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FIGHT

LOVE

UNLEASHING THE POWER OF
HOW TO **SURVIVE** A PLAGUE

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Acts Up

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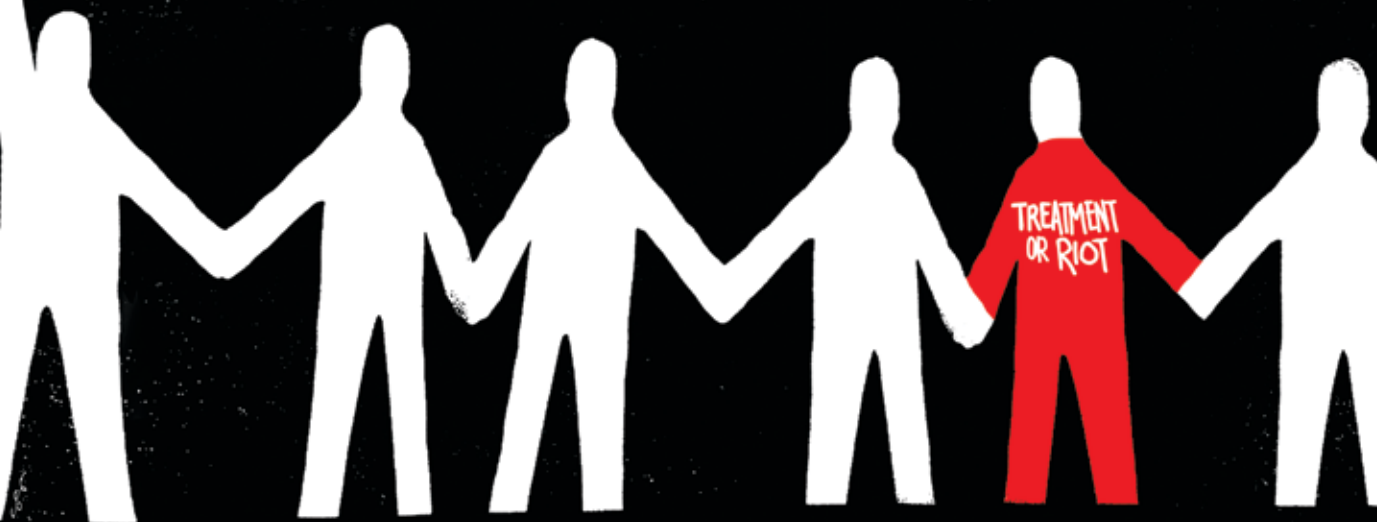
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HOW TO SURVIVE A PLAGUE

A FILM BY DAVID FRANCE

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"HOW TO SURVIVE A PLAGUE" MUSIC SUPERVISION: THE RED HOT ORGANIZATION ORIGINAL SCORE BY STUART BOGIE & LUKE O'MALLEY FEATURING THE SONGS OF ARTHUR RUSSELL
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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 troops 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
January 12, 2013



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LEARN FIGHT LOVE

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 affect 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 a group of several hundred people known as the AIDS Coalition to Unleash Power (ACT UP) who challenged the people in seats of power who controlled U.S. government budgets,

federal and state policies, medical research, drug approval and global drug pricing.

The diverse set of activists were bound by a singular desire: to respond—in the face of stigma and government immobility—to a mysterious disease targeting people in the prime of their lives. They came together to keep their friends, family members and lovers from dying of AIDS.

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 funders, the members of ACT UP, TAG and other advocacy groups working with them helped spare the lives of millions of people.

Today, there are nearly 8 million people living with HIV on treatment. And, because that treatment doubles as prevention by reducing, by 96%, the chance the virus can be transmitted, the securing of the drugs and enabling access to them has also spared countless children from contracting the disease in utero, prevented many new infections and has kept millions of children from being orphaned when their parents died of AIDS.

Their story happened in particular places and times, notably New York's Greenwich Village, San Francisco, CA and Washington, DC in the early 1980s through the mid 1990s. Though AIDS movement was started by mostly white, gay men, soon, it included people of all races, genders and sexual orientation.

The heroism of the earliest AIDS activists stands as an inspiration to a new generation of activists of all kinds. The story of how the first AIDS activists

helped turn a diagnosis of being HIV-positive from an automatic death sentence into a treatable disease is evidence that when enough informed, empowered, dedicated people come together at the right times, in the right places, in the right ways—the worst and most seemingly hopeless problems of the world can be solved.

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.

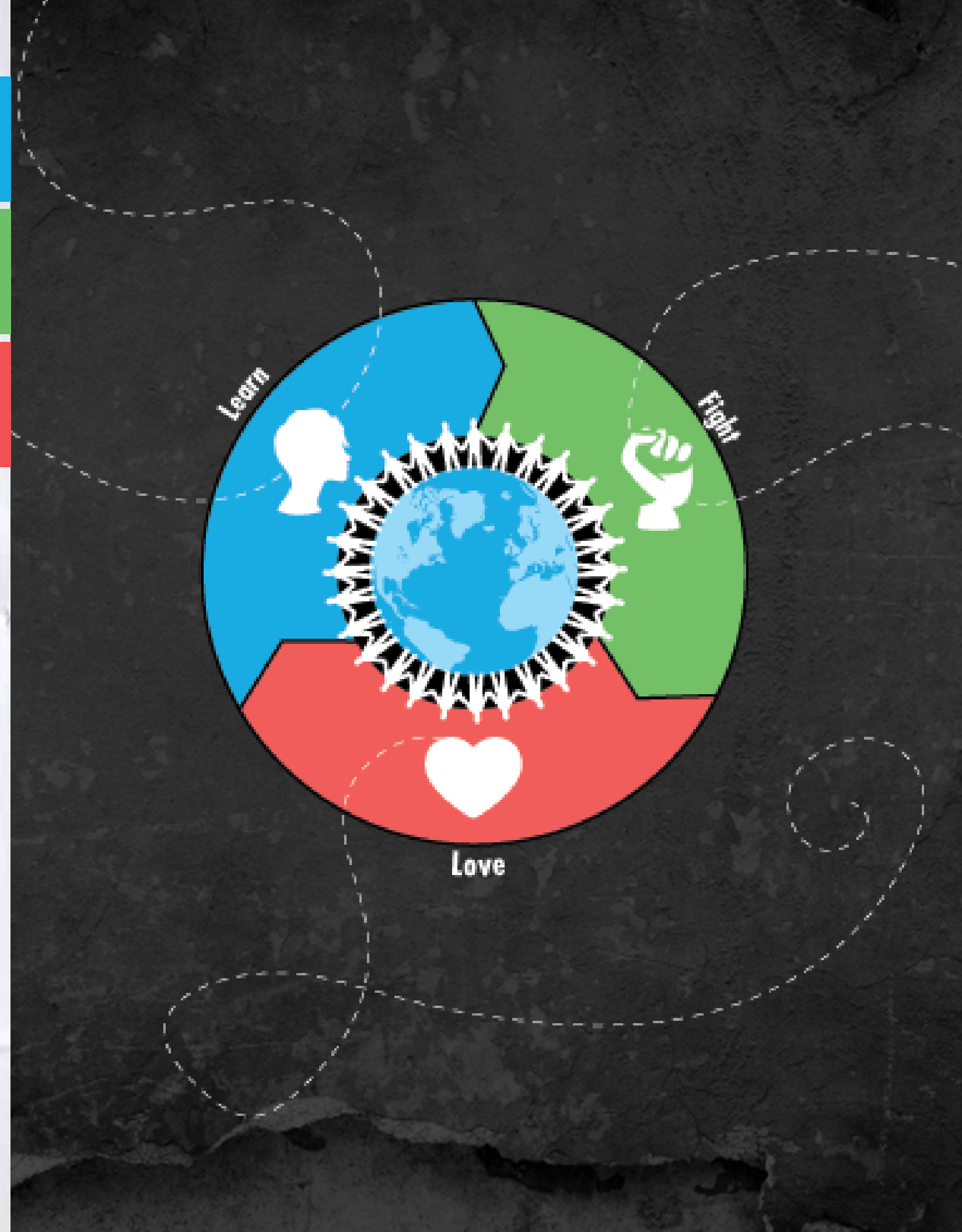
Effective activists use their heads to learn. They become experts about their issue and about the political and power dynamics that must be addressed to affect change.

They let themselves be filled with rage and raise their fists to express that they are furious and ready to fight.

And they love, leading from their hearts, leveraging compassion to build coalitions and practicing empathy by working alongside people with whom they have fundamental differences.

Michael Manganiello, of HCM Strategies and Margaret Anderson, of Faster Cures summarized the work of AIDS activists in their piece "Back to Basics: HIV/AIDS Advocacy as a Model for Catalyzing Change" thus: "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, 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.



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



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 for help.

“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, 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.”

*BACK TO BASICS: HIV/AIDS Advocacy as A Model
For Catalyzing Change — Michael Manganiello, HCM
Strategists, and Margaret Anderson, Faster Cures.*

Early AIDS activists were 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 scientific research institutions,

they did extensive homework. This allowed 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. Being taken seriously, requires being fluent in the terminology of the experts.

Understanding the systems affecting a given issue is also key. Barriers to change are sometimes unintended consequences of deep-seated bureaucracies; faulty, inefficient structures; ill-informed leaders or outdated laws and/or policies.

A working knowledge of the power structure surrounding a given issue is critical as is knowing which people and organizations control decisions at each juncture. Getting the right leaders and organizations on the side of a cause is as powerful as the largest public demonstrations.

Effective activists know where the money is, how it flows and who controls it. Being able to influence the application of funding is essential to any successful 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 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.”

Even those who took passive paths of activism, such as Gandhi, were often driven by an inner fury and deep-seated passion for their cause. Though the outward manifestation of their activism took a more peaceful form, inside they were as enraged and indignant as any.

AIDS activists fought hard, and visibly, in the public eye. They took to the streets, made noise, stood up, laid down in the streets in “die-ins,” carried fake coffins (and then the actual dead and their ashes) at their demonstrations and created a scene. Their fury—and messages—were captured by the press.

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 imprisoned. More than once.

They were laser-focused in their mission. Whether storming the halls of power with banners and bullhorns or meeting with researchers, doctors, drug developers, funders, members of Congress or the United States government, they never deviated from their fundamental objective of securing life-sustaining drugs for all with HIV in need.

Finally, AIDS activists were relentless. They seldom took “no” for an answer. They made sure their voices were heard and stuck to their plans. When forced to retreat, they regrouped and returned to fight another day.



LOVE by Connecting with Others

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

Consider the actions of a young fruit seller names Mohammed Bouazizi in Tunisia who was accosted by police officers emboldened by the corrupt dictatorship of President Ben Ali, and who was publicly humiliated as they dragged him from his cart. Rebuffed by local authorities when he sought retribution, Bouazizi saw no hope of change. In protest against the leadership of his country Bouazizi self-immolated in the central square for all to see. News of his death in January 2011 spread quickly across social media and started a movement that became known as “the Arab Spring” and included a series of rebellions in nations throughout the Middle East aimed at over turning governments.

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 choice that catalyzed wide spread change. But each was part of a larger community. None acted alone.

Social change can start with one person but it gathers momentum and has 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. But the fight to end the plague is at a critical tipping point. A new era of fierce AIDS advocacy is required to secure the bi-partisan political will and resources necessary to make what's possible a reality. With a quick response now, an AIDS-free generation—and maybe 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

More than 30 years since HIV was identified as the cause of AIDS and 15 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 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 AIDS, ultimately, a vaccine and cure are also required 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 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, 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," Clinton said.

The heroes of *How To Survive A Plague* accelerated the development of life-sustaining medication (and biomedical prevention modalities.) 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. In about 15 years, the relentless work of the early AIDS activists helped turn a diagnosis of HIV from a certain death sentence to a 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, millions of AIDS deaths and spared millions of children from being orphaned. That's the good news. But the bad news is that only eight of the more than 34 million people estimated to be living with HIV globally currently have access to the drugs. The remaining 26 million people (and more each day) face imminent illness and death. More than 750,000 of those 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—despite the fact that the medication to save them exists.

The goal of early AIDS activists was the development of life sustaining 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, namely: access to care, prevention, scientific research and the defense of human rights. If modern activists, governments, non-government organizations 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 frontlines in the battle to end AIDS.

ACCESS TO CARE

In 1995, a new class of antiretroviral HIV drug—known as "protease inhibitors" or PIs—was FDA-approved. It changed the game overnight. By preventing the human immunodeficiency virus (HIV) from bonding to, and killing, the cells of the immune system, PIs, when taken in combination with other antiretroviral medications, stopped HIV from destroying immunity. This prevented people with HIV from developing acquired immunodeficiency syndrome, or AIDS.



Protease inhibitors proved more than preventive. They allowed people supine with AIDS to rise from their deathbeds. The recovery was so dramatic it was coined the “Lazarus effect” — referencing the biblical 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 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 the virus can be transmitted.

It has long been known that 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 care both saves lives and helps stop viral spread.

To ensure that medicine is delivered to all in need living with HIV around the world, widespread, voluntary testing must be made available for people at risk for HIV. And, the public needs to be re-educated about what constitutes “risk.” For example, anyone who has had or is having unprotected sex is at risk for HIV and should be routinely testing. It is confidential, free and painless.

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 does the world increase the number of people with HIV on treatment? Two ways. One, if nations that can afford to more heartily support their bilateral programs to

provide HIV testing and care to their people. And two, if the wealthiest nations provide health care options to their people while contributing as much as they can to multilateral programs such as the Global Fund to Fight AIDS, Tuberculosis and Malaria. Doing so helps 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 in ways that allow more people and nations access to the best treatments available. 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. However, while some European nations are wealthy and can afford non-generic drugs for their people dependent on public health, others cannot. Wars about the pricing and intellectual property laws governing the formulations of HIV medications are leaving many in need without.

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



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.

Improved and more widely available prevention tools and tactics help stem the spread of HIV, especially among people exposed to people who don’t know they’re living with HIV and therefore wouldn’t know to seek treatment.

Condoms (male and female) work, and they are cheap. But debates over the connection between the dispersal of condoms and increased sexual activity have made funding condom dissemination tricky via some programs in some parts of the world. Research indicates that both comprehensive sex education and the dispersal of condoms do not 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. Adult, voluntary male circumcision has also proved to be an effective form of harm reduction because it significantly reduces the risk of HIV infection.

Biomedical forms of prevention exist as well, from 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 as knowing one’s status can lead to changes in behavior that can protect others (such as practicing safer sex) as well as lead someone to commence treatment which also protects others.

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 no income change their behavior and stop having survival sex is less effective a prevention strategy than offering stipends to encourage behavior change by addressing the root cause of the behavior. Women with money are less likely to have unprotected sex for money.

Offering age-appropriate, comprehensive sex education to all people, including young children, and older adults could have a

positive impact on reducing HIV caseloads. Teaching all sexually active people—including children and grandparents—how to have sex more safely can simultaneously 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 trials as “evidence” of drug use or sex work. The publicity surrounding these cases has raised questions over whether prosecutions resulting from the possession of condoms or sterile injecting equipment 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 access to health care is likely to undermine both individual and public health.



The end of AIDS is feasible only with better protection of human rights—therefore the human rights of all people, especially those with or at risk for HIV, must be 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. Global AIDS leaders said, at the United Nations’ High Level Meeting on HIV/AIDS in 2006, “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.”

They were prescient, and right. 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.

The misperceptions and myths surrounding HIV lead to fear which in turn can lead those living with the virus to be ostracized, disenfranchised, discriminated against, unfairly criminalized and in some places, even beaten or killed. Faced with such options, it’s easy to understand why those at risk are too afraid to come forward to know or disclose their HIV status and/or to seek medical care.

There are many, disproportionate acts of emotional and physical abuse against people with HIV. They can include: socially ostracizing them, romantic rejection, firing them from a job, kicking them out of a school, banning them from a pool, bringing criminal charges against them or even physically hurting or killing them. All these things, and the press coverage surrounding them, 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 get help if needed. Therefore, shaming, threatening or harming people with HIV backfires as a means of “protection.”

Similarly, outdated and unnecessary travel restrictions for people with HIV fuel the fire of people’s fear of people with HIV. Much headway has been made in the removal of travel bans but to date, 45 countries maintain them for people living with the virus. 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.

Equal access to quality health care for all people will help stop AIDS. Prosecuting those who commit LGBTQ and racial hate crimes would help. Defending vulnerable woman and children and ensuring overarching

gender equality would help. As would giving people the basics 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 children when their survival is at risk on a daily basis.

Clearly, it will take more than pills and prevention tactics to stop the AIDS plague. 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 stop AIDS will make the planet a safer and healthier place for everyone.



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

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

The cost to administer HIV treatment for the lifetimes of the 34 million people estimated to be living with 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 accessing treatment are on newer medications. The medications themselves lead to conditions that require additional medical care and in doing so, increase the cost of long term care for people with HIV. Ultimately, even a functional cure (one that allows a person’s body to control whatever HIV may remain in

their body without medication while rendering them non-infectious) is preferable to a life-time of swallowing pills that cause other health concerns and that put the person at risk for discrimination and harm due to the stigma around HIV. By rendering people with HIV less threatening, therapeutic vaccines and a cure could help reduce HIV-related stigma.

There is a period of time during which a person may be living with the virus and not test positive for its presence which means there will always be people who are unaware they have HIV potentially unwittingly passing the virus along. Preventive vaccines resolve this issue.

Cure science has had some major breakthroughs in the past 24-months and certain insights and proofs-of-concept (like the Berlin Patient, the first person cured of HIV) have clarified the 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. And, given that what is being discovered as scientists hunt for the AIDS cure is shedding light on how we may control other diseases like certain types of leukemia and cancers, accelerated investment in the end of AIDS may also advance solutions to other diseases. Ironically, a vaccine and the cure may one day conflate. The AIDS cure could involve (as part of a multi-pronged attack) a therapeutic vaccine. Therapeutic vaccines are those given to people who have diseases to help cure them. Preventive vaccines are given to help avoid people contracting disease.

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), a global ambassador for the Elizabeth Glaser Pediatric AIDS Foundation and serves on the CDC/HRSA advisory committee for HIV and Viral Hepatitis.



WINNING ON THE FRONTLINES 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 things that need to be conquered to end AIDS will make the world a healthier place for all. Here, a shortlist 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. Many people living with HIV are co-infected with hepatitis C. 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 hep C are expensive and not easily accessible to many in need, particularly in the developing world. Activists are lobbying for increased testing of hep C and for lower prices and greater access to the newest hep C treatment for all in need.

BETTER PREVENTION AND TREATMENT STRATEGIES FOR INJECTION DRUG USERS

It has been well documented that providing sterile injection equipment (including needles and syringes) to people who inject drugs can greatly reduce the spread of HIV and hepatitis C. Safer injecting sites 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 among those who inject drugs. 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

The potential for some pain medication to lead to addiction, a growing dependency on pain killers, cases of prescription pain relief being taken from medicine cabinets and sold on the street or abused by teenagers for recreational purposes as well as and legal cases in which physicians have been convicted for “over prescribing pain medications” have led to diminished access to medicine legitimately require for the reduction of pain, particularly among disenfranchised patients. Activists in this arena are pushing for patients’ rights to connect with the medication they require for a comfortable and healthy life..

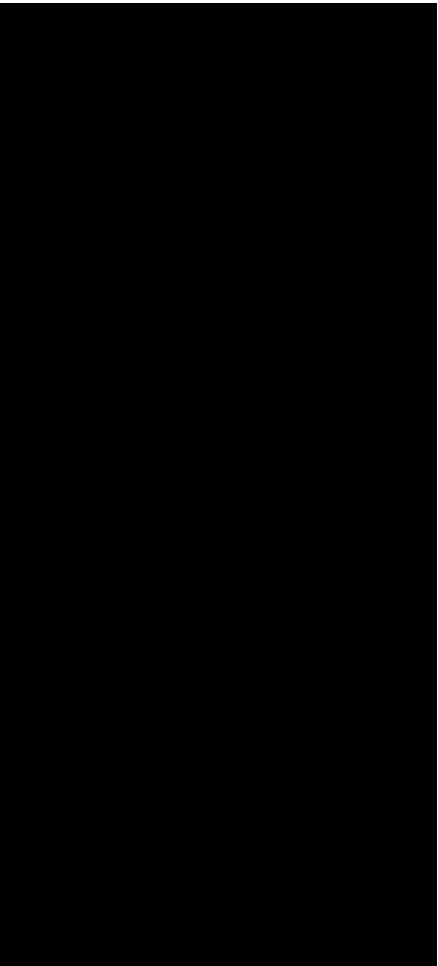
DECRIMINALIZATION OF SEX WORK

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 engaging in sex work from accessing educational and prevention services, screening for sexually transmitted infections and access to health care in general. Given that condoms (male and female) and lubricants can reduce risk of STIs, baring sex workers from these harm reduction tools heightens the risk that STIs will spread. And, as treatment can double as prevention when someone is living with HIV (since 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 and public health. 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 such as the U. S. 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 single health concern. Activists are working to encourage high levels of support for health care on the part of all nations. This year is particularly key as it is a “replenishment year” for the Global Fund; nations around the world will announce their commitments in the summer of 2013 and activists are pushing hard to maintain funding levels for global health in challenging economic times.

For a list of organizations supporting these and other issues, please see page 37 of this guide.





LESSONS

LEARNED FROM

FIGHTING AIDS

BY GREGG CONSALVES

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/or 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), 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, 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, healthcare 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 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. Here, he gives some advice to those inspired by *How to Survive a Plague*.*

ACTIVISM THEN & NOW

Legendary AIDS Activist Peter Staley Talks With Newly-Minted Fighter for Human 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 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 threatening those



PHOTO: © William Lucas Walker

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."

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 they 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 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...

Back then they thought you were going to be dead in two years so they paid you.

PS: 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



PS: It 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 [Streets] 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 camp 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 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 inspire those who are on your side.

"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."

No one has figured out how to use the Internet to replace the experience of a group of people coming together in 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 maternal 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

Org(s) with which you advocate: HIV Prevention Justice Alliance (HIV PJA; countdowntoaid2012.org) and U.S. Positive Women’s Network (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 Gangle

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

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 healthcare 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 people living with HIV (PLHIV). 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 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 US 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

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 healthcare they need. No one should be denied that healthcare 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 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

Org(s) with which you advocate: The SERO Project (seroproject.org)

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

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 candle light 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 (ARVs). 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 it 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 way 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 am afraid of doing my work. My work evolves 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. On the course of trying to save the lives of my fellow community members, I am ready to face any consequences, if any.

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

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 a 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, not 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 away affects our activism.

In addition, our culture and religious affiliations sometimes over step rights of some small groups. There's always a fear of being anti-cultured 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

BY TRICIA 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 such as Pussy Riot in Russia and the Occupy Movement in the United States, have adopted similar strategies, borrowing and reinterpreting images from earlier social movements to capture the public's imagination and to inspire their engagement.

The most effective activist art communicates well across barriers of language, culture and time. It connects with those advocating for progressive change as they challenge the status quo of their time. There is often a certain similarity in many images of protest; their individual artistic representation reflects and serves the needs of the movement—and the moment.

Each new movement looks

to the past for symbols and language that can be appropriated and endowed with new meaning to inspire contemporary audiences. While the iconography of activist art inevitably evolves over time, it often draws on historic imagery.

For example, the raised fist has been adopted and re-interpreted by revolutionaries the world over. From the raised right hand in a 19th century painting of the French revolution to the elevated, clenched fist of the black power movement; from the raised hands of ACT UP protestors to the purple fist in the Pussy Riot banner, a clenched fist thrust skyward is now a universally recognized expression of street protest.

The social movement created by ACT UP was fueled by passion, anger, tenacity and creativity. The art and graphic employed by ACT UP reflected those things.

ACT UP's posters were more than a simple call to show up; they were carefully crafted images that commented on the culture, articulated the issues and "asks" and shouted at the viewer. They were designed to communicate with equal power to the activists they were designed to motivate and in the media. When photographers and videographers captured

the real-life action of those in ACT UP, they also captured the art they used to support that activism. The resonance of the words and graphics employed by ACT UP remains relevant today. Watching *How To Survive A Plague* highlights that effective art can influence audiences across many decades.

ACT UP's placards bearing the slogan "Silence=Death" over a bold pink triangle, and other memorable graphics of the times, created by artists like Avram Finkelstein and Vincent Gagliostro, "visually articulate[d] the heart and soul of the movement." The unforgettable "Silence=Death" posters drew its power both from its graphic simplicity and from the historical reference embedded in it. The pink triangle referenced the patches sewn onto the uniforms of gay men in Nazi concentration camps. Gay artists of the late '70s and '80s reinterpreted the symbol of the pink triangle turning it from one representing exclusion and degradation, into a symbol of defiance. As AIDS affected the gay community in the '80s the triangle was twisted again, flipped upside down to represent both gay pride and—paired with the words Silence=Death—a call to speak out about AIDS.

Gagliostro, now a filmmaker living in Paris, wrote about the

source of the inspiration for the "Silence=Death" poster upon the release of *How To Survive a Plague* in September 2012:

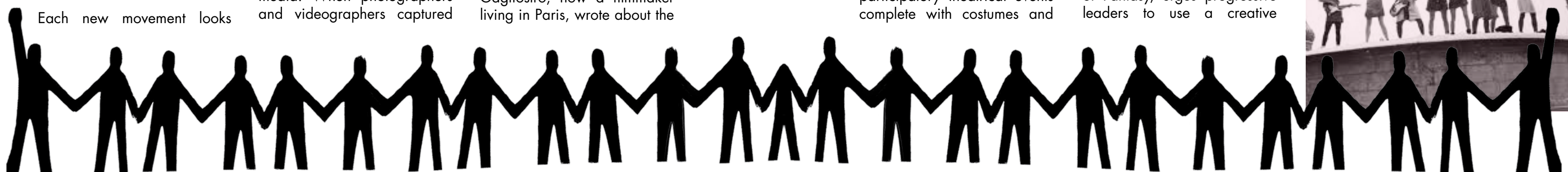
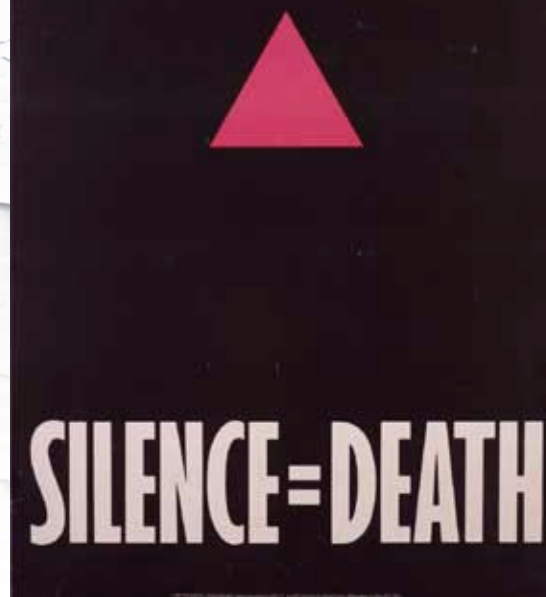
"When I would leave an ACT UP meeting charged with the task of creating graphics for the next planned demonstration, my first thought was how do I keep the crowd shouting and yelling. They were my inspiration. I had to inspire them. I always made my graphics first for them, for us. Yes, the graphics needed to articulate and disseminate our knowledge about a particular image 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."

Getting people to become, and show up as, activist then, as now, is hard. Art can inspire people in ways that lead to engagement and action. Beyond using powerful visual art, ACT UP employed street theater to entice people to action. ACT UP's protests were often staged as live, participatory theatrical events complete with costumes and

roles. ACT UP famously staged die-ins—occasions where people lay prone in the streets to highlight the dead and dying in order to keep others alive and well.

There's a direct line between the image of ACT UP's Peter Staley as he stands on the roof of the FDA to hang a "Silence=Death" banner while hundreds of protestors stand below watching and the image of the women of Pussy Riot performing on a roof, carrying a flag that combines the fist of protest with the symbol of femininity. Performance art often uses and incorporates the space in which it is performed. ACT UP conducted their protests at the FDA, the NIH, and even the White House in order to have those buildings and brands become part of the visual experience. They knew the press would cover the protests and since they unfolded at the target of that protest, the targets of their activism were highlighted in the media. Similarly, Pussy Riot chose a certain on which to stage their protest; doing so allowed the turrets of the Kremlin to appear in the background of live media coverage, video and photos.

Stephen Duncombe, founder of the Center for Artistic Activism at New York University, in his book, *Dream: Politics in the Age of Fantasy*, urges progressive leaders to use a creative



approach to protest that truly engages participants, directly reflects the cause, and creates a public spectacle. Duncombe notes the tactics of 'Reclaim the Streets' as they protested former New York Mayor Rudy Giulaiani's clean up campaign which privatized public space including community gardens by building new gardens in highly trafficked public spaces. Duncombe writes, "With the notable exception of ACT UP and its spin-offs, the dominant progressive protest model throughout the 1980s and 1990 was dull and deadly." Whether it is a pop-up public garden or a die-in, well-staged, collective, performance art has the power to command media attention—and in doing so, force the public to take notice.

While we need art, as Gagliostro stated, "to articulate the heart and soul of a movement," we also need story to make sense of it. The best documentaries focused on social justice frame the narrative of a movement by combining the power of journalism with the artistry of filmmaking and the power of art as activism.

"Journalism is the first rough draft of history," said Washington Post publisher Phil Graham. Journalist's reports and analysis of events as they unfold lays the groundwork for

the insight and perspective that comes with time. The nature of the documentary form requires more time than writing or publishing a photo. Not only does *How to Survive a Plague* chronicle how art was used to ignite an era of activists, it is, in and of itself, a piece of art that advances contemporary activism.

How to Survive a Plague film director David France covered HIV/AIDS in New York as a journalist, writing some of the first major stories published on the mysterious and devastating

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

— Vincent Gagliostro, artist and activist

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 uses historical references to inspire modern audiences to activism of all types.

Much of the footage France used to make the film was taken while France was writing about

AIDS for outlets like the New York Post. Newly affordable videotape allowed people involved in early AIDS activism to record public actions, protests, even weekly planning meetings, for posterity. But it took the art and craft of filmmaking to render nearly 700 hours of raw material into a compelling narrative that enabled the historical bits to be arranged in a context that gave it new meaning and relevance for a modern era.

Curators, critics and cultural leaders have designated *How to Survive a Plague* a 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."

ACT UP protested the Catholic Church's stance on HIV/AIDS by 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. A new documentary about the radical group, *Pussy Riot: A Punk Prayer*, premiered at the 2013 Sundance Film Festival, won a special jury prize, and will air on HBO. In the same way *How to Survive a Plague* uses a focus on AIDS activism to teach about all types of activism, Pussy Riot's message goes far beyond merely criticizing the oppression of Putin's regime to speak to the need for wide-spread freedom. The 21st century feminists support LGBT rights, gender equity and the right to free expression as much as they protest the oppression of the current Russian regime.

Another activist documentary, *The Square* (Al Midan), tells the story of Arab Spring from inside Egypt's Tahrir Square starting with the resignation of Mubarek. Created by those who are living the revolution, the film also premiered at Sundance 2013 and won the audience award. Notably, *The Square* uses street art, images and phrases painted as a motif throughout the film, providing a kind of visual poetry that

separates the phases of the revolution and the protests. In doing so, it both highlights the power of art as activism—and wields it itself.

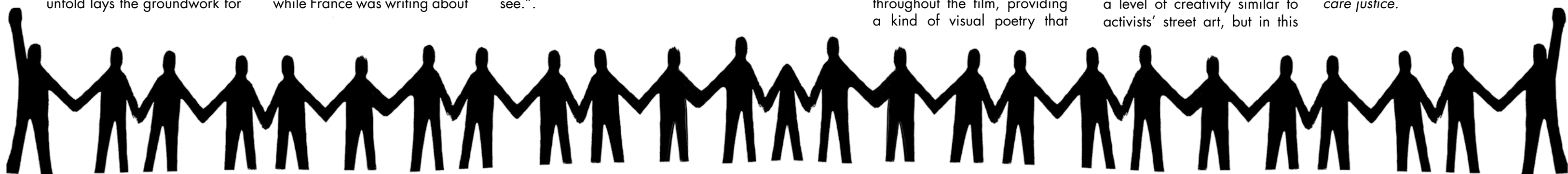
As the story of the ACT UP movement demonstrates, reaching and engaging the public are the first steps in reshaping cultural history. Early members of ACT UP organized people into a sustained movement that achieved substantial cultural, political and legal goals. Their approach is instructive to the potential social change leaders of today. Examining the dynamic relationship between activism and art through history informs our understanding of how we can bolster contemporary social movements.

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 of them also possess and harness a creative spirit that is expressed and manifest through the images, words, and events they use to capture public imagination.

The social issue documentary filmmaker, whether or not their film depicts activist art or uses the art as a visual element in the making of the film, employs a level of creativity similar to activists' street art, but in this

case, using moving imagery and a compelling 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. As *How to Survive a Plague* takes us through ten years of ACT UP's history, from tragic loss to bittersweet victory, we become deeply engaged. We cry at the passing of Bob Rafsky and we cheer for Peter Staley as he delivers his friend Victor Russo's compelling words at the 1990 AIDS Conference, calling for an end to the discrimination of people with HIV/AIDS. In the exposition of these personal narratives, the art of documentary film making inspires in a way that feels more intense than what we might experience seeing a placard or banner. Given that we now live in a time in which audiovisual media dominates our culture, the documentary film is perhaps one of the most powerful tools we can use today to inspire world-changing activism.

Patricia Finneran, a long-time supporter of creative documentary, has held senior positions at IFP, AFI and Sundance Institute. She led the campaign to ensure that How To Survive A Plague educates a new generation on the story of early HIV/AIDS activism, and energizes the fight for health care justice.



CAMPAIGN SO FAR - OUR IMPACT

The *How to Survive a Plague* Engagement Campaign has been working with dozens of organizations in the US 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 amount Student Global AIDS Campaign (SGAC) expanded chapters and reach by. Proceeds from sale of the soundtrack benefitted SGAC.

40 international AIDS service and social justice organizations receive the educational DVD package for free.

35 the amount of locations RESULTS held community screenings, engaging their constituents.

GHC (Global Health Corps) is using the film in orientation for public health workers

The US Department of State is using the film to engage international audiences on LGBT rights and the role of activism in a democracy

WORLD AIDS DAY 2012

75 Community Screenings in one week! Google Hangout featuring filmmakers, Twitter campaign to support funding for AIDS treatment access and research.

INFLUENCER SCREENINGS

AIDS2012, Ford Foundation, Bill & Melinda Gates Foundation, Open Society Foundations, U.S. Department of State

CAMPAIGN PARTNERS WHO HAVE HOSTED SCREENINGS AND EVENTS INCLUDE:

- ACT FIVE
- 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
- Faster Cures
- Gay Men's Health Crisis
- GLAAD
- 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 Medicine (UAEM)
- UN AIDS

AWARDS AND NOMINATIONS FOR *HOW TO SURVIVE A PLAGUE*



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

IN THE HALLS OF POWER

BY REGAN HOFMANN

Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Disease 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.

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 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?

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.

“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.”

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 is an internationally recognized expert on HIV/AIDS, a member of the board of amfAR and an ambassador for the Elizabeth Glaser Pediatric AIDS Foundation. Currently a consultant focused on global health, she was formerly the editor-in-chief of POZ Magazine.



INSIDE OUT ADVOCACY

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

One of the biggest challenges for anyone in any social movement is balancing the various aspects of an “inside-outside” strategy of advocacy.

In short hand, this means that you need people “outside” a system or organization or office of a person you are trying to influence to change or respond. 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 Black Panthers 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 used 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 support 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 are trained in negotiation, 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 to deliver the same asks 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/it often like(s) to meet with representatives from “inside” group—a group that may or may not include some of the people who participated in the “outside” group in order to clearly understand the issues and needs of the movement and to discuss ways of change or resolution. When the “inside” group includes some from the “outside” group, it show 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 groups 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.



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 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.

Brazilian Interdisciplinary AIDS Organization (ABIA)

Abiaaids.org/br (note: the website is in Portuguese)

This non-governmental organization was established in 1987 to fight the AIDS pandemic in Brazil by offering assistance and access to health care for people with HIV/AIDS. It also advocates for the protection of the human rights of those living with the virus. Their work evolved over the years to include public policy, education and prevention.

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 (CRIA) 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 live longer, healthier lives.

The AIDS Coalition to Unleash Power (ACT UP)

actupny.org | actupphilly.org | actupsf.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 (think real corpses placed on the steps of Congress, 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

"ACTV" 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. Stay tuned in 2013 for some groundbreaking global engagement strategies from this dynamic duo and their team.

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.

AIDS Law Project

aidslawpa.org

The 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 to sick to travel. The 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.

The Foundation for AIDS Research (amfAR)

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 new crop of leaders to help herald in the cure for AIDS.

Andrey Rylkov Foundation for Health and Social Justice

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.

AIDS Vaccine Advocacy Coalition (AVAC)

Avac.org

The 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.

The 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.

The Centre for Health, Human Rights and 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.

The Center for Artistic Activism at New York University

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.

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+ establish 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.

The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF)

[Egpaaf.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.

Faster Cures

[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.

Gay Men's Health Crisis (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.

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. The HIV Prevention Justice Alliance (HIV PJA), one of Health GAP's programs, 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 au courant. 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 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 AIDS Vaccine Alliance (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 that 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 Treatment Preparedness Coalition (ITPC)

[itpc.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.

Medicins Sans Frontiers (a.k.a. Doctors Without Borders)

[Msf.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.

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.

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, non-profits and a variety of local partners they maintain independence are work without political agenda or religious orientation. When disaster strikes around the world, Save the Children save 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 (as we go to

press, website coming soon)

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.

The 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.

The 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.

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. On 30 August 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 Coalition

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.

Women's Legal Centre

Wlce.org.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, particularly health care.

Universities Allied for Essential Medicine (UAEM)

Essentialmedicines.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, ensure that university medical research meets the needs of people worldwide and empower 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.

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 Student Global AIDS Campaign. 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 treatment adherence. 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 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 timeframe. 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, "take-home" learning 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, research 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 there unique challenges? The article "Learn, Fight, Love" lays out the theory of change.
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 getting arrested 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 AFFECTING 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. The website also has a full listing of U.S.-based screenings. 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@surviveaplague.com*

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 *How to Organize* 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, 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](#)

SIGN UP Connect Online.

Go to [surviveaplague.com/partners](#) to find links to the organizations highlighted on page 10.

CONNECT in Real Life.

Join a “Learn | Fight | Love” meet-up. Find out how at [surviveaplague.com/meet-up](#)

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.

The elections are November 6. It’s your right. Exercise it.



LEARN



FIGHT



LOVE

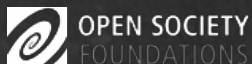
surviveaplague.com

The How to Survive a Plague team would like to thank



+impactpartners

SUNDANCE
INSTITUTE



Thanks to Tickets For Youth Supporters
Joy Tomchin | Donald Capoccia | Henry van Ameringen