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HOW TO **SURVIVE** A PLAGUE

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HOW TO SURVIVE A PLAGUE

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A LETTER FROM THE FILMMAKER

How to Survive a Plague bears witness. The film documents what I saw with my own eyes in those first long dark days of the worst plague in America—it shows both the tragedy and the brilliance leading up to 1996 when effective medication finally made it possible to think of HIV/AIDS as a chronic condition, like diabetes. I witnessed all this in my role as a journalist, not an activist. Instead of a bullhorn or placard, I carried a notepad and pen. There I am in the background of these frames. You can see brief glimpses of me nearly hidden in those crowds of activists, pressed against the walls of their meetings or counting their heads as police officers carted them off, trying to stay out of their way.

In fact, I spent the better part of ten years shadowing people like Peter Staley, Mark Harrington, Garance Franke-Ruta, and David Barr. Why? Because to me it was clear from early on that they were doing something that had never been done before in the history of health care advocacy. Through the grassroots institutions they helped build, ACT UP and TAG, they invented a new kind of activism, one that has inspired generations since. And at a time when so little progress was coming out of the halls of government and Pharma, I believed that if anybody was going to break the logjam and save lives it would be these guys—and that's exactly what happened.

Key to their success was an innovative approach they named "the inside-outside strategy." On the "outside" stood the majority of activists in their ranks—shock troopers who could mobilize quickly and stage dramatic protests that garnered worldwide media coverage. Humor and ridicule were among their weapons, as were embarrassment and no small amount of audacity. They became the angry, hopeful, forceful face of the plague.

The goal of the "outside" ranks was to pry open the doors to the fortresses where decisions were being made—life-or-death decisions for anybody with an HIV infection—so that a small elite group of them could go "inside."

Back then, science was an Ivory Tower

discipline removed from the real world of ordinary people. It took up to a dozen years for a new drug to be tested and released. Even after the onset of the AIDS epidemic, with its grim prognosis of just 18 months, a hermetic sense of academic sluggishness prevailed. They knocked on doors at the NIH and FDA, then knocked them down when their pleas were not answered.

That's how the "inside" forces flooded in and demanded a place at the table for patients and their advocates in every aspect of medicine and science. Their task was daunting. In order to become full partners in the research, they had to become experts themselves. I watched Peter, Mark, Garance, David, and the others turn to textbooks and teach themselves the fundamentals of science—quizzing one another on the basics of immunology and virology, cellular biology and pharmaceutical chemistry.

They won their place at the table thanks to the activists who remained "outside," but earned respect for their opinions and suggestions on the "inside," and became equal partners in the arduous work that lay ahead. Together, they helped bring about the treatment revolution that made HIV survivable.

Millions of lives have been saved thanks to them. That's a daunting legacy to leave behind by any measure. It shows us that anything is possible—literally anything. Even the most disenfranchised people can change the world.

Their legacy also includes a powerful new model for social activism that is equally relevant today. Their change-making blueprint has been adopted by thousands of other health activists, from breast cancer to autism. Pro-democracy activists in Russia are studying their techniques, replicating their sensational street theater, and knocking on the doors of power themselves. LGBT rights campaigners in places like Albania and Greece are learning the lessons of ACT UP and TAG as they begin building new movements for social change.

For them, *How to Survive a Plague* does bear witness. And at the same time it shows how to survive anything. You do that by learning, and fighting, and loving.

David France
January 12, 2013



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LEARN

FIGHT

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Unleashing Your Power to Change the World: Lessons Learned from *How to Survive a Plague*

Activism is not a spectator sport.

The difference between those who watch the news and lament the problems of the world and those who get off the couch and do something about them is the difference between a passive citizenry and an active democracy.

If you are reading this, chances are you're the type of person who gets off the couch.

Intention and engagement are not automatically linked. Those whose actions effect meaningful social change dive headlong into the world's toughest problems—and stick with them, especially when the going gets tough.

How to Survive a Plague tells the

story of the AIDS Coalition to Unleash Power (ACT UP), a group of several hundred people who challenged the powerful interests that controlled U.S. government budgets, federal and state policies, medical research, drug approval, and global drug pricing.

Diverse in background, these activists were bound by a singular desire: to act—in the face of stigma and government intransigence against a mysterious disease killing their friends, family members, and lovers, and that threatened their own lives.

They exemplified the activist ethos: they convened, empowered themselves with information, harnessed their fury, and aligned their actions and skills to address one of the world's most difficult problems—finding drugs to keep people with HIV alive.

ACT UP's efforts resulted in the accelerated development and approval of what is today a list of 33 antiretroviral drugs that keep people with HIV from developing AIDS and dying. By engaging politicians, government leaders, and Pharma, the members of ACT UP, TAG, and the other advocacy groups that worked with them, helped save the lives of millions of people.

Today, there are nearly 8 million people on treatment, living with HIV. And because that treatment reduces viral transmission by 96%, it also doubles as prevention. Securing, and enabling access to these drugs has also kept countless children from contracting the disease in utero, prevented thousands of new infections, and spared millions of children from becoming AIDS orphans.

The story of AIDS activism begins in New York City, San Francisco, and Washington, DC in the late 1980s, and quickly spreads across the country. Though started primarily by gay white

men, it soon grew to include people of all races, genders, and sexual orientations. Their heroism stands as an inspiration to new generations of activists of all kinds.

The first AIDS activists helped turn a diagnosis of being HIV-positive from an automatic death sentence into a treatable disease. Their success is evidence that when enough informed, empowered and dedicated people come together at the right time, place, and in the right way—they can solve the most intractable problems of the world.

The strategies and tactics of AIDS activists offer a model for all who want to change the world for the better.

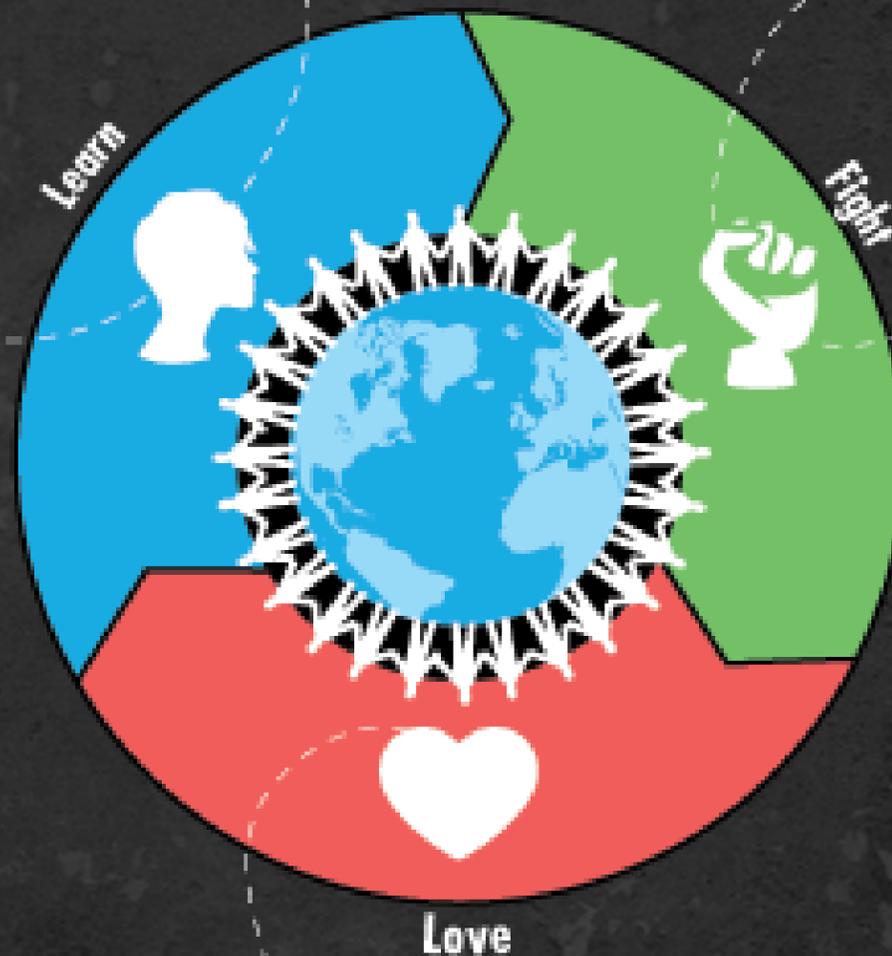
There are three main components to the model: learning, fighting, and loving.

Effective activists use their heads to learn. They become experts about their issue and about the political and power dynamics that must be addressed to effect change.

They channel righteous anger in to right action; they use the symbolic power of the fist to organize, protest, and be heard. In short, they fight.

And they love, leading from their hearts, using their compassion and empathy to build coalitions and to work alongside people with whom they may have fundamental differences.

FasterCures a medical research 'action' tank published a powerful report on the history of ACT UP and early HIV/AIDS advocacy titled "BACK TO BASICS: HIV/AIDS Advocacy as a Model for Catalyzing Change" It summarizes the model as follows: "Change is possible. But in order to create change, the focused voices of advocates must be heard through the din. Individuals and organizations must do the hard work of becoming ready to question the status quo,



34.2
million

the number of people estimated to be living with HIV/AIDS around the world

33

the number of life-saving antiretroviral HIV/AIDS medications (ARVs) available today

8

million
the number of people with HIV/AIDS currently accessing ARVs worldwide

26.2
million

the number of people with HIV/AIDS globally not accessing treatment

1.7
million

the number of AIDS deaths globally in 2011; 24% fewer deaths than in 2005

2.5
million

the number of new HIV infections in 2011; down from 3.2 million in 2001

and be smart enough to present well-founded alternatives. Strong leaders in government must pave the path and prepare to stay the course. Specific strategies with clear goals must be established in order to hold people accountable."

Using the lens of HIV/AIDS activism, the outline below explores the concept of "Learn | Fight | Love" in greater detail.



LEARN about the Issues and Barriers to Change

Simply knowing what is wanted generally, such as improved medicine, gender equality, or human rights, is not sufficient to effect social change.

Powerful activists know as much, or more than, the people they are trying to influence. They are able to frame pathways to their goals and articulate those pathways to those from whom they are asking help.

Early AIDS activists became experts on the science of HIV and the systems by which drugs are researched, developed, and approved. Before they met with leaders at the Food and Drug Administration (FDA), the National Institutes of Health (NIH), or other research institutions, they did extensive homework. This helped them to secure seats at the tables where key decisions were being made and to have maximum credibility when they advocated for change at those tables. They also knew how to influence the political leaders who set policies and budgets and how best to attract media attention—two things that go hand-in-glove.

Great activists master the language of their issue or cause. They become fluent in the experts' terminology.

Understanding the eco-system of an issue area is absolutely necessary for both advocates—those working on the inside—and activists—those working on the outside—to be effective. Barriers to change are sometimes the unintended consequences of deep-seated bureaucracies; faulty, inefficient structures; ill-informed leaders; or outdated laws and policies.

Understanding the power structure—which people and what organizations control

"Change is possible. But in order to create change, the focused voices of advocates must be heard through the din."

"BACK TO BASICS: HIV/AIDS Advocacy as a Model for Catalyzing Change" – Michael Manganiello, HCM Strategists, and Margaret Anderson, FasterCures.

decisions at each juncture—is also critical. For ACT UP, working with a leader such as Dr. Anthony Fauci on the inside, was arguably the equivalent of public demonstrations outside the NIH.

Finally, it's about money: how it flows and who controls it. Understanding and influencing the budget process can be essential to the success of a movement.



FIGHT for Health Care Justice

Anger is a key driver for activists. It fuels some people to greater levels of risk taking. Many of the people who have changed the world were indignant enough to show up, stand up, push back, and fight back.

Legendary AIDS activist Larry Kramer, a founder of ACT UP, said, "We were fighting for our lives and for our friends...who were dying like flies all around us, so we were motivated."

That motivation was manifested within the tradition of non-violence and civil disobedience closely associated with the work of Mahatma Gandhi, and later Martin Luther King. Gandhi once said, "A small body of determined spirits fired by an unquenchable faith in their mission can alter the course of history."

The members of ACT UP were those determined spirits. They fought hard, but always non-violently. They took to the streets, made noise, stormed meetings, conducted "die-ins," carried empty coffins, and later, the actual bodies and ashes of dead loved ones—they were not afraid to make a scene. Their fury—and their message—was often captured by the press, but always by their own cameras and video recorders.

Their weapons included clearly articulated demands, arresting graphics on t-shirts and placards, memorable and often shocking slogans—and a great deal of courage. Many who fought to change the way the world treats people with HIV have been jailed. More than once.

They were laser-focused in their mission. Whether storming the halls of power with banners and bullhorns or meeting with researchers, drug developers, government officials and others

who actually held the power, they never deviated from their fundamental objective of securing life-saving drugs for all people with HIV.

Finally, AIDS activists were relentless. They never took "no" for an answer. They made sure their voices were heard and kept focused on their goals. When forced to retreat, they regrouped and returned to fight another day.



LOVE by Connecting with Others

Many people contemplating getting involved in social change wonder whether individual actions can really have an impact. The answer is unequivocally, yes.

History is full of examples of individuals who catalyzed movements, from Susan B. Anthony to Nelson Mandela, Vaclav Havel to Rosa Parks. Some made a career of change; others responded to a moment of action that inspired widespread change. None acted alone.

Social change can start with one person, but it only gathers momentum and reaches its potential for maximum impact when individuals come together. Those who altered the world partnered with others of different backgrounds and beliefs and worked with them toward a common end.

The strong sense of community and shared responsibility captured in *How to Survive a Plague* was instrumental in sustaining a decade-long fight. Love, for themselves, for each other and for life, gave AIDS activists the strength to persevere—and triumph.

ENDING AIDS NOW

*The tools and knowledge to stop the AIDS pandemic are in hand. A new era of fierce AIDS advocacy is required to secure the political will and the resources necessary to turn what's possible into a reality. With a quick response now, an AIDS-free generation—and even a vaccine and cure—could be possible in our lifetimes. Here, we examine the opportunity of the moment and how we best finish what the activists in *How to Survive a Plague* began.*

By Regan Hofmann

Some 30 years since HIV was identified as the cause of AIDS and 17 years beyond the activists' victories highlighted in *How to Survive a Plague*, the fight to end AIDS is at a critical juncture. Global experts agree: the end of AIDS is possible.

It has been proved that effective HIV treatment doubles as prevention by reducing the probability of viral transmission by 96%. When more people access treatment, there are fewer new cases of HIV, fewer AIDS deaths, and fewer AIDS orphans. The faster we get more people linked to care, the more dramatic the declines in infection rates, illness, and death. While more widespread treatment is key to beginning to end the AIDS pandemic, it will ultimately take a vaccine and a cure to actually end AIDS. There have been significant breakthroughs in vaccine and cure research—at least one person has been cured of HIV infection and while the method by which he was cured is not easily replicable, the insights offered by his case have opened up several new avenues for potential cures.

Given that we now know how to stop AIDS, the burning question is whether or not we will seize the opportunity before us to spare the lives of millions of people who need not get sick or die.

In November of 2012, U.S. Secretary of State Hillary Rodham Clinton announced the release of "The President's Emergency Plan for AIDS Relief

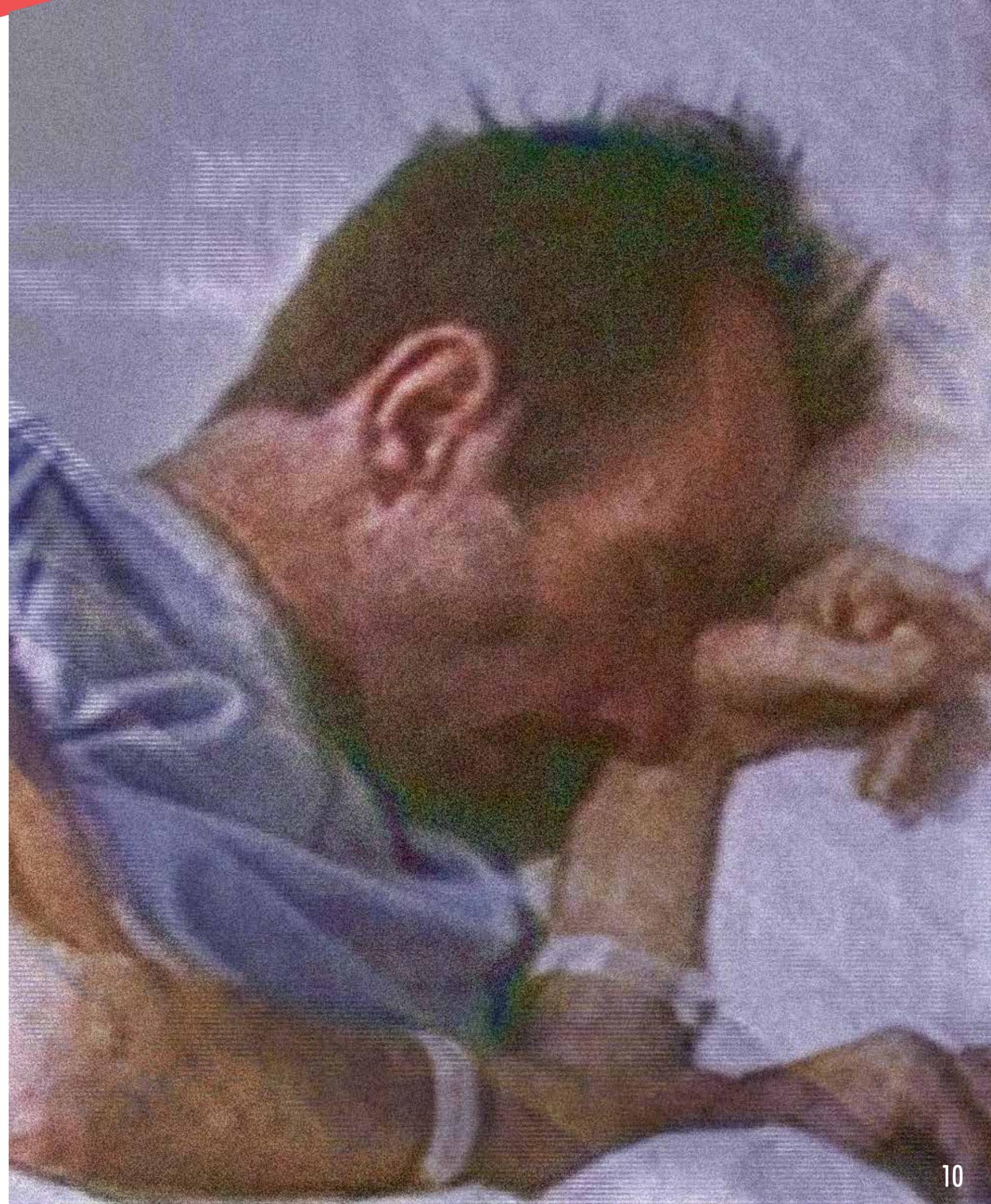
(PEPFAR) Blueprint: Creating an AIDS-free Generation." The plan lays out a comprehensive road map by which many nations working together could begin to end the pandemic.

"The goal of an AIDS-free generation may be ambitious," Clinton stated a year earlier, "but it is possible with the knowledge and interventions we have right now. And that is something we've never been able to say without qualification before. Imagine what the world will look like when we succeed."

The heroes of *How to Survive a Plague* accelerated the development of life-saving medication. The urgency of their fight was palpable and it was driven by personal desperation; every day, they watched their friends and lovers get sick and die, even as they worried about their own health. In about 9 years, the relentless work of the early AIDS activists helped turn a diagnosis of HIV from a near certain death sentence to a mostly survivable condition for those who could access care and treatment.

The antiretroviral treatment that early AIDS activists fought for has prevented millions of new infections and millions of AIDS deaths, and it has spared millions of children from being orphaned. That's the good news. The bad news is that only 8 of the more than 34 million people estimated to be living with HIV globally currently have access to these drugs. The remaining 26 million people (and more each day) face imminent illness and death. More than 750,000 of those living with HIV—and without treatment—live in the United States.

So the battle is far from over. Ironically, the existence of effective treatment has led to a dangerous complacency about AIDS and diluted the urgency of the fight. But for those who can't get treatment, having HIV today is every bit as horrific as it was in the early 1980s. And there are more people living with HIV on the planet than ever before. When ACT UP first started, thousands of people were dying each year from AIDS. Today, millions are dying—even though the medication to save them exists.



Among the goals of early AIDS activists was the development of life-saving medications. Today's AIDS activists are called to fight for universal access to those medications for people with HIV—and to push for vaccines and the cure.

The battle to begin to end AIDS must be fought simultaneously on four key fronts: access to care; prevention; human rights; and research. If modern activists, governments, non-government organizations, the private sector, and global health organizations are willing to invest to make rapid headway in these four areas, there is real hope that millions more might survive this plague.

Here, a closer examination of the four key front lines in the battle to end AIDS.

ACCESS TO CARE



In 1996, a new class of antiretroviral HIV drug, known as “protease inhibitors” or PIs, changed the AIDS treatment landscape overnight. Protease inhibitors use a high-tech mechanism for preventing viral replication. Taken in combination with other antiretroviral medications (an approach often called “cocktail therapy”), PIs stop HIV from destroying the body's immune system and causing illness.

Protease inhibitors were so effective that they even helped people who had already developed AIDS. When people who were quite sick took the PI “cocktail,” their bodies suddenly began to rebuild their immune systems and heal. The recovery was so dramatic it was coined the “Lazarus effect”—referencing the story of Jesus raising Lazarus from the dead.

Continued research has led to the development of more than 33 drugs to control HIV. Further, in 2011, it was proved (in a study known as “HPTN 052”) that effective HIV treatment doubles as prevention. Medicine taken by people with HIV to protect their own health protects others by lowering—by a whopping 96%—the risk of viral transmission.

In addition, HIV treatment given to pregnant women living with HIV can reduce the chance that their baby will be born with the virus to less than 1-2%. And if a short course of HIV medications is given to people who may have been exposed to the virus within 72-hours (an approach known as “post-exposure prophylaxis” or “PEP”) HIV infection can possibly be prevented. It is clear that universal access to HIV treatment both saves lives and helps stop viral spread.

To ensure that medicine is delivered to all who need it, widespread, voluntary testing must be made available to everyone at risk for HIV. And the public needs to be re-educated about what constitutes “risk.” Anyone who has unprotected sex is at risk for HIV and should get tested regularly.

Health care system infrastructure and support services must be improved—and made more affordable—so people have ways to access testing and treatment.

So how do we increase the number of people with HIV on treatment? Two ways. One, the nations that can afford to must increase their support for their own programs that provide HIV testing and care to their people. And two, the wealthiest nations must also contribute as much as they can to multilateral programs such as the Global Fund to Fight AIDS, Tuberculosis and Malaria, as doing so will help address the funding needs of less wealthy nations with high HIV burdens.

As part of making health care more affordable for people with HIV, HIV drugs need to be priced at levels that allow more people—and nations—access to the best available treatments. Currently, there are battles around the globe over the pricing, production, and distribution of generic HIV medications, particularly in Europe, India, and the Far East. For example, manufacturers of non-generic drugs are trying to block access to generic drugs in Europe. But while some European nations pay for non-generic drugs for the people dependent on public health services, others cannot. Struggles over drug pricing

and intellectual property laws governing the formulations of HIV medications are resulting in a crisis of access to care.

The high price tags of the newest medications mean that even among the lucky 8 million on treatment, many are limited to taking older drugs that have serious side effects, which, by making them harder to take, can undermine adherence to drug regimens and treatment efficacy.

PREVENTION



Consistent and effective treatment doubles as prevention. But since less than one quarter of HIV positive people are on treatment, the need for other types of prevention remains.

Condoms (male and female) work, and they are cheap. Needless debates over the connection between the dispersal of condoms and increased sexual activity have hindered condom dissemination campaigns in some parts of the world. Research indicates that neither comprehensive sex education nor the dispersal of condoms result in increased levels of sexual activity. But because science does not always trump myth or spiritual beliefs, prevention remains more challenging than it arguably should. Voluntary adult male circumcision has also proved to be an effective form of harm reduction because it significantly reduces the risk of HIV infection. Availability of clean injection equipment also results in lower rates of HIV infection.

Biomedical forms of prevention exist as well, in the form of pre- and post- exposure prophylaxis (PrEP and PEP). And newer ones, like microbicides (topically applied gels and creams containing ARVs), are being studied for efficacy.

HIV testing is related to prevention. Knowing one's status can lead to changes in behavior that can protect others (such as practicing safer sex), or commencing treatment, which can also prevent transmission.

In order to be successful, prevention campaigns must be created and tailored to resonate with their target audiences. Ideally, they acknowledge the realities and challenges of the real world and offer strategies that are feasible.

For example, suggesting that women with no education or income change their behavior and stop having “survival sex” is less effective as a prevention strategy than offering them stipends that address the root motivation for the behavior. Women with money are less likely to have unprotected sex for money.

Offering age-appropriate, comprehensive sex education to everyone is another prevention strategy. Educating all sexually active people how to have sex more safely can lead to behavior change that would protect individual and public health and save future health care dollars.

The possession of tools of prevention (such as condoms or clean injection equipment) has recently been presented in several notable criminal trials as “evidence” of drug use or sex work. The publicity surrounding these cases has raised questions over whether these prosecutions will make people less likely to use condoms and sterile works. Refusing to address the real world needs of sex workers and injection drug users by driving them away from tools of prevention and limiting their access to health care is likely to undermine both individual and public health.

HUMAN RIGHTS



The end of AIDS will be possible only if the human rights of all people, especially those with or at risk for HIV, are better protected. Failing to address the crisis of inequitable human rights around the world undermines prevention, testing, and treatment efforts, and makes it harder to secure the political will and financial resources necessary to end AIDS.

Now, more than ever, human rights must occupy the center of the global struggle against HIV/AIDS. At the 2006 United Nations' High Level



Meeting on AIDS, global leaders issued a statement recognizing that “the full realization of all human rights and fundamental freedoms for all is an essential element in the global response to the HIV/AIDS epidemic.”

The biggest enemy of these rights is stigma.

Even after 30 years and all the campaigns dedicated to education and awareness, the stigma surrounding people living with HIV remains an enormous barrier to people knowing their status and seeking medical help.

Due to the many misperceptions and myths surrounding HIV/AIDS, people living with HIV are often ostracized, disenfranchised, discriminated against, unfairly criminalized, and in some places, even beaten or killed. Faced with these potential dangers, it’s easy to understand why many at risk are too afraid to come forward to find out or disclose their HIV status or seek medical care.

These acts of discrimination and, in some cases, criminalization, borne of misplaced fear and prejudice, only serve to deepen the stigma around HIV. In doing so, they prevent people from educating themselves and others about the disease. They also discourage people from seeking medical care to discover their status or to get the necessary medical help. The shaming, threatening, harming or jailing of people with HIV is self-defeating as a prevention strategy and backfires as a means of “protection.”

Similarly, outdated and unnecessary travel restrictions for people with HIV only serve to fuel the fire of people’s fear and prejudice. While much headway has been made in removing many of the early travel bans, 45 countries still maintain some type of travel restriction for people living with HIV.

Bolstering the protection of people’s human rights will allow the tools of prevention, testing, and treatment to be applied more widely and more effectively in the field. There is a direct

correlation between people being safe and having improved health.

Guaranteeing equal access to quality health care for all people will help stop AIDS. Prosecuting those who commit anti-LGBTQ and racial hate crimes will help. Defending vulnerable women and children and securing overarching gender equality will help. As would ensuring all people the basics necessities of life (food, water, shelter, safety). People are less likely to attend to their health and care about their future or the future of their nation or their community when their survival is at risk on a daily basis.

Clearly, it will take more than pills and prevention tactics to stop the AIDS pandemic. It will also require a major focus on ensuring human rights for all. Ending AIDS requires the permanent correction of some of the world’s worst ills and imbalances. The things we need to do in order to eliminate AIDS will make the planet a safer and healthier place for everyone.

SCIENTIFIC RESEARCH



Even if we could manage to quickly test and treat all the people living with HIV, did a much better job on the prevention front, and succeeded in defending everyone’s human and health care rights, those things alone will not eliminate AIDS. We also need vaccines and a cure.

Aggressive funding for the research and development of vaccines (preventive and therapeutic) and for a cure to AIDS are essential. It is far preferable to control the virus without the use of lifelong treatment, both in terms of the health of people with HIV and the expenditure of health care dollars.

The cost to administer HIV treatment for the lifetimes of the 34 million people estimated to be living with the virus globally is prohibitive. It’s also not the best medical option. While the newer HIV drugs have fewer side effects than their older

relatives, some serious side effects remain. (And too few of the 8 million people currently receiving treatment are on those newer medications.) The drugs themselves often lead to conditions that require additional medical care, increasing the cost of long-term care for people with HIV. AIDS vaccine efforts have been ongoing since 1984, with little progress. A working vaccine could stop transmission completely. As with polio, and it could even eradicate HIV altogether, sending it the way of small pox. To get there, we will need more money and better ideas, two prime targets for activism.

There is a period of time, just after exposure, when a person may be infected with the virus and still not test positive for its presence. This means there will always be people who will be unaware they have HIV and could unwittingly pass the virus along to someone else. Preventive vaccines would resolve this issue.

Cure science has had some major breakthroughs in the past 24 months and certain insights and proofs-of-concept (such as the Berlin Patient, the first person cured of HIV) have helped focus research around a cure, honing scientists’ efforts and piquing investors’ interests. Increasing funding for cure research at this time is a critical piece of ending AIDS. Ironically, a vaccine and the cure may one day conflate, as the AIDS cure could involve, as part of a multi-pronged attack, a therapeutic vaccine. (Therapeutic vaccines are those given to people who already have a disease to help cure them. Preventive vaccines are given to help people avoid contracting disease in the first place). And given that the discoveries from AIDS cure research often shed light on efforts to control and cure other diseases, including certain types of cancers, accelerated investment into ending AIDS may also advance solutions for other life-threatening disease.



WINNING ON THE FRONT LINES BY FIGHTING HARD ON THE FLANKS



When fighting to end the AIDS pandemic, activists wage battles in arenas both directly and indirectly related to the virus itself. Many of the problems that need to be conquered to end AIDS will make the world a healthier place for all. Here is a short list of key issues related to HIV that, if addressed successfully, will help accelerate the end of AIDS.

WIDESPREAD TESTING AND ACCESS TO NEW, AFFORDABLE TREATMENT TO ADDRESS THE PANDEMIC OF HEPATITIS C

Hepatitis C is another viral pandemic for which there is now a cure. If a person's HIV is treated but hepatitis C infection is not, they remain at risk for premature death. If only HIV is treated, a person can't achieve full good health and rates of morbidity increase. Therefore, people with HIV should be screened for hepatitis C, too. New treatments for hepatitis C are much easier to undergo than previous ones; they have far fewer side effects and therefore have a high success rate. But the newest treatments for hepatitis C are expensive and not easily accessible to many in need, particularly in the developing world. Activists are lobbying for increased testing for hepatitis C and for lower prices and greater access to the newest hepatitis C treatments.

BETTER PREVENTION AND TREATMENT STRATEGIES FOR INJECTION DRUG USERS

It has been well documented that providing sterile injection equipment (including syringes) to people who inject drugs can greatly reduce the spread of HIV and hepatitis C. Maintaining safe locations in which people can inject drugs using clean injection equipment have also been shown to reduce the spread of disease. But resistance to the dissemination

of sterile injection equipment (those against it argue that doing so condones usage despite data to the contrary) and safer injection sites leaves people who use injection drugs with too few options to manage addiction safely. Opiate substitution therapy (such as offering methadone to replace heroin) has been shown to halve the risk of HIV infection. Activists are working to ensure that these proven forms of harm reduction get to more people who could benefit from them.

ACCESS TO PAIN RELIEF MEDICATION

People with recurring or chronic pain who have insufficient access to pain medicine often turn to self-medication with illegal drugs, including injection drugs—an HIV risk. But the potential for abuse, addiction, and dependency on pain killers has resulted in restrictions on the availability of certain pain medications. Incidents of prescription pain relief drugs being taken from medicine cabinets and sold on the street or abused by teenagers for recreational purposes, as well as legal cases where physicians have been convicted for "over prescribing pain medications" have led to diminished access to necessary pain relief medication for people who legitimately need it, particularly among patients in disenfranchised populations. Patients' rights activists are pushing to ensure that patients can get the medications they need to live comfortable and healthy lives.

DECRIMINALIZATION OF SEX WORK

The criminalization of sex workers—an effort to control and limit sex work—backfires as a means of protecting public health because it keeps those who are engaging in sex work from accessing educational and prevention services, including screening for sexually transmitted infections (STIs), and accessing health care in general. Given that condoms (male and female) and lubricants can reduce risk of STIs, preventing sex workers from using these harm reduction tools heightens the risk

that STIs will spread. And as treatment can double as prevention when someone is living with HIV (antiretroviral therapy can reduce the risk the virus will spread by 96%), denying sex workers who are living with HIV access to care undermines their individual health and public health generally. Activists are working to secure equal civil and health care rights for sex workers.

INCREASED FUNDING FOR GLOBAL HEALTH

Multilateral funds like the Global Fund for AIDS, Tuberculosis and Malaria and bilateral programs in the U.S. such as the President's Emergency Plan for AIDS Relief (PEPFAR) and others deliver health care services for people with HIV while supporting the capacity of existing health care systems, expanding general health care infrastructure, bolstering the recruitment and training of health care workers, and offering a variety of related health services to people who enter the system for a single health concern. Activists are working to encourage high levels of support for health care on the part of all nations.

For a list of organizations supporting these and other issues, please see page 41 of this guide.

Regan Hofmann is the former editor-in-chief of POZ and poz.com, an AIDS activist, and a consultant working on global health. She is on the board of the Foundation for AIDS Research (amfAR), is a global ambassador for the Elizabeth Glaser Pediatric AIDS Foundation, and serves on the CDC/HRSA advisory committee for HIV and Viral Hepatitis.

LESSONS

LEARNED FROM

FIGHTING AIDS

BY GREGG GONSALVES

So you've just seen *How to Survive a Plague*. What next? Well, first of all, realize you've only seen the first act of a long, long story. The fight for AIDS treatment is far from over: 15 million people around the world need immediate access to these life-saving drugs and only about half of those in dire need have them now. It's estimated there are more than 34 million people living with HIV around the world. With only about 8 million currently on treatment that means that 26 million people all told are living with HIV—and without the medicine that can save them. The urgency you saw, and perhaps felt, watching David France's film is waning now. After more than 30 years, people in the United States and around the world have grown weary of hearing about HIV/AIDS. While the crisis is far from over, the funding for AIDS is in danger of being cut. If that happens, the accomplishments of the AIDS activists described in the film could easily be washed away in a new era of apathy and neglect.

You have a role to play.



Here are some pointers to help you become an active part of the solution to spare millions from AIDS:

1. JOIN UP.

How do you start? Well, by starting! Back in the 80s and 90s, AIDS activists knew nothing—except that silence=death and that inaction was worse than making a few mistakes. To help defend all the ground that's been gained in the fight against AIDS, contact a local AIDS organization and ask how you can help mobilize resources locally, in your state or province, in your country, and across the globe.

2. STUDY.

Know your %&@#. Passion and commitment can't replace a strong grasp of the issues and the facts under consideration. In the old days, we had to learn things from scratch, nowadays you can turn to the Internet to find what you need. For great and accurate insight on HIV/AIDS policy and statistics, visit amfAR.org (amfAR is the Foundation for AIDS Research), or kff.org (the site of the Kaiser Family Foundation). When doing your own research, be careful. There is a lot of garbage out there, so check and double-check information before running with it.

3. MEET WITH LEADERSHIP.

Go see your elected officials. You don't have to storm the NIH or participate in a die-in at the FDA to make a difference. In the U.S., it's easy to make an appointment with your members of Congress and their staff. Tell them why HIV/AIDS is important to you and let them know that you expect them to support AIDS funding in Congress, champion global health, and not cut funds when the epidemic is still with us. Ideally, bring a friend: show your elected officials that it's not just you, but a number of people in your community who care about HIV/AIDS.

4. WRITE.

Follow up on meetings with elected officials and their staffs with letters or emails. Send them new data and reports when they emerge. Write a blog or an op-ed for your local newspaper. Remember that most people don't know what you know: AIDS is still a crisis and misperceptions that it's under control could lead to the danger of slipping backwards after we've made so much progress. In all of your writing, keep your correspondence simple and make it personal; make a few key points and try to connect with your reader.

5. COME TOGETHER.

Don't mourn, organize. Gather people in your community to work with you. Try to reach out broadly to different groups that represent a wide spectrum of people where you live. Meet regularly, give yourselves tasks, and keep up the momentum. The Monday night meetings at ACT UP kept us on our toes; you can do the same if you keep to a schedule, have things to do, report back to each other, and strategize about and think through the issues as a group.

6. GET MAD.

Don't be afraid to protest: perhaps your elected official isn't supportive of HIV/AIDS. Don't let that stop you. Remember: he or she works for you! You may have to spice things up a bit: a picket outside of the local office is a simple thing to do. In this case, the more the merrier. A group of people handing out fliers with the facts and big posters with short statements about your elected officials can make a big difference. Having a diverse group of people with you is important. If you can get civic leaders, religious figures, health care workers and others to go with you, even better. Roping in influential allies is critical.

7. CONQUER YOUR FEARS BY JUST DIVING IN.

The earliest groups of AIDS activists discovered that effective advocacy isn't rocket science. The biggest barrier to activism is getting started. If getting started seems scary and daunting, know that engaging doesn't have to be that hard. Really, just take the first step. And remember, there are others out there, like me, who've got your back. ACT UP comprised only a few hundred members in the beginning. Now, there are many, many more people around the country and around the world "acting up." All of us need all of you to join us.

Gregg Gonsalves started his activist career with ACT UP in 1990. He discovered he was living with HIV in 1995. A long-time advocate for better approaches to AIDS research and an ardent fighter for people's rights to accessing care and treatment, Gonsalves is currently a Visiting Lecturer in Law at Yale Law School, co-director of the Global Health Justice Partnership, and remains, today, one of the leading AIDS activists in the world.

ACTIVISM THEN & NOW

Legendary AIDS activist Peter Staley talks with newly-minted fighter for human rights and health care rights Michael Tikili of Queerocracy and Health GAP about what it takes to be an effective change agent—and how yesterday's lessons apply to today.

Michael Tikili: How did you become an AIDS activist?

Peter Staley: My primary motivation was finding out I was HIV-positive in late 1985. It was a very frightening time. I was deeply closeted and working as a bond trader on Wall Street. The [news that] Rock Hudson [had AIDS] had just hit, the country was in a panic and there were no drugs [to save people from AIDS]. A diagnosis of HIV was considered a very quick death sentence.

MT: What did you do when you were diagnosed?

PS: I told my family and tried to build a support network. But I was desperate to find treatments to save me. As I looked into it, I realized the government wasn't doing anything. My frustration began to build and about a year and a half later, ACT UP was born. I passed their very first demonstration on my way to work one morning and decided I had to be a part of it. For a year, I continued to work on Wall Street and went to ACT UP meetings at night. I couldn't sustain the double life. My CD4 cells crashed and forced the issue. I went on disability right before ACT UP's one-year anniversary in 1988. I came out as a full-fledged AIDS activist in their first anniversary demo where I got arrested and appeared on the local news channel.

MT: Was it difficult to be an activist while working on Wall Street?

PS: It was hard. Mostly because of how difficult it is to live in some sort of closet. I had three closets: I was hiding my sexuality, the fact that I was HIV positive, and the fact that I was an activist. I wasn't going to very many demonstrations because I was afraid of getting caught on TV or appearing in a photo. So I became head of ACT UP's fundraising committee. That allowed me to be involved without



PHOTO: © William Lucas Walker

threatening those closets. But it was a real juggling act and very emotionally draining. Ultimately, something had to give. So I left Wall Street and went on disability. The disability checks allowed me to work as a full-time volunteer activist for ACT UP and activism became my entire life.

MT: How did your life change?

PS: Life was just much easier. I flourished. I probably wouldn't have if I didn't have that financial lifeline of a disability check. In the early 1980s it was much easier for people with HIV to get disability. All you had to do was say, "I'm HIV positive," and the government would say, "Fine, here's your check."

Back then, they thought you were going to be dead in two years so they paid you. So Michael, how did you get become an activist?

MT: Activism happened naturally for me. When I moved back to New York after graduate school, while searching for community, I started getting involved in Queerocracy. There, I came across Health GAP. I was always passionate about HIV/AIDS, particularly on the global level, and [I was interested in combating] how the lack of treatment access was [hurting] people in the developing south. Particularly because I still have family in West Africa, an organization that helped others in another country resonated with my

personal beliefs. So I jumped on board with Health GAP and have been working with them since.

PS: How did your friends and family react to your activism?

MT: When I was arrested for participating in my first act of civil disobedience, many members of my immediate family freaked out. I think because I am a black man and the idea of getting arrested doesn't sit well [with our community]. After my arrest, when I was trying to raise money for jail support and a lawyer, people were not that supportive. I think they felt if I was going to jail for a cause, money should already be there [to help me]. But the organizations I was working with didn't have massive amounts of money. In the beginning, people thought I was kind of crazy. But once I started showing up in newspapers and on TV, people became more supportive. Since that time, they've understood what I'm doing.

PS: I found the same thing. When the issue you're fighting for appears in the media in the context of a good story, it tends to impress family and friends and they get behind you. But people can be nervous before that happens. I once had a boyfriend, Kevin Sessums, who freaked out when I told him I was working to put that giant condom over Jesse Helms' house. He thought you couldn't do that to a U.S. Senator and worried I was going to end up in jail for 20 years. He cried on the shoulder of one of his best friends, David Geffen. Geffen sided with me and said, "Kevin, this is who Peter is and what activism is and you've got to support him and trust he knows what he's doing." I was having trouble raising the money to build the condom because it was huge...it had to go over a two-story house. To my surprise, David Geffen paid for it. He handed me a giant wad of cash—\$3,500—and said, "Don't ever tell anybody I paid for this." But 25 years later, the story's gotten out and he doesn't seem to mind.

MT: How critical is the role of good press to the impact of activism?

PS: It's all about the press. If you do an action and there's no press it's like a tree falling in the woods. An action is a failure when it doesn't get good media coverage. There are some benefits to the activists themselves for just having built up the courage to carry out an action and actually pulling it off. But from a movement perspective and in terms of [the impact] on the issue you're fighting for, the press is essential to really help the cause. I try to always be mindful of that and ask, "Am I doing this action just for myself or will this really help the movement?" I think you should only pull the trigger [on an action] if you've got some high degree of confidence that the latter is true. It can become dispiriting to do a series of actions that don't end up registering [with the wider world].

MT: Tell me about your first arrest...



PS: It was at ACT UP's first anniversary demo. It involved affinity groups—small groups of activists all agreeing to get arrested together. Wave after wave of people sat down and blocked traffic at the corner of Broadway and Wall [Street] in Manhattan. I joined one of the first waves. There was so much camaraderie that day and well over a hundred arrests. To be surrounded by that kind of energy made it so much easier and thrilling. It really helps to have a larger community behind you and to have a well-organized action with lawyers on standby and volunteers at every police station working on your release. What I most remember fondly was our time in jail. There were dozens and dozens of gay men and lesbians poking fun at the cops and whistling at them when they walked by our cells. We started singing campy theater songs together. It was just a blast. I have very fond memories of my first arrest. How about you?

MT: I'd always been afraid of getting arrested because as I was growing up it was nailed into my head that I should avoid it and not have a record like many men of color. The idea of being arrested—even in the name of activism—was unsettling at first, but it did make a difference to be arrested with friends. My first arrest was in upstate New York. We were protesting [AIDS] budget cuts. We shut down the Capitol by blocking all the entrances. It was beautiful. They took us in and we all hung out in a little conference room together playing cards and shooting the breeze.

PS: How many times have you been arrested now?

MT: I think six. How about yourself?

PS: Ten. Exactly ten. And because of the amazing lawyers ACT UP always had I don't have a record, which is very cool. When I got arrested back in the day, I was doing it as part of this huge organization and at a moment in time when the gay community rose up in unison. These days, activism is conducted in a very different social context. In many ways it's harder if you don't have an entire community behind you, participating at the same time. How do you feel about your generation and the willingness of people your age to participate in [modern] social movements?

MT: Once, getting arrested was sort of a badge of honor and people respected you for it. Now, there's such tension between police and all protestors, especially in New York City. I think because of that, people aren't as willing to be arrested because you don't know how you're going to be treated in jail or how long you're going to be there. I think it's

harder in general today for people to be activists.

PS: You're so right. With the current economy and people struggling for work there's a lot on everybody's plate. That doesn't mean they don't care about the world. Today's activists don't have the advantage of what really fed ACT UP—people watching their lovers and friends dying all around them. That was a huge motivating force. It's a lot harder to build movements and community today. My generation needs to cut yours a break in that regard, but it doesn't get any of us off the hook. How does Queerocracy try to expand its base in this environment?

MT: We go after anyone who is queer and tell them they should be doing more than just going to gay bars. It usually works. I'm pretty convincing at times. I'm starting to believe I have a knack for it. It's different to answer that question for the AIDS movement. I feel a lot of the people who contribute to the HIV movement are concentrated in AIDS service organizations and work with an agenda that directs where and how individuals get involved. AIDS organizations are not unified in one direction today. It would be very hard in this landscape to get everyone on the same page.

PS: I agree it is harder to get everybody into the same room these days, but I think [that] it's essential. That goes to a question I have about the Internet and social media—two things your generation has today that we didn't have in ACT UP. How helpful are they to modern movements?

MT: I love and swear by social media. [Learning to wield it well] is a right of passage for a modern activist. A modern movement can't survive without social media. I was trained that to get people to actions you have to call them three times. But today, a lot of people rely on Facebook to disseminate information. And Twitter has a huge impact. Tweeting at people allows you to interact with people who

are nowhere close to you. You'd be really surprised by what a single tweet can do, especially a celebrity tweet since many are followed by millions of people.

PS: I agree. Social media is a great outreach and recruitment tool and a good way to influence friends and wider circles of people. It can serve as a way to almost bypass having to get press stories about certain actions. If you're savvy enough and you film your own civil disobedience or have somebody film it for you, you can get it up on YouTube in seconds and it starts getting tweeted around and getting posted on Facebook [and the word spreads]. The down side is it can fail to reach the broadest possible audience; it often ends up just preaching to the converted. But social media is a great way to get your action out there and

"I feel a lot of the people who contribute to the HIV movement are concentrated in AIDS service organizations and work with an agenda that directs where and how individuals get involved."

inspire those who are on your side. No one has figured out how to use the Internet to replace the experience of a group of people coming together in a room and strategizing about what to do. Chat rooms can't really do it effectively or fast enough. There is nothing like a group of people riding the emotional rollercoaster created when something sparks in somebody's head, they think, "This might be a great idea," they raise their hand, they give an impassioned speech, and instantaneously, the room comes alive and people are like, "Yes! That's what we could do." And someone else chimes in with, "And we could do this on top of it," and the feedback creates an explosion of energy and creativity. You always need to have a central place where people can come together face-to-face and feed off each other's emotions and creativity.

MT: I agree. I've been to actions where I didn't know anyone and I felt isolated among a crowd of thousands.

PS: How do you galvanize today's youth to become involved in activism?

MT: I cater my messages to my audience. If I'm talking to a younger audience, I'll highlight the fact that HIV/AIDS is not over and that the rates are still high and that we need advocacy to let people know that we're still at risk and to keep them safe. It's good to tailor your messages as specifically as possible. For example, if you're talking to women, emphasize the importance of the need for prenatal care for women with HIV. It's really important to mention something that will resonate specifically.

PS: It always helps to show examples of how activism can actually change the world. I think there is a lot of cynicism out there these days about being able to do that, especially with our political system the way it is. But change has happened through history. When I first got involved in ACT UP, somebody said I had to see the documentary *The Times of Harvey Milk*. It blew my mind when I saw the California-based community beat back a vile referendum that was being voted on statewide that would prevent gay people from being teachers. To see the success of that activism empowered me. That's my hope for *How to Survive a Plague*. It shows that activism is hard, but that ultimately, it can work.

MT: What advice would you give to engage today's activists?

PS: I find it a very difficult question because at ACT UP we didn't do much outreach. We didn't drag people in. People were kicking down our doors and flooding in on their own. The drive to be an activist has to come from within. This work is not easy. And the change doesn't happen overnight. But hopefully, reminding people that change can happen is enough of a spark to get them engaged.

MAKING THEIR MARK

Six young activists focused on social and health care justice share what drives them to try to change the world—for the better

NAME: DEVARAH (“DEE”) BORREGO
MASSACHUSETTS, USA

Org(s) with which you advocate: HIV Prevention Justice Alliance (preventionjustice.org) and U.S. Positive Women’s Network (pwn.usa.org). Twitter: @USPWN

Why you do what you do: It’s important as young people that we learn from our elders and come together to combat this epidemic. When I was infected, I was extremely undereducated about what it means to be HIV positive today. I believed that HIV was a death sentence, and it was only through learning more about the virus and myself that I found the strength to share my own story. If my speaking out and being honest about my experiences can help another young person remain HIV negative, then it’s worthwhile. I’m blessed to have a strong support network that helps me to stand up and advocate for other HIV-positive transgender people. I use my voice to advocate for my community.

The most powerful lesson you have learned from the work of ACT UP is: To persevere and keep talking about HIV. The straight forward messages ACT UP brought us, like SILENCE = DEATH, were incredibly impactful on my own activism. I firmly believe that if we don’t keep talking about HIV/AIDS, we will continue to have people die from the virus. For me, that idea expands to include [conversations about] gender identity and sexuality, because if we don’t talk about our sexuality, our gender, and the very core of who we are in an honest and open way, society will continue to devalue the lives of people in our communities.

The biggest issue you are fighting for is: The inclusion and rights of HIV-positive transwomen. I think the transgender community, as a whole, has made great strides in the past decade in increasing its visibility and the understanding society has of trans people, but there is still a lack of discussion around HIV and the transwomen’s community in the media and the broader society. If we want to combat this disease in all communities, there needs to be more people with HIV who will speak out about their experiences and how discrimination and stigma augment the challenges inherent to being a transwoman in 21st century America.

Dee Borrego



Robert Suttle



Loon Gangte



Amirah Sequeira



Moses Mulumba



Jeremiah Johnson



Traditional media that matters most to you: Film and television. As a child of the ‘80s, I grew up with TV and movies that offered a lot of strong, positive messages around building a sense of identity. But these messages never included any representation by the queer community, especially transgender people. Nowadays, there is so much more visibility of trans people on TV and in the movies that public perception of trans people is changing. However, there is so much less focus in film and on TV about HIV than I would like to see. The visual media is the way young people, like myself, are most able to relate to the world around them.

Social media has changed activism by...making it easier to reach populations, like the trans community, which are often very isolated geographically. Social media brings people together who might otherwise feel completely alone. Social media campaigns have a lot of power to sway public opinion on important matters, like equality for transgender and gay people and the need to protect oneself from HIV. Connecting with others in a multitude of ways is powerful in that it lets us show that being HIV positive or transgender is not something to be feared, hated, or criminalized.

You will feel most successful when...I know that prejudice against HIV positive and transgender people is over. Many young people today are being exposed to information about transgender and HIV-positive people, and I hope someday that society will be completely accepting of all people, regardless of their HIV status or gender identity. I pray that someday the murders and violence against trans people and HIV-positive people won’t happen with the regularity that they do now and that no one will be discriminated against or killed for being who they are. The biggest success for me would be the elimination of the HIV criminalization laws across our nation, and further legislation that protects the rights of the transgender community and systems that allow trans people equitable treatment under the law.

NAME: JEREMIAH JOHNSON
NEW YORK, USA

Org(s) with which you advocate: UNAIDS (unaids.org) and Columbia University

Why you do what you do: Since finding out I was HIV positive in 2008, I have become all too familiar with the injustices faced by people living with HIV.

The stigma surrounding the virus is debilitating, and it continues to unjustly destroy the lives of HIV-positive individuals. At the time of my diagnosis, I was serving as a volunteer in the Peace Corps in Ukraine. Despite my best efforts to finish my service, I was kicked out because of my HIV status and forced to return home early. Thanks to the help of the ACLU, I was able to get the Peace Corps to change their discriminatory policy and allow HIV-positive volunteers to continue their service. The outcome was certainly gratifying. However, I have found that behind each victory against stigma and discrimination looms more of the same that we must continue to combat. While working at the Northern Colorado AIDS Project as a case manager and prevention specialist, I met clients who told me that their doctors were afraid to touch them. I saw an individual die because they were too afraid to seek treatment after they tested positive. I saw many individuals' lives in constant crisis because they didn't have access to the mental health care they need to address their own internalized stigma. I continue to do this work because, while many in America have begun to see HIV/AIDS as less of a priority, I see [AIDS awareness] as a job that is far from complete. It is my job to talk with as many people as I can to keep the discussion of [the need to remove] stigma alive and to remind everyone that this battle is far from over.

The most powerful lesson you have learned from the work of ACT UP is...that silence really does equal death. I have never been one to shout too loud or make a spectacle, but seeing the tremendous bravery of early AIDS activists, even in the face of insurmountable odds, is profoundly inspiring. It is thanks to their example that I, even from the start of my diagnosis, have known that I had to keep talking to people about my status and about my experience as a young gay man living with HIV. It doesn't matter whether I'm speaking one-on-one with my family and friends, voicing support for other individuals living with HIV, or standing in front of a group and shouting at the injustice that exists for PLHIV (People Living with HIV). The important thing is to never suffer in silence.

The biggest issue you are fighting for is...the destigmatization and decriminalization of HIV/AIDS. Since becoming infected, I've had many discussions about why so many young men who have sex with men (MSM) continue to contract HIV. Condom fatigue, "bug chasing," and the psychological impact of post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP) on people's willingness to practice safer sex are often cited as possible reasons for the rising incidence of new infections. In general, these explanations blame the individuals who get infected. It's as though young MSM take the good messages and resources that society gives them and twist them into some sort of justification for at-risk behaviors. But what about society's ongoing failures [to educate people and link them to care]? Certainly, there is a personal responsibility to protect oneself and others from getting infected, but one's ability to do so is severely compromised when an individual does not have the support they need to make decisions to protect their individual health. In most of America, it is still not safe to be openly gay or HIV positive. Talking openly to others about your sexual orientation or challenges associated with practicing safer sex can lead to consequences ranging from shame and discomfort to legal problems. It is wonderful that there are more resources now for uninfected individuals to protect themselves and for PLHIV to not transmit the virus, but how good are those resources if stigma prevents people from accessing them? For me, it is important for us to continue to break down these barriers—like stigma—that are still fueling the epidemic.

Traditional media that matters most to you: As far back as I can remember, I have been enthralled by the magic of writing and the messages that can be conveyed through a good novel. While other forms of media are often more accessible and provide a necessary first glimpse into an important issue, the intimacy of a good book can transform someone's point of view on a more profound level. It's like spending hours in someone else's mind and getting to understand their reasoning.

Social media has changed activism by...making it more accessible to more people. However, it has, in some ways, lessened the personal nature of activism. There is no doubt that the petitions circulated on Change.org have power and do gather enough signatures to challenge the status quo. But activism is more than the click of a button. Often, in order to really change the opinions that oppress marginalized groups, discussions must be had. We have to be brave enough to step away from our computer screens and talk about HIV/AIDS with the people in our lives and with our leaders in society.

You will feel successful when you...and others living with HIV no longer have to fear coming out about our HIV status. This seems so far off in so many ways, but there is no reason that it can't happen. There is a lot of work to be done, however. Laws need to be changed both in the U.S. and abroad so that the rights of PLHIV are no longer at risk. PLHIV need to feel empowered enough to talk to as many people as possible about their experience. And HIV/AIDS activists must continue to do whatever they can to raise funds and raise awareness to finish the work to end stigma and, ultimately, to end the epidemic

NAME: AMIRAH SEQUEIRA
WASHINGTON, DC, USA

Org(s) with which you advocate: Health GAP (heathgap.org) and Student Global AIDS Campaign (SGAC; studentglobalaidscampaign.org)

Why you do what you do: There is no reason why people should suffer when the tools and resources exist to provide them with the health care they need. No one should be denied that health care based on their gender, sexuality, race, or geographical location. I do the work I do through SGAC because I believe the power of young people is magical. It really is! When we activate youth to work together and advocate effectively for what we need and want, we see results.

The most powerful lesson you have learned from the work of ACT UP is...ALWAYS speak truth to power when people are being marginalized. Strategic political activism and advocacy does change the world and save lives. NEVER be afraid to challenge authority.

The biggest issue you are fighting for is...the end of AIDS. Sound unrealistic? It's not.

Leaders you love: SGAC members, students, and youth. They inspire me every day, and are such incredible leaders in this movement. Their devotion, fearlessness, and willingness to work together in grassroots activism is magnificent.

Traditional media that matters to you most: Books! I love to read, particularly to read history, and refuse to use/buy a kindle, e-books, etc. I also find a lot of my inspiration from archives—at newspapers, government, or organizational archives. The New York City Municipal Government archives

are a great place to find inspiration from incredible social movements that have taken place in NYC, as are the ACT UP archives in the New York Public Library. (Read through Mayor Koch and Mayor Dinkins papers in the city archives, particularly the department of health files. You'll see the impact that groups like ACT UP had on the government and the way in which they were affecting change. Be prepared to get really angry though.)

Social media has changed activism by... allowing activists to write their own news and histories for the world to see, rather than relying on media outlets to tell their stories. The world can watch political moments and social movements unfold in real time, and calls to action can be instantly disseminated to reach millions of people globally. That said, while social media can help boost specific types of activism (petitions, letter/email writing campaigns, Twitter campaigns, etc.), nothing replaces the power of thousands of people taking to the streets. Though I see the value of social media, my organizing has shown that traditional tactics—like calling people directly and showing up at events with a clipboard to collect names and numbers—works just as well, if not better, at getting people into the streets.

You will feel successful when you... when WE (the AIDS movement and the world) see zero new [HIV] infections and treatment provided on demand across the world.

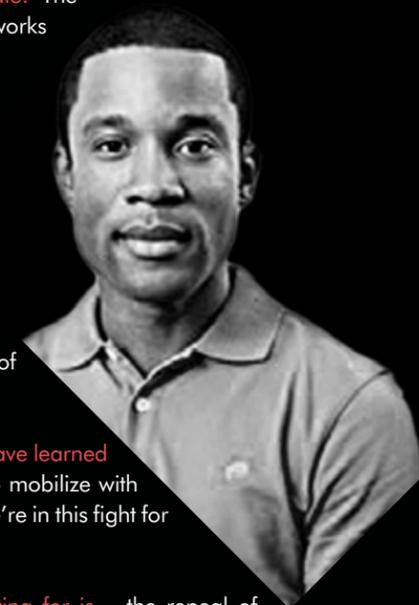
NAME: ROBERT SUTTLE
LOUISIANA, USA

Org(s) with which you advocate: The SERO Project (seroproject.org) works to repeal laws criminalizing HIV.

Why you do what you do: To whom much is given, much is required. I feel I have been given a second chance, after my conviction, to make [my life] count. I can't stand to see people suffer at the hands of injustice.

The most powerful lesson you have learned from the work of ACT UP is: To mobilize with passion and a pure sense of "we're in this fight for our lives together."

The biggest issue you are fighting for is... the repeal of HIV-specific statutes enforced across the United States. HIV is not a crime.



Traditional media that matters to you most: Music. I love gifted artists that write or sing meaningful songs that tell what it is people are going through, how they feel. I love the work of artists whose music touches our souls.

Social media has changed activism by... leaps and bounds. People are informed and engaged on situations and issues in real time, which allows communities and networks to mobilize into action.

You will feel successful when... I'm no longer registered as a sex offender in the U.S. and that HIV-specific laws will no longer be enforced to discriminate, stigmatize, prosecute or convict people living with HIV/AIDS.

**NAME: LOON GANGTE
DELHI, INDIA**

Org(s) with which you advocate: I am the president of the Delhi Network of Positive People (dnppplus.org), India.

Why did you become an activist? I have lost too many of my friends (99%) to HIV. People say it's because of HIV, but I disagree. They are dying because of what they don't know and what they can't get.

Many are dying just because they don't know that there's any HIV treatment. Or, even if they do know, it's simply too expensive and they can't afford to buy the medicine (as we have only patented drugs where I am).

Every year at the candlelight memorial on World AIDS Day, people remember their lost friends and families by lighting a candle. I also used to take part in the memorial. But I realized no matter how many candles I burned, they were absolutely of no use to my lost friends. Instead, I decided to do something for my friends, and for people in my community, while they are alive. This is why I work to ensure that people living with HIV/AIDS in my community get antiretroviral treatment (ARV). I have been working full-time as an AIDS activist since 2008 trying to save people's lives—or at least prevent their premature deaths—from AIDS.

What issue(s) do you focus on and why are these important to you and to the world? I focus on connecting people with HIV to ARV treatment.

As a person living with HIV, and for all PLHIV, HIV treatment is the single most important thing in the world. Nothing else can suppress the virus that replicates and makes billions of copies every day; it can only be stopped by taking your medicine on time.

ARVs are completely useless unless people living with HIV can afford and have easy access to them.

My focus is that any PLHIV, irrespective of who they are, must have access to treatment. I know ARVs are effective not only because the science has proved it, but also because I have proved it to myself, in my body, as I have been taking ARVs since the last 10 years.

Since 2000, Indian pharmaceutical drug companies have been making cheap-but-effective ARVs (generics). As a result, it has been possible to get more people on treatment. Today we have approximately 8 million people worldwide whose lives are saved by ARVs—many of those people rely on generic forms of ARVs. However, rich countries like the U.S. and countries in Europe are trying to use every possible means and ways to stop the production of generic ARVs.

What is the most powerful lesson you have learned as an activist? Crazy thoughts/ideas and crazy people can change the world.

I said this when we were planning to have this big rally/protest in March of 2010. One of our friends proposed we aim for 5,000 people. We all said, "Yes," but nobody knew where the money was going to come from or whether we would have a single penny or how we would organize. Yet we went ahead with super crazy idea and managed to execute this rally where people from all over India came using their own money. We were also joined by a few activists from neighboring Asian countries. We managed to pull more than 3,000 PLHIV together in the street of Delhi to demand that the Indian government not succumb to pressure from the European Union on the India-European Union Fair Trade Agreement. We also managed to mobilize funds, much more than we needed, without writing a single proposal to donors. Following our rally, we heard public statements from our Prime Minister and Commerce Minister that they would not do anything that would hamper the health of India's citizens. Yet the battle is far from over and is still going on.

Are you ever afraid doing the work you do? If so, what scares you and how do you overcome your fear? Not a single time or for a single second am I afraid of doing my work. My work revolves around saving people's lives. I am not killing or trying to kill people. All my efforts are to protect people, so why should I be afraid? Who should make me afraid?

I never do something because of funder/donor pressure or due to pressure from anyone for that matter. I am clear I am here to work to protect the needs of my community. Period. In the course of trying to save the lives of my fellow community members, I am ready to face any consequences.

Is there anything else you'd like to offer? Advice, tactical tips, insight? Make them uncomfortable. Not by using violence, but non-violently. As long as the people you are pushing for change are comfortable, they will not address the issues you raise. When they are uncomfortable they will address you and your issues.

Don't stop. If you start, don't give up mid-way. See your mission through to the end, until either you win or lose. If you get lost along the way, find a new route and keep going.

**NAME: MOSES MULUMBA
KAMPALA, UGANDA**

Org(s) with which you advocate: I am the executive director of the Center for Health, Human Rights & Development (cehurd.org), Uganda.

Why did you become an activist and are you full- or part-time? I became an activist because of my passion for advocating for human rights. Human rights can not be realized without activism. The only way I could send the message out was becoming an activist. I work part-time

in activism, but the rest of the work that I do, e.g., teaching and research, feed into activism as well.

What issue(s) do you focus on and why are these important to you/to the world? My area of focus is human rights, but since it is a wide area of work, I choose to focus on the right to health, which needs a lot of attention as communities we work in don't view health as a right. To me, making a change towards the right to health is key to ensuring all of the other human rights are realized.

What is the most powerful lesson you have learned as an activist? In my experience as an activist, I have realized that it is not possible to do successful activism if communities are not engaged. In activism, no matter the mode, communities need to be at the forefront of any call for activism.

How has social media changed activism? Social media is just picking up in our part of the world. As such, social media is relevant to more policy/high level elites in activism. The interrelation within communities is still very low. This has affected the magnitude of the impact of social media in activism.

Are you ever afraid doing the work you do? If so, what scares you and how do you overcome your fear? Of course there are instances when one has to fear while involving in activism, especially in young democracies where we work. There is a thin line between moving activism as human rights and engaging in some political talk. Some times we have had to make this line bigger, which, in a way, affects our activism.

In addition, our culture and religious affiliations sometimes overstep the rights of some small groups. There's always a fear of being anti-culture and nonreligious towards some of our work.

Please finish the rest of this sentence: "I will feel most successful when..." I will feel most successful when there has been a tremendous change on the right to health in my community of focus.

ART AND ACTIVISM

Examining the dynamic relationship between activism and art—creativity in action—through history informs our understanding of how we can bolster contemporary social movements.

BY PATRICIA FINNERAN

How to Survive a Plague tells the story of a successful movement for social change whose leaders used creativity and art to advance their cause. Contemporary activists who capture the public imagination such as Pussy Riot in Russia and the Occupy Movement have adopted similar strategies. Each new movement looks to the past for symbols and images that can be appropriated and endowed with new meaning to inspire their contemporaries.

An iconic 19th century French painting shows the figure of Liberty leading a revolution, a t-shirt features the fist of the black power movement, a photo of an ACT UP protest captures the movement, a Pussy Riot banner shows a somewhat playful purple fist. The raised fist is a universal expression of street protest adopted and re-interpreted by revolutionaries the world over. The creative representation of the human hand evolves to serve the needs of the media, the movement and the moment.

The artists behind ACT UP appropriated a simple geometric symbol, the triangle, to create a poster that captured the essence of their struggle.

The placards bearing the slogan “Silence=Death” with the bold pink triangle, created by artists including Avtttram Finkelstein and Vincent Gagliostro, draw power from the embedded historical reference, while the graphic simplicity which could be reproduced on posters met the needs of the moment when flyers rather than Facebook were the organizing tools of the day.

The pink triangle refers to the patches sewn onto the uniforms of gay men in Nazi concentration camps. The pink patches were slightly larger than other identifiers, and the bearers singled out for abuse. Gay artists of the late ‘70s and ‘80s reinterpreted this symbol of exclusion and degradation into one of defiance. As AIDS affected the gay community in the 1980s the triangle, often flipped up rather than

down, represented both gay pride and combined with the words Silence = Death, an exhortation to speak out about AIDS.

Gagliostro, now a filmmaker living in Paris, wrote about the source of the inspiration upon the release of *How to Survive a Plague* in September 2012:

“When I would leave an ACT UP meeting charged with the task of creating graphics for the next planned demonstration, my first thought was how do I keep the crowd shouting and yelling? They were my inspiration. I had to inspire them. I always made my graphics first for them, for us. Yes, the graphics needed to articulate and disseminate our knowledge about a particular issue to the general public, government officials and/or drug companies. But as important as it was for the graphics to communicate a message, it was equally important that they speak to and galvanize the movement itself. I needed my work to politicize the issue of HIV/

AIDS for my community because, quite frankly, we needed bodies to show up at the demonstrations.”

ACT UP’s media-ready posters, news photographers and videographers would capture the real-life action while those posters, photographs and video conveyed their message to mainstream media audiences.

ACT UP’s creative activism extended beyond the visual realm to the protests themselves, which were often envisioned as a kind of performance art. They were staged as live, participatory theatrical events complete with costumes and roles. People staged die-ins, lying in the streets to highlight the roles of the dead and dying to keep people alive.

Performance art incorporates the space in which it takes place. As evidenced in the by now famous image of Peter Staley standing on the roof of the FDA to hang a Silence = Death banner, with hundreds of cheering protestors standing below, ACT UP took their protests directly to the FDA, the NIH, even the White House. (The giant condom placed on the home of Senator Jesse Helms is perhaps the apotheosis of this approach.)

Twenty years and a continent away, the performance artists Pussy Riot chose a building at the center of Red Square, a rooftop stage features the turrets of the Kremlin as a backdrop.

As they perform a punk prayer in protest of Putin’s repressive regime, they carry a flag that combines the fist of protest with the symbol of femininity.

Stephen Duncombe, in his book, *Dream: Politics in the Age of Fantasy*, urges progressive leaders to use a creative approach to protesting that will truly engage participants, directly reflect the cause, and create a public spectacle. As Founder of the Center for Artistic Activism, he practices what he preaches. He points to the tactics of ‘Reclaim the Streets’ with whom he worked. They protested Mayor Rudy Giuliani’s clean-up New York campaign which privatized public space (including community gardens) by building new gardens in highly trafficked public spaces. Whether it is a pop-up public garden or a die-in, well-staged collective performance art captures media attention and forces the public to take notice.

While we need art, as Gagliostro so eloquently stated, art to “visually articulate the heart

SILENCE=DEATH



ART INSPIRES, STORY MATTERS

and soul of a movement”, we also need to make sense of it. For that, we need storytelling.

We live in a time in which audiovisual media pervades our culture, the documentary film is the perfect media to capture the narrative of a movement. And the best social justice documentaries, such as *How to Survive a Plague*, combine journalistic integrity with the artistry filmmaking.

“Journalism is the first rough draft of history,” so said Washington Post publisher Phil Graham, a stalwart of traditional print journalism. Documentary is the predominant historical record. The printed word—books!—certainly holds an important place, but the immediacy and accessibility of film and video extends its reach and power to attract and engage broad audiences.

Journalists reportage and analysis of unfolding events lay the groundwork for the insight and perspective that come with time. The nature of the documentary form requires more time than a news piece, a published photo, or a spot on

network of cable news.

Director David France covered HIV/AIDS in New York as a writer; he wrote some of the first major stories that were published on the mysterious and devastating disease. By mining the most dramatic and compelling aspects of the story of HIV/AIDS and the activism that forced action that ultimately made the plague survivable, France transcends his own nearly three decades of reportage.

Contemporaneous to France’s writing about AIDS for outlets including the *New York Times*, those involved in the late ‘80s and early ‘90s captured their activities on newly affordable videotape. Public actions, protests, even weekly planning meetings, were captured for posterity. But it took the art and craft of filmmaking to render nearly 700 hours of material into a compelling narrative that put their work in to a context that gives it new meeting.

Curators, critics and cultural leaders have designated *How to Survive a Plague* a worthy work of film art. In fact, many have called upon audiences

to see the film as a kind of passionate tutorial on activism. Frank Bruni wrote in *The New York Times* that the film serves as “a model for the here and now of social change.” Dana Stevens of Slate suggests, “if its essence could be bottled [the film] could serve as a tonic for demoralized political organizers, a bracing reminder that change is possible when a group of committed people come together to fight injustice, indifference, and prejudice.” Writing in *The Playlist*, Kate Walsh said of the film, “[it] should be shown as Social Justice 101. France’s film is the definitive ACT UP New York documentation that audiences in our Occupied world need to see.”

Flash forward to 2011 and a small group of protestors using highly creative public expression to protest a repressive regime and a political leadership that is blocking reform. One can see the legacy of ACT UP’s work, and harken in the work of Pussy Riot. Theatrical, colorful, and surprising, they are activists first, and use performance art as a means to an end.

ACT UP protested the Catholic

Church’s for its response to HIV/AIDS famously staging an action in St. Patrick’s Cathedral the most famous church in the US. Pussy Riot staged a performance in the Cathedral of Christ the Savior in Moscow to protest the close ties between the Church and Putin’s political regime. The documentary *Pussy Riot: A Punk Prayer* premiered at the 2013 Sundance Film Festival a year after *How to Survive a Plague*. The group’s message goes far beyond Putin, they are 21st century feminists and they support LGBT rights, gender equity and the right to free expression as much as they protest the current regime.

Any conversation on contemporary activism must include the Arab Spring, which played out live on the Internet and television. The documentary, *The Square (Al Midan)*, created by Egyptian-American director Jehane Noujaim and a team of people who are living the revolution, captures the story of the revolution from inside the movement. It focuses on the events taking place in an around Cairo’s Tahrir Square starting with the resignation

of Mubarek, and through the end of 2012. *The Square* uses street art, images and phrases painted as a motif throughout the film. The street art provides a kind of visual poetry that separates the phases of the revolution and the protest; it is activist art in the service of story.

“Artists have the power to visually articulate the heart and soul of a movement.”

-- Vincent Gagliostro, artist and activist

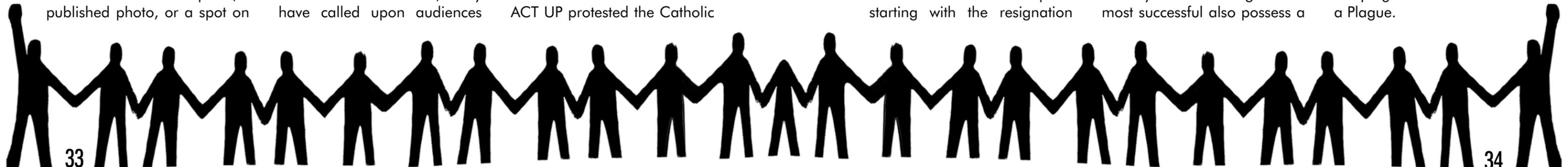
Like David France’s documentary, these films profile activists, artists and revolutionaries and provide audiences with a narrative that extends beyond the iconic imagery. Each of those films is art that advances contemporary activism.

Art can help us imagine a world beyond injustice and inspire us to envision change. Activists have goals and plans, tenacity and courage. The most successful also possess a

creative spirit that is realized in images, words, and events that capture the public imagination.

The social issue documentary filmmaker, whether or not their film depicts activist art, uses creativity and a narrative to take the viewer deeper in to the story of change. The best filmmakers introduce us to characters we relate to and cheer for. *How to Survive a Plague* takes us through ten years of ACT UP, from tragic loss to bittersweet victory. We cry at the passing of Bob Rafsky; and we cheer for Peter Staley as he delivers his friend Vito Russo’s compelling words at the 1990 AIDS Conference calling for an end to the discrimination of people with HIV/AIDS. A banner can’t deliver that same emotional punch. Since screen images of various sizes dominate the media landscape, the documentary film may be our most powerful tool in the art of activism and creative change.

Patricia Finneran produces and advises on documentary film and related engagement campaigns. She led the campaign for How to Survive a Plague.



CAMPAIGN SO FAR—OUR IMPACT

The *How to Survive a Plague* Engagement Campaign has been working with dozens of organizations in the U.S. and internationally to engage audiences and use the film to provide a model for advocacy and social change and to energize the work of organizations supporting HIV/AIDS awareness, treatment, and research. Post-screening discussions and 'meet-ups' have connected thousands of audience members with leaders in health care justice.

GRASSROOTS PARTNER HIGHLIGHTS

30% The increase in the number of Student Global AIDS Campaign (SGAC) chapters, fueled by their partnership with the campaign. Plus, SGAC receives proceeds from the sale of the soundtrack.

35 The number of screenings hosted by RESULTS, which works with thousands of citizens to fight poverty and promote social justice.

140 The number of AIDS service and social justice organizations around the world that will receive a free educational DVD package of the film.

WORLD AIDS DAY 2012

75 The number of screenings on college campuses and hosted by partners leading up to World AIDS Day 2012. Events included: a screening at MOMA which included Larry Kramer; a 'Hangout' at Google's NY HQ with David France, Peter Staley, artist Angelique Kidjo and contemporary AIDS activists; a screening at the State Dept. with Dr. Anthony Fauci, plus a Twitter campaign calling for funding for AIDS treatment access and research.

INFLUENCER SCREENINGS

International AIDS Conference / AIDS 2012, Ford Foundation, Bill & Melinda Gates Foundation, Open Society Foundations, U.S. Department of State.

Global Health Corps is using the film in orientation for public health workers.

The U.S. Department of State is using the film to engage international audiences on LGBTQ rights and the role of activism in a democracy.

CAMPAIGN PARTNERS WHO HAVE HOSTED SCREENINGS AND EVENTS INCLUDE:

ACT V: The End of AIDS

ACT UP (New York, Philadelphia, Boston, San Francisco)

AIDS Community Research Initiative of America (ACRIA)

AIDS Foundation Chicago / HIV Prevention Justice Alliance

AIDS UNITED

amfAR

American Medical Students Association (AMSA)

Black AIDS Institute

Broadway Cares/Equity Fights AIDS

GLAAD

GMHC

Gay, Lesbian and Straight Education Network (GLSEN)

Health GAP

Human Rights Campaign

Partners In Health (PIH)

Planned Parenthood

RESULTS

Student Global AIDS Campaign (SGAC)

Treatment Action Group (TAG)

Universities Allied for Essential Medicines (UAEM)

UNAIDS

AWARDS AND NOMINATIONS FOR HOW TO SURVIVE A PLAGUE





IN THE HALLS OF POWER

BY REGAN HOFMANN

Regan Hofmann: You are well known for spearheading the decision to invite AIDS activists in to meet with members of the National Institutes of Health. What led you to encourage meetings between activists and government officials?

Tony Fauci: For some time I had been reading and listening carefully to what the activists were saying. I began paying much more attention to the content of what they were saying than to the confrontational techniques that they were using. In addition, I began to develop relationships with some of them; these relationships were working

Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases at the National Institutes of Health, reflects on his decision to invite AIDS activists to join decision makers at the table — and on the power of having patients participate in the development of health care solutions.

their way gingerly towards mutual trust and respect. It became clear to me that what they were saying, asking for, and even demanding made perfect sense, and I found myself agreeing with them very much more than disagreeing with them. When that happened, the only option as far as I was concerned was to fully engage them and push for the rest of the government to do so.

RH: Did you encounter resistance among your professional peers when you suggested the activists be given audience at the NIH?

TF: Some of my peers understood and agreed with what I was doing; however, I got significant resistance from several others. I tried hard to convince the recalcitrant ones, but when I could not convince them, I ordered them to do so (if they reported to me), and if they still refused, then the consequences to them became more dire.

RH: What fears did you/your peers have about the decision to meet with activists? Were those fears realized?

TF: I never really had any serious fears about the decision to meet with activists because I was convinced that much of what they were pushing for was the correct thing to do. Some of my peers were concerned that meeting with the activists would significantly disrupt the scientific process. I disagreed with this concern and, in fact, I was correct since, if anything, it enhanced the scientific process. There was the issue that some members of the scientific community and even government officials would be upset with me personally for “opening the door” to a process that might have negative consequences. No one likes to have colleagues upset with them; however, since I was convinced that there would not be negative consequences, I was not bothered too much by people being upset with me. I knew that at the end of the day, they would realize that this was the correct thing to do.

RH: What were you thinking when you looked out your office window and saw activists demonstrating on the lawns of the NIH?

TF: I had a reaction of “Wow! They really know how to get our attention.” I actually felt a feeling of respect and admiration for their passion and commitment. I got upset when I saw that the police were arresting some of them, even though the police really did not have much choice. That is why I communicated with the police and told them, if possible, not to arrest people and asked that they bring a small group of the activists up to my office to start a dialogue. In the scene from *How to Survive a Plague* where Peter Staley was being taken by the police off the small canopy in front of Building 31 (my building) on his way to getting

arrested, I was actually coming down to the lobby and the police were bringing Peter through with handcuffs on. I had already developed a relationship of respect with Peter and as he passed me, he gave me a big smile and said: “Hi Tony, we did it and I am the first one to get arrested.” I felt like hugging him. The police looked at me strangely.

RH: Did the activists respond as you had hoped/anticipated in meetings with senior government officials?

“I had a reaction of ‘Wow! They really know how to get our attention.’ I actually felt a feeling of respect and admiration for their passion and commitment.”

TF: The activists responded even better than I expected. They came armed with facts, legitimate concerns, and reasonable suggestions. Sometimes, they were off the mark; however, they were right on target more often than they were off. As time went by, they became more knowledgeable and even more effective.

RH: Was it the right decision to let them in? Does having people directly impacted by an issue at the table when decisions about that issue are being made help officials make better decisions?

TF: It was unequivocally the right decision to let them in. I believe that better decisions are made when people who are directly impacted by an issue are at the table. However, their impact differs from situation to situation. It never hurts to have them there in any case; however, the degree to which they can contribute will vary depending on the issue being discussed and the decisions being made. With the AIDS activists, it was critical

to have them there in the discussions about the design of clinical trials and the impact of certain regulatory restrictions on access to drugs in clinical trials since their input was extremely helpful to the proper implementation of what we were doing.

RH: Has there been a long-term impact of giving activists a seat at the table, a voice in discussion? If so, was it a positive or negative one?

TF: The long-term impact has clearly been positive since the process of clinical trial design and dealing with real world problems associated with a disease (such as HIV/AIDS) really needs input from those involved.

RH: What advice would you give to young activists who want to reach someone at your level?

TF: Prepare yourself by trying as best as possible to familiarize yourself with the scientific and policy facts and issues. Having done this, start off softly by indicating that you want to engage in constructive discussions. Give the officials a chance to digest that you are acting in good faith. If you get no response or if you are ignored, then gradually step up the pressure, including by going to the press with your issues. Make sure that you can defend your position with facts. It is very difficult for officials to walk away from facts.

RH: Can you mention three things activists should NOT do if they wish to be granted access to the halls of power?

TF: 1) Do not assume that everyone in the halls of power is against you, even though it may seem that way sometimes; 2) do not try to gain access until you are fully aware of the issues and have tried to educate yourself. If you come in ill-prepared, you will lose credibility and you might make it much more difficult for yourself to engage in the future; and 3) do not be confrontational unless you have exhausted a more measured approach.

RH: What lessons can all activists glean from the work of early AIDS activists that may still be relevant today?

TF: Be persistent, be consistent, and try to know your subject at least as well as the people that you are trying to deal with.

- Regan Hofmann



INSIDE-OUTSIDE ADVOCACY

How to create social change using pressure on both sides of an issue.

An effective formula to advance social change: activists protest outside the halls of power to create pressure, while colleagues advocate with the decision makers on the inside to advance their cause directly.

In shorthand, this means that you need people “outside” a system or organization, or just the office of a person you are trying to influence. These people get the attention of the target and leverage the media to highlight that there’s an issue or problem that needs resolving. And you need people “inside” those same arenas to educate, deliver your “asks,” and negotiate with your target for ways to resolve the issue or problem.

Most successful social movements have components of both. Think of the different roles played by the SNCC and the NAACP for example.

The “outside” group conducts protests, rallies, and demonstrations. They picket and march and participate in civil disobedience to get their issue in the media—and to make their targets pay attention and feel pressure to respond. This group uses their bodies, voices, art, collective power (and often, palpable and visible anger and discontent) to stir action.

The “inside” group stands at the ready to push the asks of those who conduct the protests, rallies, and demonstrations. This group is typically comprised of experts armed with facts, details, and data to support the arguments of the outside group. They are the ones who negotiate and are often trained in policy, law, and any areas of specific expertise relevant to a given social movement. They are often people who have worked inside the systems and institutions or industries with which they are negotiating. This group is comprised of diplomats and

negotiators, experts and educators.

If the “outside” group are activists, the “inside” group are advocates. The members of the “inside” group are often less overtly strident than those in the “outside” group; but it’s really just a matter of tone of expression—ultimately, they are doing the same things in different ways. The most successful advocacy involves both types of groups working with equal force, but wielding different types of tools. Great communication between the groups and a willingness to work in concert and to propose the same solutions heightens the efficacy of both types of groups.

When a “target” (a person, institution, or company) is ready to take action, they often like to meet with representatives from the “inside” group—a group that may also include some of the members of the “outside” group—in order to clearly understand the issues and needs of the movement and to discuss ways of moving towards change or resolution. When the “inside” group includes some from the “outside” group, it maintains solidarity between the two. And having an “outside” member or two with the “inside” group can keep the heat on a target, while showing that the “outside” group is willing to cooperate as long as their needs are sufficiently addressed. “Targets” who are willing to meet with members of both groups (such as Dr. Fauci did) can gain the respect of a wider community. When all three groups come together, it offers the best chance for the smoothest resolution of conflict.

As you think about your own role in social change, consider which type of group suits your personality best. And if you are leading social change, ensure you have both types of groups assembled and that your “target” knows both exist.

- Regan Hofmann

RESOURCE GUIDE

Top Organizations Leading the Charge for HIV Health and Health Care Justice

Activism takes many forms. It can be as simple as signing a petition, registering for e-news, liking an organization or cause on Facebook, following and promoting a group's work on Twitter or donating funds. Or, it can involve direct engagement from volunteering to fundraising, from participating in a demonstration to political lobbying, from advocacy to working for an organization, cause or movement. The first step is identifying which organization fits best with your goals, talents and resources. The following is a sampling of organizations from around the world with histories of success fighting for the rights, health and safety of people living with, and affected by, HIV/AIDS—as well as related conditions.

AIDS COMMUNITY RESEARCH INITIATIVE OF AMERICA (ACRIA) acria.org

ACRIA focuses on educating patients and health care providers about treatment options and guides them on how best to navigate the complexities of health care. Founded in 1991 as the Community Research Initiative on AIDS (ACRIA) by a group of physicians, activists and people living with the virus who were frustrated by the slow pace of government and academic AIDS research, the organization has since helped develop medications that allow people living with HIV to live longer, healthier lives.

AIDS COALITION TO UNLEASH POWER (ACT UP) actupny.org | actupphilly.org | actup-sf.org | actupboston.org

ACT UP played an integral role in accelerating the development, approval and dissemination of life-sustaining drugs for people with HIV/AIDS. Known for their often shocking, and effective, demonstrations (disrupting Mass at St. Patrick's Cathedral, human ashes thrown onto the White House lawn), the members of ACT UP continue to unite in anger engaging in direct action to end the AIDS pandemic. Their "Civil Disobedience Manual"

is a must-read for any activist. The story of how ACT UP has helped saved many lives is documented in *How to Survive a Plague*.

ACT V: THE END OF AIDS actfive.org

"ACT V" refers to the fifth, and final, act in Shakespearean drama. It's when resolution and redemption occur. The relatively new, global AIDS organization is named thus as its goal is to shepherd in the end of the pandemic. It's run by Leigh Blake (of Red Hot, Artists Against AIDS, Keep A Child Alive and Arms Around the Child) and global AIDS activist Paul Zeitz.

AIDS.GOV aids.gov

AIDS.gov is the U.S. government's comprehensive web site for information and resources on HIV/AIDS; it offers the latest on U.S. policy, program and funding information. It offers a user-friendly AIDS service provider tool at: www.locator.aids.gov. The site notes that while most states offer both anonymous and confidential testing, some do not. For U.S. based patients interested in obtaining anonymous testing it suggests contacting local health departments or calling 1-800-CDC-INFO (1-800-232-04635)

AID FOR AIDS INTERNATIONAL aidforaids.org

Aid for AIDS (AFA) operates the world's largest medicine recycling program, redistributing unused, unexpired medication to those without affordable treatment access. Its innovative program, "¿Cuánto Sabes de VIH y Sida?" (How Much Do You Know About HIV and AIDS?), provides peer-to-peer HIV-prevention education and serves more than 100,000 teenagers in Latin America and the Caribbean annually. AFA also serves immigrant communities in New York with HIV case management, outreach and testing.

AIDS FOUNDATION OF CHICAGO (AFC) aidschicago.org

Their tagline is "A Source of Hope. A Force for Change." They are both. Their mission is to lead the fight against HIV/AIDS and improve the lives of people affected by the pandemic. They offer prevention, testing, care, housing, case management, food assistance and grants. They fundraise through events and engage in advocacy in their hometown and on Capitol Hill. Founded in 1985 by community activists and physicians, AFC is a local and national leader in the fight for effective, compassionate

public policy aimed at protecting the rights and lives of people living with and at risk for contracting the virus. The AIDS Foundation of Chicago's programs, are lead partners in the Learn | Fight | Love Alliance.

AIDS LAW PROJECT OF PENNSYLVANIA aidslawpa.org

This nonprofit public-interest law firm based in Philadelphia, Pennsylvania provides free legal assistance to people with HIV/AIDS and those affected by the pandemic. They are the only public-interest law firm in the U.S. dedicated to HIV and AIDS. They educate the public about AIDS-related issues, train case management professionals to become better advocates for their clients with the virus and work on local, state and national levels to achieve fair laws and policies. They make home and hospital visits for clients too sick to travel. They cover a span of issues from HIV-related discrimination to confidentiality of HIV-related information, HIV testing protocols to public/private benefits, housing to wills, living wills and powers of attorney, financial/consumer debt to immigration.

AIDS POLICY PROJECT aidspolicyproject.org

This community of advocates, political strategists, community organizers, health professionals and people living with HIV/AIDS are working together to support the development of a cure for HIV.

AIDS UNITED aidsunited.org

AIDS United's mission is to end the AIDS epidemic in the United States. They pursue that goal through national, regional and local policy/advocacy work, strategic grant making and capacity building. AIDS United works to ensure all living with the virus can access the care and treatment they need to survive.

AMFAR, THE FOUNDATION FOR AIDS RESEARCH amfar.org

This fundraising, research and advocacy powerhouse invests directly in finding a cure for HIV/AIDS. To date, amfAR has invested more than \$340 million to fund 2,000+ cutting-edge research teams worldwide. Known for their A-list celeb-studded fundraisers, they have the freedom and flexibility to respond quickly to the most promising research. Their "ARCHE" grantees work in collaboration with others and their new "Generation Cure" initiative is cultivating a new crop of leaders to help herald in the cure for AIDS.

ANDREY RYKOV FOUNDATION FOR HEALTH AND SOCIAL JUSTICE (ARF) en.rylkov-fond.org

This Moscow-based, grassroots organization was founded in 2009 and fights to promote and develop humane drug policy based on tolerance, protection of health, dignity and human rights. The foundation uses four key strategies in its work, namely: advocacy, "watchdogging," provision of services and capacity building. It advocates for the introduction of evidence-based and internationally recognized opioid substitution treatment and for the dissemination of clean needles and syringes.

AVAC avac.org

This non-profit founded in 1995 uses education, policy analysis, advocacy and a network of global collaborations to accelerate the ethical development and global delivery of AIDS vaccines, male circumcision, microbicides, pre-exposure prophylaxis ("PrEP") and other emerging HIV prevention options as part of a comprehensive response to the pandemic.

BLACK AIDS INSTITUTE (BAI) blackaids.org

BAI aims to correct the disproportionate rate at which African Americans contract, and die from, HIV/AIDS. Under the dynamic leadership of Phil Wilson, their motto—"Our People, Our Problem, Our Solution"—speaks to the self-empowerment and self-preservation that serve as the cornerstones of their work. In conjunction with The Kaiser Family Foundation, BAI has created a national public awareness campaign called "Greater Than AIDS" (greaterthan.org). BAI is a lead partner in the Learn | Fight | Love Alliance.

CENTER FOR HEALTH, HUMAN RIGHTS & DEVELOPMENT (CEHURD) cehurd.org

This indigenous, non-profit, research and advocacy organization is pioneering the enforcement of human rights (such as sexual and reproductive health rights, trade and health, and the medical ethics affecting vulnerable and less-advantaged populations such as: women, children, orphans, sexual minorities, people living with HIV/AIDS, people with disabilities, refugee populations, internally-displaced people and victims of violence, torture, disaster and conflict) as well as the legal right to health in Eastern Africa. It works to ensure that laws and policies are used as the principle tools for the promotion and protection of health and human rights. Their programs focus on human rights advocacy, community empowerment and research and documentation.

CENTER FOR ARTISTIC ACTIVISM artisticactivism.org

The Center is a home for artists, activists and scholars to explore, discuss, analyze and strengthen connections between social activism and artistic practice. Their goal is to make more creative activists and more effective artists. As they say, "We aim to win."

CENTER FOR HEALTH AND GENDER EQUALITY (CHANGE)

genderhealth.org

CHANGE has advocated for the sexual and reproductive health and rights of women and girls worldwide since 1994. The U.S.-based non-governmental organization has as its mission ensuring that the U.S. foreign policies and programs protect women's and girls' sexual and reproductive health within a human rights framework. CHANGE believes that every person has the right to basic information, technologies and services needed to enjoy a healthy and safe sexual life free from coercion and preventable illness.

THE CENTER FOR HIV LAW AND POLICY

hivlawandpolicy.org

The Center for HIV Law and Policy (CHLP) is a U.S.-based legal and policy resource and strategy center for people with HIV and their advocates. CHLP works to reduce the impact of HIV on vulnerable and marginalized communities in the U.S. and to secure the human rights of people affected by HIV. The Center works with experts and community members from local direct service providers to identify, create and share high-quality legal and policy resources and advocacy strategies.

DELHI NETWORK OF POSITIVE PEOPLE (DNP+)

dnpplus.org

Registered in 2000 as a trust, DNP+ provides a platform to help empower patients to make informed treatment decisions at every stage of the HIV trajectory. They offer support, service delivery and advocate for human rights. DNP+ established Delhi Mahlia Samiti (DMS), a women's forum focused on improving the quality of life in women and children living with HIV in Delhi thereby reducing vulnerabilities of women, girls and children.

ELIZABETH GLASER PEDIATRIC AIDS FOUNDATION (EGPAF)

pedaids.org

The non-profit foundation is dedicated to preventing pediatric HIV infection and eliminating pediatric AIDS through research, advocacy and prevention, care and treatment programs. Founded in 1988, EGPAF currently works in 15 countries around the world. Their global staff of more than 1,000 people (87% of whom work directly in the field) makes EGPAF a global leader in the push for an AIDS-free generation.

EQUAL EDUCATION

equaleducation.org.za

This is a movement of learners, parents, teachers and community members working for quality and equality in South African education through analysis and activism. Unequal educational opportunities still remain amongst the greatest obstacles to equality, dignity and freedom in today's South Africa.

FASTERCURES

fastercures.org

The D.C.-based think tank works to accelerate medical solutions to the world's most deadly diseases. They educate stakeholders about the barriers to breakthroughs, and help ensure research funding is applied for maximum impact. Their publication Back to Basics: HIV Advocacy as a Model for Catalyzing Change (fastercures.org/Publications/HIVAIDS-Change.php) offers a terrific analysis of how a diagnosis of HIV went from a death sentence to a treatable disease.

GMHC

gmhc.org

While based in New York, GMHC has national influence and reach. Founded by gay men in 1981, their diverse constituents and beneficiaries now include people of all ages, gender and sexual orientations. One of the first, and still one of the best, providers of HIV/AIDS prevention, care and advocacy, the mighty GMHC sets a platinum standard for fighting HIV/AIDS.

GREATER THAN AIDS

greaterthan.org

The GreaterThan.org website offers one of the most comprehensive sets of resources for individuals to get informed and take action on HIV/AIDS at a variety of levels. Greater Than AIDS is a long-term, multi-platform educational media project created by the Kaiser Family Foundation in partnership with The Black AIDS Institute. Leading supporters include the U.S. Center for Disease Control, Elton John AIDS Foundation, Ford Foundation and Walgreens (a major private sector partner). Greater Than AIDS' "Pride" initiative offers targeted media content and outreach to the LGBTQ Community in the U.S.

HEALTH GAP

healthgap.org

The "GAP" stands for Global Access Project; they're dedicated to ensuring affordable, life-sustaining access to care for all people with HIV/AIDS because they believe that health care is a human right. They see universal access as key to ending the pandemic globally and campaign against short-sighted policies that deny treatment to millions and fuel the spread of the virus. Health GAP is a lead partner in the Learn | Fight | Love Alliance.

HIV PREVENTION JUSTICE ALLIANCE (HIV PJA)

preventionjustice.org

Their slogan—"HIV/AIDS is not just a disease, it's proof positive of social injustice"—says it all. They maintain that fighting against AIDS is fighting for human rights and social justice, particularly when it comes to marginalized communities. Working to herald in a paradigm shift in HIV prevention, they insist that society and our leaders address social determinants (such as poverty) that fuel viral spread. HIV PJA is a lead partner in the Learn | Fight | Love Alliance.

HOUSING WORKS

housingworks.org

New Yorkers know and love their SoHo bookstore, and trendy thrift shops. Co-founder and CEO Charles King was an early ACT UP leader. Their innovative approach to raising money to fight the dual crisis of AIDS and homelessness was helping thousands of people long before the term "social entrepreneur" became a cliché. NYC-based Housing Works is also a major force in the advocacy arena in Washington, DC, and has been on the ground in Haiti since 2008.

INTERNATIONAL AIDS VACCINE INITIATIVE (IAVI)

iavi.org

This global not-for-profit organization focuses on the development of safe, effective, accessible, preventive HIV vaccines for use throughout the world. Founded in 1996, IAVI works with partners in 25 countries to research, design and develop AIDS vaccine candidates. The organization also conducts policy analysis and serves as an advocate for the AIDS vaccine field. It supports a comprehensive approach to addressing HIV and AIDS which balances the expansion and strengthening of existing HIV prevention and treatment programs with targeted investments in the design and development of new tools to prevent HIV. IAVI is dedicated to ensuring that a future AIDS vaccine will be available and accessible to all who need it.

INTERNATIONAL HIV/AIDS ALLIANCE

aidsalliance.org

This innovative global partnership of 41 nationally based, independent civil society organizations and country offices, seven technical support hubs and an international secretariat work together to mobilize communities against HIV/AIDS. They support community action on HIV, health and human rights to end AIDS.

INTERNATIONAL TREATMENT PREPAREDNESS COALITION (ITPC)

itpcglobal.org

This global network of community organizations, local NGO's, researchers and activists is dedicated to securing access to effective, affordable and quality treatment for all people living with HIV. They push for global scale-up of access to care; since research shows that antiretroviral HIV treatment, taken properly, can lower the risk of transmission by up to 96%, ITPC's work protects both individual—and public—health. ITPC's David Barr is featured in *How to Survive a Plague*.

MÉDICINS SANS FRONTIÈRES (A.K.A. DOCTORS WITHOUT BORDERS)

msf.org |

doctorswithoutborders.org

Founded in Paris in 1971, MSF is a worldwide, self-governing movement of 23 associations. The international, independent, medical humanitarian organization delivers emergency aid to people affected by armed conflict, epidemics, natural disasters and exclusion from healthcare. MSF offers assistance to people based on need, irrespective of race, religion, gender or political affiliation. Their actions are guided by medical ethics and the principles of independence and impartiality.

ONE

one.org

A global, grassroots group with more than 3 million members, ONE fights extreme poverty and preventable diseases, particularly in Africa. ONE is known for raising public awareness and pressuring political leaders to support smart and effective policies and programs (meaning, those that actually save lives). A non-partisan org, ONE was co-founded by Bono and others focused on improving the health and well-being of the world's most disenfranchised.

PARTNERS IN HEALTH

pih.org

The mission of Partners In Health (PIH) is to provide what it calls "a preferential option for the poor" in health care, advancing and acting on the belief that health care is a human right. PIH began its work in Haiti and has delivered high-quality medical care and social support to the poorest of the poor living in rural Haiti for 25 years. Its groundbreaking work—providing free comprehensive HIV/AIDS treatment for the poor—is a model for public health programs worldwide. PIH now has partnership programs in numerous countries, notably Rwanda which has been cited as an historic success story by the WHO, *The New York Times*, *The Atlantic* and others. The PIH's Take Action network offers ways to get involved in the movement for health care justice.

PATHFINDER INTERNATIONAL

pathfind.org

Their mission is to ensure that people everywhere have the right and opportunity to live a healthy sexual and reproductive life. They work in more than 20 countries to provide women, men and adolescents a range of quality health services, from contraception and maternal care to HIV prevention and AIDS care and treatment. They strive to strengthen access to family planning, ensure availability of safe abortion services while improving the rights and lives of the people they serve.

PLANNED PARENTHOOD

plannedparenthood.org

Planned Parenthood provides high quality, affordable reproductive and sexual health care and prevention education to millions of women, men and young people across the U.S. and in 17 countries in Africa, Asia, and Latin America. Planned Parenthood is among the world's largest providers of confidential HIV tests, screening over 4 million people a year for sexually transmitted

diseases. The Planned Parenthood Action Network is a powerful resource for those interested in learning about and supporting the organization's regional, national and global advocacy work.

PSI psi.org

The mission of PSI is to measurably improve the health of poor and vulnerable people in the developing world, principally through social marketing of family planning and health products and services, and health communications. Social marketing engages private sector resources and uses private sector techniques to encourage healthy behavior and make markets work for the poor.

QUEEROCRACY queerocracy.org

Queerocracy is a New York City-based organization working to build a new generation of LGBTQ leaders to challenge institutional injustice within a queer framework. Through direct action, grassroots organizing, community engagement, education, leadership development and art, their goal is to build a strong and sustainable movement of queer leaders focused on working towards social and economic justice within their own lives.

RESULTS results.org

Their vision is a world where the devastating impacts of poverty no longer cripple the ability of individuals and families to sustain themselves and contribute their talents to the world in which they live—where all people have a fair chance at success. They encourage citizens to pressure their leaders for effective anti-poverty programs to receive the attention, policies, and funding they need. Their mission is to create the public and political will to end poverty by empowering individuals to exercise their personal and political power for change. Combining voices of passionate

grassroots activists with strategic grass-tops efforts, they help leverage millions of dollars for programs and improved policies that give low-income people the health, education, and opportunity they need to thrive.

SAVE THE CHILDREN savethechildren.org

The independent organization creating lasting change in the lives of children in need in the United States and around the world is known for their commitment to accountability, innovation and collaboration. They empower communities, children and families to help themselves. Working with other organizations, governments, nonprofits, and a variety of local partners, they maintain independence and work without political agenda or religious orientation. When disaster strikes around the world, Save the Children saves lives with food, medical care and education and remains to help communities rebuild through long-term recovery programs.

THE SERO PROJECT seroproject.com

The not-for-profit human rights organization promotes the empowerment of people with HIV, combats HIV-related stigma and advocates for sound public health and HIV prevention policies based on science and epidemiology rather than ignorance and fear. Sero is particularly focused on ending inappropriate criminal prosecutions of people with HIV for non-disclosure of their HIV status, potential or perceived HIV exposure or HIV transmission. By engaging a network of people with HIV who have been criminalized and empowering them to advocate on their own behalf and their compelling personal stories, Sero helps build a growing grassroots movement to mobilize the advocacy necessary to end HIV criminalization and promote a human rights-based approach to end the HIV epidemic.

SEX WORKER EDUCATION AND ADVOCACY TASKFORCE (SWEAT) sweat.org/za

This organization focuses on the decriminalization of sex work. Together with other civil society organizations, SWEAT advocates for the removal of all laws that prosecute sex workers. Unlike legalization, this approach involves industry regulation rather than government oversight, and acknowledges human rights for all. SWEAT's multi-initiative approach includes media engagement, policy debate, and coalition building. It has compiled numerous issue, position, and discussion papers on sex work, current local and national laws, decriminalization, and sex work conditions.

SEX WORKERS PROJECT sexworkersproject.org

The Sex Workers Project provides client-centered legal and social services to individuals who engage in sex work, regardless of whether they do so by choice, circumstance or coercion. One of the first programs in the U.S. to assist survivors of human trafficking, it has pioneered an approach to service that is grounded in human rights, harm reduction and in the real life experiences of its clients. Serving a marginalized community, the organizations also engages in policy and media advocacy, community education and human rights documentation, working to create a world that is safe for sex workers and where human trafficking does not exist.

STAYING ALIVE FOUNDATION stayingalivefoundation.org

The prevention-based org launched by MTV believes in stopping the spread of HIV before it starts by focusing on the delivery of fresh, relevant prevention messaging that breaks through to a young, global audience, arming them with the information and empowerment

they need to stay safe from HIV/AIDS. They back innovative programs on the ground, by funding the creative and ambitious young leaders that run them.

STUDENT GLOBAL AIDS CAMPAIGN (SGAC) studentglobalaidscampaign.org

These next-gen leaders are working at college campuses across the country (85 and counting). Since they came of age in a global era, they are not only fighting for prevention and treatment access, but also the elimination of debt in the developing world and reform of global trade rules. Their media-savvy strategic campaigns are aimed at decision-makers and raising public awareness. SGAC is a lead partner in the Learn | Fight | Love Alliance.

TREATMENT ACTION CAMPAIGN (TAC) tac.org/za

Founded in 1998 in Cape Town, TAC advocates for a unified, quality health care system to provide equal access to HIV prevention, care and treatment services for all people. Their mission is to ensure that every person living with HIV has access to quality comprehensive prevention and treatment services to live a healthy life. With more than 16,000 members, 267 branches and 72 full time staff members, TAC has become the leading civil society force behind comprehensive health care services for people living with HIV/AIDS in South Africa. Since 1998, TAC has held government accountable for health care service delivery; campaigned against official AIDS denialism; challenged the world's leading pharmaceutical companies to make treatment more affordable and cultivated community leadership on HIV and AIDS. TAC has received numerous international accolades, including a nomination for a Nobel Peace Prize in 2004. In 2006 the New York Times named TAC, "the world's most effective AIDS group."

TREATMENT ACTION GROUP (TAG) treatmentactiongroup.org

The independent AIDS research and policy think tank comprised of science-based treatment activists fights for better treatment, education and access to care for people with HIV. They also focus on accelerating vital research and effective community engagement with research and policy institutions in pursuit of vaccines and a cure. TAG's indomitable Mark Harrington is featured in *How to Survive a Plague*.

URBAN JUSTICE CENTER urbanjustice.org

For 29 years, the Urban Justice Center has served New York City's most vulnerable residents through a combination of direct legal service, systemic advocacy, community education and political organizing. They assist clients on numerous levels, from one-on-one legal advice in soup kitchens, to helping individuals' access housing and government assistance, to filing class action lawsuits to bring about systemic change. They represent the most deprived and abused people in society, including members of the working poor, and issues related to discrimination and oppression.

UNIVERSITIES ALLIED FOR ESSENTIAL MEDICINES (UAEM) uaem.org

This organization believes that universities and publicly funded research institutions will be part of the solution to the access to medicines crisis by promoting medical innovation in the public interest and ensuring that all people regardless of income have access to essential medicines and other health-related technologies. The not-for-profit, rooted in a global movement of university students promotes access to medicines and medical innovations in low- and middle-income countries by changing norms and practices

around academic patenting and licensing, ensures that university medical research meets the needs of people worldwide and empowers students to respond to the access and innovation crisis. Comprised of committed students from all over the world, supporters of UAEM fight for social justice and health equity, for millions of people do not have access to essential medicines.

WOMEN'S LEGAL CENTRE wlce.co.za

The non-profit, independently funded law centre was started by a group of lawyers who seek to achieve equality for women in South Africa. As access to justice is largely inaccessible to poor women, particularly black women, the WLC plays an important role in litigating in their interest and providing them with access to free legal advice. The Centre has identified 5 strategic focus areas. They are: violence against woman, fair access to resources in relationships, access to land/housing, access to fair labor practices and access to health care.



CONVERSATION STARTER

A FACILITATOR'S GUIDE FOR DISCUSSION PROMPTED BY *HOW TO SURVIVE A PLAGUE*

You've seen the movie. You're inspired. Now you're ready to host a discussion about the movie and talk with others about getting engaged and taking action.

Where to begin?

In advance: Set an objective for your meeting or discussion group. As a student, you may want to get others involved in a cause or group such as the Student Global AIDS Campaign activist initiative, faith-based group, or film club. If you work with an AIDS service organization, the film and discussion around it is an opportunity to connect with people in your community, encourage HIV testing, support linkage to care, and foster discussion. It's also a great way to strategize with others about raising money or reaching out to more people in need of testing and, potentially, treatment. If you work in the sphere of human

rights, focus on the strategy and tactics that ACT UP used. In all cases, share this guide with your group members in advance. In case some of the participants don't have Internet access, consider printing out some sections and having them on hand to share at the start of the meeting. Identify which of the articles in this guide speak to the core issues you wish to explore in your discussion and suggest participants read those in advance, even if they haven't yet seen the movie.

The film addresses a wide variety of issues. Are there experts in your community whose experience would provide a useful point of reference? Consider inviting them to join your group discussion. Before inviting them to speak, make sure they see the film and talk with you about it.

1 FIND A GOOD SPACE AND TIME

It could be the local library, a school, a coffee shop, a café, a diner or an AIDS-service organization. Or, of course, your home. Consider whether you can schedule the meeting right after the screening, or whether you need to move to another space. Find a place that allows for refreshments. If you can provide refreshments, great. If not encourage folks to bring a drink or snack for after the screening. Ideally, create a conversation circle. If that's not possible, be sure to include comments from all over the room so no one feels left out.

2 REACH OUT AND INVITE OTHERS TO JOIN YOU

The best place to start is by sending personal invitations via email, text or, better yet, letting people know with a phone call or in person. Tell people they are welcome to bring others.

Think about who you want to attend and where and how they receive information. Then, consider the best ways to reach them, such as fliers or post cards in public places, ads in the local or regional paper, via email, text message, or via social media like Facebook or Twitter. Seasoned activists say that in order to get a person to show up, you need to reach out three times, including once in person or on the phone. It's a good idea to call people the day before to remind them to attend.

3 SET AN AGENDA

Your agenda may be something simple such as creating a welcoming space for the group to engage in a thoughtful discussion about the film and its implications for 60 to 90 minutes. Limit the formal discussion to 90 minutes, call an official end and then let those who wish to do so talk amongst themselves. Have a list of questions, quotes, themes and important topics from the film handy to prompt discussion/questions, especially if the conversation lags.

4 COVER THE BASICS

Once you have your group gathered, cover the basics. Introduce yourself as the facilitator and establish that you'll be leading the discussion. Describe any relationship you have to the work described in *How to Survive a Plague* and/or how the film has inspired and motivated you.

Review housekeeping logistics (location of wash rooms, water, food if available, etc.). Consider asking for volunteers to help with timekeeping and note taking. Share your objectives for the group discussion, explain the format and the time frame. Let people share their reactions to the film and discuss their personal connection to the issue. In order to build community and encourage people to work together, brainstorm ways that members of the group or the group itself can effect change.

5 SET THE TONE

If your group is new, or there are new people joining, suggest that everyone in the room introduce themselves. Next, clarify the rules of engagement. Ask people to listen respectfully to others, refrain from interrupting and be concise. Let participants know that you will interrupt anyone monopolizing the conversation. Ask people to raise their hands and indicate they wish to speak. You can say you'll try to get to everyone—at least once.

6 PROVIDE TOOLS

Give participants pencils and note cards. Some people may not wish to speak out but may have questions they feel comfortable sharing by writing them down and having the facilitator share with the group on their behalf. Share copies of the appropriate sections of the Guide.

7 ASK QUESTIONS TO WARM UP AND ENGAGE THE GROUP

Start the discussion by choosing a question from the list below. If you decide to share your own experience, or that of a colleague or special guest, make sure you spend 5 minutes on this first part of the discussion. Involve the group early on so people feel part of the experience.

Don't be afraid of brief pauses in the action. Sometimes, people are just thinking.

8 SHARE YOUR OWN EXPERIENCE, OR THAT OF A TRUSTED COLLEAGUE

It breaks the ice if the facilitator opens up. Also, by setting an example of candor and courage, you can prompt more interesting conversation in others.

9 LEAVE TIME FOR CLOSURE

Leave time at the end of the discussion to summarize themes and highlight take-home messages, and to make plans about any follow-up items.

Discuss with the group whether they would like to meet again and, if so, collect contact information from participants so you can send out details of your next meeting. Allow for leadership roles to rotate through the group. Ideally, create an action item or an agenda for the next meeting (e.g. creating a flier, researching the issue, recruiting new members, etc.).

10 WHAT NEXT?

Partner up: maintain the momentum of your group, consider working with other (affinity) groups, schools or organizations to further your agenda. The filmmakers of *How to Survive a Plague* have found that audience members may have felt a lot of emotions by the end of the film. You may want to take a moment for a "group hug," which simply means acknowledging how people feel.

THE FOLLOWING "CONVERSATION STARTERS" ARE GROUPED THEMATICALLY

ASSESS THE GROUP'S EMOTIONAL RESPONSE.

What inspired you most about this film? What moved you most?

What does this film make you want to do? What did this film teach you that you didn't know?

Did this film make you more willing to get engaged?

If so, why?

EXPLORE THE THEORIES OF SOCIAL CHANGE.

Why were the early AIDS activists so successful?

What were their unique challenges?

How did they overcome them?

How effective was the role of street theater in the AIDS movement?

How essential is the involvement of the media in any movement?

What types of tactics draw media attention?

IDENTIFY THE CHALLENGES OF ACTIVISM.

Does civil disobedience have to be part of a movement for social change?

Would you feel comfortable getting arrested?

How does one overcome fear?

ASSESS THE ROLES OF POWER AND ACCESS IN EFFECTING CHANGE.

How do people gain access to the halls of power?

How do people secure the attention and engagement of local, state, and national politicians?

How did the activists in the film appeal for funding from government?

How would you approach this in your community or country today?

Where are some good places to go to become an expert on the issues?

What are the elements of AIDS activism that allow it to be effective, timeless, and widely applicable?



For information about purchasing a copy of *How to Survive a Plague* for educational or personal use, visit surviveaplague.com. To host a formal screening of *How to Survive a Plague* at your company, school, university or non-profit or non-government organization, contact: info@rocofilms.com

Thanks to the Ford Foundation for support of the film and the campaign. Thanks to Bertha BRITDOC Connect Fund, The Fledgling Fund, Open Society Foundations, Elton John AIDS Foundation and private donors for campaign support.

WORDS OF WISDOM

FIVE AIDS ACTIVISTS WEIGH IN ON WHAT IS REQUIRED TO CHANGE THE WORLD

Find out more about the system you are trying to change than anyone who works in that system knows, and use that information to define to them how the system must change to meet your community's needs. Hold them accountable, follow the money, make them have bad dreams, question their conscience, and present them with a better way to do things moving forward.

Mark Harrington, Executive Director, Treatment Action Group

The deep, dark secret to effective advocacy work that will result in dramatic progressive social change and literally save millions of lives is to just do it. I am always amazed at how easy it is to win if you just follow the rules: choose an audacious goal, find out who can give you what you want and don't stop harping on said target (bringing more and more people with you each time) until you win. No one ever won with a good policy argument alone. You need to be in their face daily—but it's that easy! For [a great] road map of how to win, see the Midwest Academy's strategy chart in the book *Organizing for Social Change* by Bobo and Max.

Jennifer Flynn, Managing Director, Health GAP

Advocacy is not just about making a commotion, but about fulfilling one's internal perception of what will make the world a better place. I believe that everyone has a small, still voice that says, "This is my journey, my path, exactly what I am being called to do." Do not be distracted by the loud clamors of homophobia, racism and sexism. The noises that say to strong women, "Don't be strong." Noises that say to gay people, "Don't be gay." Far too often those noises drown out that small voice with harsh messages of what people should be or do. It is important to know yourself as you build yourself. And do not ever let anyone steal your joy.

Marjorie J. Hill, PhD, CEO of Gay Men's Health Crisis

If you know your cause is right, don't be deterred no matter what others say. Always keep one foot on the inside, always ready to talk, and one foot on the outside, always ready to take it to the street. And, above all, work harder than your opposition and be more creative. That's how to win.

The Reverend Charles King, President and CEO, Housing Works

What makes activism work is anger and fear. It can not work without them.

Larry Kramer, co-founder, ACT UP and Gay Men's Health Crisis



SO, NOW WHAT?

You're fired up to change the world. Here are some great ways to get started.

Find Us:

On Twitter: [@surviveaplague](#)

On FB: [facebook.com/SurviveAPlague](#)

Online: [www.surviveaplague.com](#)

CONNECT on and off-line

Check out the resource guide on pages 41-46, or link directly from [surviveaplague.com/resources](#).

CONNECT with Us

Email the team behind *How to Survive a Plague* at info@surviveaplague.com

GET CREATIVE

Art meets activism on our tumblr page: [surviveaplague.tumblr.com](#).

SPREAD THE WORD

Share photos from your volunteer work, activism or meet-ups across your social media networks.

VOTE with Your Feet

Volunteer. Join a group. Start your own affinity group. Learn how at [surviveaplague.com](#).

VOTE with Your Wallet

Support our "free tickets for youth" initiative.

VOTE. Just Plain Vote

It's your right. Exercise it.



LEARN



FIGHT



LOVE

surviveaplague.com

The *How To Survive A Plague* engagement campaign is made possible by:



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SUNDANCE
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