy to injection drug users, how are they suddenly going to green light giving those same high risk groups ARVs? The answer? They probably aren't. PrEP is for rich people who are willing to pay out of pocket for safer, condomless sex.

Prevention works, but it's not easy as some people will always have unsafe sex and share injection drug works. What people need to recognize is many of the people who do these things would rather not do them. When people have "survival sex" or sex-for-money to secure food, housing, safe havens from violence, or if they are in abusive relationships, they are often not empowered to advocate for their sexual health. And people who are disenfranchised who become

addicted to drugs (often as a result of despair or to numb the pain of terrible living conditions) often don't have the resources to connect to the care they need to change their behavior.

Mother-to-child prevention of HIV is only ultimately successful if we keep the moms alive and the babies safe as they grow up. Focusing on keeping mothers alive helps ensure that the children who were born HIV-free remain that way.

We need to develop vaginal and rectal microbicides (gels, creams or topical agents laced with antiretroviral drugs) as soon as possible. Not everyone is in a position to negotiate for safer sex, including many people in marriages who believe their partner may be unfaithful. Receptive partners in particular need means they can control to ensure their sexual health. And the world needs to acknowledge that many straight people have anal sex.

We need to talk openly, maturely, respectfully and without hysteria about sex. Unless we get over our squeamishness about talking about sex, people will continue to die needlessly. What's worse? Facing your own discomfort about frank dialogue around sex, or watching people die?

T**here is an overwhelming amount of scientific data proving that discussing sex with children and teens leads to young people waiting to have sex until they're older, and arguably, more emotionally equipped to negotiate for their sexual health.** We need to talk to our children openly and frankly about sex, in age appropriate ways, much sooner than most people think. Kids have sex these days at 11 and 12. They should be taught how to do it safely.

"Abstinence-only" or "abstinence until marriage" sex education backfires. The National Survey of Family Growth showed a slight increase in sexual abstinence among kids. But the real headline from the same survey is that 7 out of 10 of American kids ages 15 to 24 are having sex. Many kids have oral and anal sex only to "preserve their virginity"--a decision that puts them at higher risk as unprotected anal sex is riskier than unprotected vaginal sex**.** This is largely why 34% of all new HIV infections in America are in people under the age of 30.

Homophobia and homophobic hate crimes spread HIV. So does incarceration and criminalization of HIV. Threatening to put people behind bars, beat or kill them will not help us stop the spread of HIV/AIDS. We need to criminalize gay hate crimes and decriminalize HIV. There are sufficient laws in place to deal with the rare cases when a person wields HIV in a harmful way. For those people who do end up incarcerated, we need to give them proper care while they are in prisons and jails and help them connect to care upon their release.

HIV/AIDS is the #1 killer of African American women of child bearing age worldwide. HIV/AIDS disproportionately affects black and Latino people and the health disparities experienced by African American and Latino people undermines our ability to change this. We need to resolve the health disparities that exist because of racism so that no one racial or ethnic group experiences inferior health care.

The stigma surrounding HIV/AIDS has not dissipated. When Larry Kramer's "The Normal Heart" opened on Broadway this spring, the fact that its messages (written more than 25 years ago) were perfectly resonant today reinforced that while we have made great headway medically around HIV/AIDS, the stigma is still as terrible as it was in the early days. People may be more outwardly politically correct about HIV/AIDS but they still fear, revile, judge, dismiss and discriminate against those of us living with it.

HIV-related stigma is as deadly as the virus itself. Fear of stigma keeps people from getting educated about HIV/AIDS, from getting tested, from linking to and getting care and treatment, from disclosing their status and from seeking the emotional and financial support people with HIV need to survive. It undermines our ability to secure political, social and financial capital. There's only one way to end stigma: for people with HIV/AIDS to come forward without shame, terror or apology. That will be far easier if the world starts to understand that there is no reason to fear those of us living with HIV and that the best and fastest way for all of us to stop worrying about HIV is help us get the resources we need to get the health care we deserve so we stay healthy, non-infectious and live to the day when the world will finally be HIV-free.

I am grateful to be here. Grateful to all who have fought for the lives of people with HIV, grateful to be able to join the ranks of those still fighting.

I believe we can end AIDS.

If I didn't, I couldn't get out of bed each day.

Thankfully, I'm not alone.

Always, on the days when it seems challenging to rise and dress for battle, someone calls, someone like Timothy, and reminds me we can't give up when there's so much more to do, so much more we all can do.

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http://beta.docker.poz.com/blog/30-things-to-know-on