The POZ Army: How We End AIDS Together

This summer, thanks to a rare confluence of events, the HIV/AIDS community will have an extraordinary opportunity to help save the lives of tens of millions of people living with the virus. In preparation, we want you to join the POZ Army. We are preparing for the final battle in the war on AIDS—the surge for the cure.

May 1, 2012 By Regan Hofmann

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This July, the steamy, magnolia-lined streets of our nation's capital will teem with 30,000 people who've traveled from the four corners of the globe to Washington, DC, for the XIX International AIDS Conference (AIDS 2012). The mission of AIDS 2012? To talk about how we turn the tide of AIDS together. In order to mark this pivotal moment in AIDS history, the NAMES Project Foundation, in partnership with POZ, will take the AIDS Memorial Quilt back to DC and display it in its entirety for the first time since 1996 on the National Mall and throughout the city. While the conference happens inside the convention center, an initiative called "Quilt in the Capital" will provide a people's stage—a Trafalgar Square of sorts—for those of us living with the virus and our supporters. From this stage, we will up the ante in the fight for our lives.

1996 was the year we stopped fighting for our lives. In that year, the first protease inhibitors began to bring people with AIDS back from the brink of death. Many people mistakenly thought AIDS was under control. It was not.

The reality is AIDS remains a raging pandemic. But, we have the power to end it if we do the right things at the right levels right now. It is time to reawaken the world to these facts.

There is no time to waste. The good news: We have antiretroviral treatment capable of both keeping people alive and slowing the spread of the disease (as treatment can reduce the risk of transmission by up to 96 percent). The challenge? Of the 34 million people estimated to be living with HIV, only 6 million are currently in care. On World AIDS Day 2011, President Barack Obama pledged to put 2 million more in care, bringing the global total to 8 million by 2013. But that still leaves 26 million lives—about 750,000 in the United States—hanging in the balance. And new

infections occur daily. AIDS can only be prevented in those who access treatment. For the rest? A diagnosis of HIV remains, ultimately, a death sentence.

Which is why the HIV/AIDS community must capitalize on this rare confluence of events to reignite the fight for the real end of AIDS—the cure. Treatment is necessary to keep people alive until we cure HIV. Treatment can slow the spread of the virus, and treatment may be a piece of the cure. But treatment is a means to an end; it should not be the endgame. Those of us living with HIV should not settle for a lifetime of pills with side effects. We should settle for nothing less than the cure.

“We have an unprecedented opportunity, based on solid scientific data, to control and ultimately end the AIDS pandemic,” said Anthony Fauci, MD, director of the National Institute of Allergy and Infectious Diseases at the National Institutes of Health, in Science magazine last July.

The world’s AIDS experts agree: We can begin to end AIDS. And it’s feasible we could see a cure in our lifetime. But to move up the pandemic’s expiration date, we need the collective chorus of people living with the virus and our supporters to help secure the political and financial capital to make what is possible become reality.

Given that the U.S. government is the leading funder in the global fight against HIV/AIDS, given President Obama’s pledge to scale up access to treatment and his claim that he wants an AIDS-free generation to be a legacy for his administration—and given the fact that the presidential race is in full swing—AIDS 2012 is sure to be a momentous conference. Since tens of millions of lives depend on America’s willingness to remain committed to the fight against AIDS, the eyes of the world will surely be watching what happens in DC this summer.

We must take advantage of this perfect storm of opportunity. To do so, we must mobilize our community to change history for all people living with HIV.

This is where you come in.

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Social change happens when many advocates cry out together, loudly, in unison. It’s the only way to break through the din. To help our community amplify its collective voice, POZ is launching the POZ Army.

It already exists, in a way.

The audience of POZ magazine, POZ.com and our social media network is more than 1 million strong. That’s the largest number of people living with and supportive of people with HIV/AIDS gathered in one place. No other AIDS-focused media or advocacy group has our reach and power to talk to so many people at once and to alert them to the actions that need to happen in real time—often with little notice.

The POZ Army will train all of you who wish to become recruits to be part of an expert, nimble, relentless, first-responder unit poised to lend our unified voices to put pressure behind different AIDS-related issues at key moments.

The idea of the POZ Army is not to start another advocacy group or to set the specific advocacy agenda for the HIV community but rather to galvanize the voices of people with HIV in the United States and around the world. The POZ Army will support the work that's already being done. It will serve as a soapbox and megaphone for the messages of the many advocacy groups and individuals working at grassroots levels to secure the variety of things people with HIV need to survive.

It is an army of the people, for the people, run by the people. It has the power to generate and focus the critical mass response necessary to effect real social change.

Advocacy means fighting for something. Arguing in favor of a cause, a position, an ideology, a law or a policy. It is often driven by necessity and the pursuit of human rights. Advocacy that changes the world is frequently tied to people's survival, freedom and dignity.

Few advocate better for a cause than those whose lives are most directly impacted by it. When it is a question of living or dying, it takes the game to a whole new level.

Advocacy is about starting, or participating in, a dialogue around an issue and taking action that can result in measurable differences. It allows you to feel empowered, make a mark and influence your destiny and that of others.

Advocacy can take many forms and can be practiced on many levels. It can be as simple as raising an issue or promoting your viewpoint at dinner with a friend. It can be done anonymously or lead you to be the face of a cause or issue. It can be done with your voice, a pen, a computer, your cell phone, your vote, a pin, a bumper sticker, a T-shirt or your money. Advocacy can happen when you meet with, email, Tweet, write or call politicians and try to persuade them to support your cause or issue. It can inspire you to join a group, attend a rally or financially support an advocacy organization or lobbying effort. It can happen when you encourage the media to cover an issue or when you write an op-ed or letter to the editor yourself—even when you write a blog or update your Facebook status. Advocacy can range in tone from peaceful to riotous.

Noted anthropologist Margaret Mead once said, "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has."

Advocacy really works. Consider what happened earlier this year when the Susan G. Komen Foundation decided to stop funding Planned Parenthood clinics. A critical mass of women and their supporters created an immediate, national, highly visible backlash against the breast cancer organization. Within days, the Komen Foundation changed its mind and announced that funding would continue.

A similar thing happened with the national response to the Stop Online Piracy Act (SOPA) and PROTECT IP Act (PIPA). The bills were considered an affront to the First Amendment and were viewed as Internet censorship. Websites opposing the bill went dark on January 18, 2012, to raise awareness, and as a result millions of people raised their voice by signing online petitions. Both bills were postponed in Congress because of the mass online protests.

These are the kinds of responses we need to generate from the HIV/AIDS community, and the POZ Army is capable of providing them. If even 500 people call the office of a member of Congress on a single day, that's enough response to motivate the chief of staff or legislative director to tell the Congress person there's an issue he or she needs to pay attention to.

The war on AIDS needs an army of fighters at the ready and a system capable of alerting them to crisis and directing their attention and responses. At different moments the POZ Army may support the harm reduction community to fight for the legalization of syringe exchange. Sometimes we may join forces with those seeking housing for people with HIV. We may lend our voices to protest AIDS-phobic actions or the criminialization of people with HIV. Like the National Guard, we'll go wherever we're needed, whenever duty calls.

When we come together to learn from and teach one another, and respond en masse, we have power. Unless we can show that our community-at-large is up in arms about an issue, politicians and appropriators (the people who set federal and state government budgets) may feel less motivated to help.

Many of you regularly express a desire to get more engaged. We're hoping your desire to advocate inspires you to join us. We're hoping all members of all the different HIV/AIDS advocacy groups will unite in the fight in the POZ Army. In turn, the POZ Army will serve as a much bigger stick that each advocacy organization can use when championing for a particular issue or target.

A few voices can be ignored. Tens of thousands are much harder to drown out.

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So what is our ultimate goal? We are fighting for a cure for AIDS. And we are fighting to put as many people as we can on treatment (who require it) to keep them healthy and alive until we are able to find the cure.

Thanks to the bravery and fierce fighting of past advocates, today there are more than 33 antiretroviral drugs that fight HIV infection and also slow the spread of the virus by reducing the risk of HIV transmission from people living with HIV to people who don't have HIV. Therefore, theoretically, if we could test all people who have HIV so they knew their status and if we could connect them to care, we could spare many lives and seriously impede the spread of the plague. But less than 28 percent of all Americans and a mere 18 percent of people globally with HIV are taking these pills.

The problem is the cost to support a strategy to end AIDS based on testing and treating all people with the virus is enormous. The people with HIV around the world don't have the money to pay for the pills themselves, and too few nations provide health care and antiretroviral drugs to their citizens with HIV. Bilateral (from one country to another) programs like the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and multilateral (multicountry) programs like the Global Fund to Fight AIDS, Tuberculosis and Malaria pay for most of the access to HIV meds around the world. Other governments, foundations, corporations, pharmaceutical companies and individual philanthropists help too. But we're still nowhere near being able to pick up the whole tab.

So you see the problem. Even though treatment exists and it can slow viral spread, avert death and prevent children from being orphaned, too few people have access to it to make testing and treating people the correct strategy for ending AIDS. It is a containment strategy, and we must continue to fight for access to care for as many as possible.

But if the previous generation of AIDS activists fought to secure treatment, our generation must fight for the cure.

Because to truly end AIDS, we must cure it.

Can we cure AIDS? We already have in one person.

2011 saw the confirmation of the first man cured of AIDS. The manner in which he was cured is not easy to duplicate, but what scientists learned from his case has resulted in quantum leaps forward in AIDS cure research. Many experts believe a cure is possible in the not so distant future if we significantly increase funding and configure cure research in fresh ways to get the answers we need as fast and as safely as possible. Though it is difficult to project the actual price tag of the AIDS cure, consider this: The United States spends $19 billion dollars annually on preventing and treating HIV/AIDS. It spends about $71 million dollars at the National Institutes of Health hunting for a cure.

To be successful in this new era of AIDS activism, we must take the best of what was learned by those who fought before us and apply it to today's battle. A distinguishing characteristic of the early AIDS activists who secured life-sustaining treatment was their encyclopedic knowledge of AIDS science and the governmental and health care systems they pressured for change. We must know as much as those we ask for help, and help them figure out ways to help us. The AIDS activists who came before us secured our place at the table. Now we must show up and present a compelling current argument for why we need a cure and how we might most quickly discover one. Showing up, as they say, is half the battle. It has been far too quiet on the Western front for too long. It's time to make some serious noise, and the POZ Army's going to help you hone your war cry.

Had those who came before us refused to speak up, a lot fewer of us would be here today.

To paraphrase the motto of the legendary AIDS activist group ACT UP (it stands for AIDS Coalition

to Unleash Power): Silence still equals death. We cannot allow ourselves to remain tight-lipped and complacent any longer. Because too many of our lips are sealed, we are losing the ground our louder predecessors gained on our behalf. And we are personally feeling the pain of that lost ground.

We are harassed at our jobs.
We are kicked out of swimming pools.
We are told we can't hold our grandchildren.
We can't get life insurance.
We are sent to prison for having HIV.
We are discriminated against, stigmatized, beaten and sometimes killed merely for having a biological agent in our bodies.
The end of AIDS and all its related horrors must stop with us. While it's understandable that many of us are afraid of speaking up against such wrongs, we must find the courage to do so. Because by remaining tongue-tied, we leave ourselves at greater risk.

So how do we overcome our fear? We need to get mad as hell.

Larry Kramer has said, "What makes activism work is anger and fear. I do not think it can work without that."

We—the people living with HIV—must tap into our fear and anger. We must make it politically uncomfortable for the people in power to ignore us. We must let those people know that if they make decisions that will hurt and kill people with HIV then they will weather some serious blowback—beginning with losing our vote. And we must educate the general public and the media about HIV/AIDS.

In a democracy, the people we elect and send to Washington, including our president, are supposed to work for us, not the other way around. But in realpolitik, who succeeds in getting laws passed and budgets allocated to advance their cause? The oil and financial industries, the energy and pharmaceutical companies, the wealthiest individuals who are the biggest donors to our most senior elected officials.

But governments are also susceptible to address large, public outcries. Especially when they happen in the media spotlight.

We must let the world again see the outrage that churns inside us, the kind of outrage that was so effective at the beginning of the epidemic. We must channel it this summer and realize and capitalize on our collective power to fight for our lives.

The end of AIDS is, simply, up to us.

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You can enlist and begin training at pozarmy.com.

Think of the POZ Army site as command central for all the work being done to protect and improve the lives of people with HIV—here and around the globe. It's really easy to join up. Just go to pozarmy.com and click any or all of the three buttons under "Recruitment Station." One puts you on our email newsletter list, one helps you "friend" us on Facebook, and one helps you follow us on Twitter.

We will use those three main channels to alert members of the POZ Army when it's time to suit up. We'll tell you exactly what to do and make it easy and as automated as possible to launch an attack.

The POZ Army site gives you tips, tools, videos and information to help you become an expert soldier. It provides advice on how to call the office of a Congressperson and how to use social media like a pro. It spells out what to say if a reporter sticks a microphone in your face and explains how to get yourself featured in the media. It will be a central spot to find all relevant petitions and calls to arms. And a place to connect to others and share your stories from the front lines. In short, it's the place to learn new skills and re-up supplies as needed.

Social media and new technology have entirely changed the way we advocate today. Together, they allow us to convene, communicate and raise a royal ruckus without even leaving our houses.

Occupy Wall Street (OWS) and the collective demonstrations in the Middle East known as the Arab Spring would not have been possible before social media and today's cellular technology. Those in power now know to watch groundswells of online activity.

Once, AIDS activists stood outside the walls of the Centers for Disease Control and Prevention, the Food and Drug Administration, the National Institutes of Health and the White House. They blew whistles and carried signs of protest. Over time, people with HIV got inside those organizations and offices. But not enough people living with HIV have direct connection to those in power.

Thanks to technology, we can change that. We no longer have to travel or secure a meeting to ask for our leadership's help or to tell them what we need and demand. We can broadcast our asks and invite ourselves to the proverbial tables and discussions using the new digital and cellular technology. Using the POZ Army as base camp, we can fan out through the likes of Facebook and Twitter and make our points heard loud and clear online.

When ACT UP was formed 25 years ago, the Internet was in its nascent stage. And ACT UP's protests were held primarily in large cities like New York, San Francisco, Los Angeles and Washington, DC. Today, technology allows the voices of those around the globe to be virtually linked in protest. Thanks to a simple weapon of war—our cell phones—we can do what our predecessors couldn't have dreamed of. ACT UP was several hundred strong at its peak. If a few hundred people could save nearly 6 million lives (the number of people who are currently on treatment), think about how many lives the million-strong POZ Army can save.

Not everyone has to put his or her boots directly on the battlefield. You can remain anonymous and still get involved. The POZ Army will include people living and not living with HIV, so being a part of it does not mean you necessarily need to disclose your status.

Those of us who can, will fight for those of us who can't.

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So where will we wage our first campaign? This summer in Washington, DC, using the platform of the AIDS Memorial Quilt. The Quilt is deemed a National Treasure by an act of Congress, and it is the world's most powerful symbol of the epic loss caused by HIV. The more than 47,000 panels stitched together lovingly in remembrance of 94,000 people who died of AIDS remind us of two things: the enormity of the AIDS pandemic—and the fact that it is anything but over. The Quilt carries the energy of the 25 million men, women and children taken from this world because HIV entered their bodies. And it is one of the most profound reminders of what happens if we don't respond as we should—and can—to this disease. New panels are being sewn every day. The Quilt is a connector, a catalyst, an ambassador and an educator. It is the perfect launchpad for a new era of support and advocacy for the global fight against HIV/AIDS.

The power of the Quilt is not limited to its ability to recall the past. Equally essential is the way it helps start a conversation in the here and now about HIV. It is integral to our advocacy; it affirms our humanity and makes clear our connections to and responsibilities for one another. The Quilt builds a bridge between those living with and affected by the virus and those living in the world who need to be re-awakened to the scale and tragedy of the ongoing AIDS plague.

There's no better time to unfurl the power of the 54-ton Quilt than during AIDS 2012. And there's no better place to do it than in the backyard of our president and the U.S. Congress—the people who determine the policies and budgets that impact the lives of people living with HIV/AIDS in America and abroad. This summer's Quilt in the Capital initiative provides the ultimate platform for us to reshape the dialogue and clarify that the best way to end AIDS is to cure it.

If enough of you join the POZ Army today and join us in person and/or online for Quilt in the Capital this summer, we can make a real difference. Think of how our lives could change if we cured AIDS. We would no longer face complications from HIV infection and its treatment. We would no longer face HIV-related stigmatization, discrimination and unjust criminalization. Fewer children would be orphaned. AIDS would not ravage nations to the point of implosion and conflict that require outside intervention. As a result, the world would be a safer place. And when we cure it, fewer U.S. taxpayer dollars will go to fighting AIDS, and the world can move on to solving the next medical mystery and saving other people's lives.

We are so close to getting the upper hand on AIDS. If we utilize this moment as we are being called to do, we will one day be able to bring our troops home safely.

So consider this your formal invitation to enlist in the POZ Army. Whether you want to help from

the safety and privacy of your hometown or you want to become a voice, face and leader on the national stage, POZ, with the network of existing local and global advocacy groups, can help train you to be a part of the force needed to stop the pandemic. There is a role for everyone in the POZ Army no matter your comfort level, skill set or desire to engage.

So lace up your boots, put on your real or proverbial (Day-Glo!) camouflage and join us—literally or virtually—as we head out on the road to Washington.

Welcome to the dawn of a new era of AIDS activism.

Welcome to the POZ Army. Together, we will stay true to the end.

How to Enlist

Every successful soldier carries and uses the same basic equipment: the right boots, a helmet, water and a weapon. Members of the POZ Army will also use a few basics: a cell phone, Internet access and social media.

Go to pozarmy.com to get started:

1. Sign up for our POZ Army e-newsletter.
2. Become a fan on Facebook and watch our wall for action alerts from the POZ Army.
3. Follow us on Twitter, and watch our Twitter feed for action alerts from the POZ Army.

Also watch for news of the POZ Army in POZ magazine and on our other social media sites such as Google+, Tumblr and Pinterest.

For more than 18 years, POZ has protected the identity and HIV status of its audience. We will continue to protect your privacy. We will not disclose, give, sell, lease or transfer personally identifiable information to third parties without your consent, so your privacy is guaranteed. To learn more about the POZ Privacy Policy, click here.

Illustrations by Avram Finkelstein

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