TAG Team

With stunning regularity, news media pronounce AIDS activism dead—or at best on life support. Yet the Treatment Action Group (TAG) is still ticking after 18 years. While the organization's strength lies in its ability to evolve to better address the changing epidemic, the real secret ingredient might be found in after-work margaritas.

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Mark Harrington, founding member and executive director of Treatment Action Group (TAG), a giant in the world of HIV/AIDS treatment and advocacy, can boast about many accomplishments: his paradigm-shifting work on the Treatment and Data committee of the AIDS Coalition to Unleash Power (ACT UP), 18 years of continued achievements at TAG, countless scientific articles and speaking engagements, membership on various U.N. advisory committees, even a MacArthur "Genius" grant in 1997.

But perhaps his most recognizable imprint on AIDS activism is a piece of clothing. His design graced the iconic "Read My Lips" T-shirt produced by the art collective Gran Fury. The shirt, showing images of same-sex couples kissing, was worn by scores of AIDS protesters in the late '80s to counter government silence and media lies about HIV transmission. "That," Harrington says, "was a good shirt. That's the one shirt I have from that time that I can [still] send to the laundry—it won't fall apart."

Harrington's life on the barricades began as it did for many in the late '80s. Feeling angry and powerless in the face of the epidemic, he decided to skip his drawing group one week and instead followed ACT UP's brash placards to the LGBT Community Center in Manhattan's Greenwich Village. "I remember my first meeting in 1988. Eric Sawyer [now at UNAIDS] was moderating, wearing a sarong. "There was just this energy in the air," Harrington recalls. Soon his days were a blizzard of radical activities, but he makes it sound more like summer camp than boot camp. "We drank a lot more margaritas [at Benny's Burritos on Greenwich Avenue in the West Village] than I could get away with now. It was all AIDS politics and gossip all the time. Everything we did was politics. And it was fun."

Twenty-two years later, Harrington is still at it. He's that rare firebrand, like Charles King of Housing Works, who hasn't burned out. "What happened to the ACT UP generation was that we split off and specialized," he says. He and several other ACT UPers, including Gregg Gonsalves, Garance Franke-Ruta and Peter Staley, formed TAG in 1992 to focus on the work they were doing on the Treatment and Data committee, away from the main group's increasingly fractious politics. There was also attrition. "Many activists died. But many went back to their normal lives, thanks to

the advent of HAART—which was the whole point, wasn't it?" He's referring to highly active antiretroviral therapy, which we now call ARV, or simply HIV meds. They became available by the mid-'90s. Arguably it was TAG's work prodding the National Institutes of Health and the Food and Drug Administration into action that gave us HAART in the first place. TAG's work also gave life to a type of activism that has shifted with the epidemic, noticing not only who is dying now and where, but also why. What hasn't changed is the essential TAG approach: Building a collective of activists. What has changed is that TAG has gone global—and digital.

Harrington was struck by something Franke-Ruta (now a reporter at The Washington Post) said at a panel discussion last December, during a Harvard exhibit on ACT UP artwork. Franke-Ruta called ACT UP "the last great American social change movement before the Internet era."

That may very well be true, but in the intervening years, TAG has led the way in transferring the grassroots ACT UP model to the Internet. Before today's digital age, Harrington says, "we had to create events—the media wasn't coming to us." Communications were found on wall posters rather than computer screens. "Now, we see what's on the listserv, we decide what to do." Harrington's diplomatic style—less the in-your-face anger of "Read My Lips" than a more placid, methodical intensity—may uniquely suit him for today's activism. Drawing on networks such as the International Treatment Preparedness Coalition, the AIDS Treatment Activists Coalition, and the Global Network of People Living with HIV, TAG can now take its research and advocacy mission worldwide. "After 2000, [many of] the people that still [worked in HIV/AIDS] moved to the international level," Harrington says. Like the other standard bearers, TAG has gone global. "You have to do [the work] in coalitions," Harrington says. "Ten people [from the TAG staff] are not enough." So TAG locates people who know a region, then works with them to light a local fire, in old-fashioned ACT UP style.

"We're in the confusing dark middle of the epidemic," he says. Harrington often sounds like a general waging a very long war, and it is clear from the scope and breadth of TAG's work that his army is tenaciously fighting battles on many fronts. Lifesaving treatments exist, but many people cannot get them. Science is the chief weapon in their arsenal. Whereas Health GAP/Global Access Project, the other leading U.S.–based international advocacy group, primarily agitates to dismantle bureaucratic barriers to health care, TAG remains dedicated to the principle that animated the Treatment and Data committee 20 years ago: Knowledge—about disease processes, state-of-the-art treatments and the latest drug trials—is power. And no one needs that power more than people living with HIV, TB and hepatitis.

There's more to TAG's success than data. Indeed, people on the ground describe TAG's work as fueled by science but characterized by distinctly human interaction. Albert Makone, of Zimbabwe's Community Working Group on Health, says, "TAG understands what people in [Southern Africa] go through, and they are able to help us in our domestic and regional fights for health and human rights."

Javid Syed, a TAG project director, makes the group sound more like a helpful neighbor: "I think the credit goes to the activists. Our goal at TAG is to share information and skills with fellow

activists and to support them in devising an advocacy agenda appropriate for their context," he says. "We bring the science, research and policy/advocacy understanding, but the activists devise the plans based on their capacity and opportunities. They know how to work their local resources to get what they want for themselves and their communities."

Around the world, Harrington, Sawyer and other long-term advocates have watched the ranks of those activist troops rise and fall from location to location. "In Brazil, the numbers and intensity of activism immediately declined when they got universal access [to ARV meds]," Harrington says. "But a lot of other countries are still seeing their first generation of activists." Stamina at a hub like TAG is crucial, and Harrington's best skill may turn out to be his ability to attract those activist fighter-geeks—just as tireless as he—to join TAG in its work, wherever it goes.

Today, TAG continues to expand, but not just to new geographic locations. It's also tackling infectious diseases that are killing people living with HIV. Reminiscent of the early days of AIDS in the United States, TAG unites with local activists to prompt governments to deal—because people are dying. "Everything we do is working with activists to keep people with HIV living longer," Harrington says. "Tuberculosis is curable, yet it kills half a million people with HIV every year. We focus on hepatitis and TB because they are the leading killers [of people living with HIV/AIDS]." Recalling a terrible outbreak of M/XDR TB in Kwazulu-Natal in 2006 and '07, Harrington gets indignant. "People are going on ARVs and then dying of TB! Fifty people died before they could even be diagnosed—and they all [had undetectable HIV viral loads]! So it's a worldwide issue for all people with HIV."

TAG has jumped in, trying to mobilize local activists to improve TB treatment. Claire Wingfield, a passionate AIDS activist since she founded an HIV awareness group in high school, coordinates TAG's TB/HIV project. She says governments are reluctant to face the problem posed by TB in particular: "[TB] drug resistance is the result of poor TB control. By admitting that drug-resistant TB is an issue, you are admitting that your TB control efforts have not been adequate."

Meanwhile, the Bill & Melinda Gates Foundation recently overtook the U.S. government as the leading funder of work on tuberculosis. The Gates Foundation awarded TAG a $4.7 million grant, which is overseen by Wingfield and Syed, who came to New York from Mumbai in 1989 to study at Columbia University and immediately threw himself into the cause.

In places like Africa and Asia, which have 80 percent of global TB cases, "TAG coordinates coalitions of HIV activists," Harrington says, "helping them add TB to their toolkit, then setting them loose on global agencies and NGOs [nongovernmental organizations]." What's in a TAG "toolkit"? Science, of course. As ACT UP proved in the United States, activists armed with data are almost unstoppable. Wingfield qualifies: "I am not sure that we 'set them loose'—even before these activists were involved with us they were engaged in advocacy. Our task has really been to bring increased awareness of TB/HIV science, treatment, policy and advocacy. They devise their advocacy plans in communication with us and other activists. Since some of them are the lone or one of a few voices advocating for quality TB/HIV collaborative services [in their region], it can be isolating. It's important that they feel that they are part of a movement and a network of

activists."

On the research front, TAG continues to do its signature work of fast-tracking development of better TB drugs and diagnostics. Harrington is optimistic about two new drugs coming before the FDA that seem effective against normal and drug-resistant TB. "We could be at a 'protease' moment [for TB]," he says, recalling the birth of the first truly successful HIV drug cocktails in the mid-'90s. "Treatment for drug-resistant TB would be shortened to six months from two years." But even the advent of better drugs will be useless unless serious work is done on the ground to motivate government leadership first. "Half the people in Africa have no access to a functioning TB program," Harrington says. "It's no time to turn back."

Hepatitis B and C are also killing people before they succumb to AIDS. "Both strains are common coinfections with HIV all over the world," Harrington says, "but hepatitis is rarely diagnosed or treated—even though many HIV drugs actually treat it as well. It's crazy," he says, "the WHO [World Health Organization] has HIV and TB responses, but there is no global strategy to fight hepatitis!" He gets intensely fired up when discussing this disparity.

To Harrington, there is no excuse for the current lack of attention to hepatitis. "That needs to change," he says. "There is a vaccine for B, and it needs to roll out globally." And while [incidence of hepatitis] B, at least in the United States, is declining as more and more children get vaccinated, the situation with hep C remains bleak. It is deadly, and there is no vaccine. While there is a treatment that cures many people—after months of interferon and ribavirin, 23 percent of HIV-positive people do clear the virus—the unlucky 77 percent "just have to hope something better comes along soon."

Doing TAG's heavy lifting for fast-tracking hepatitis drug development are Tracy Swan, C specialist and TAG HIV/hepatitis project director, and Lei Chou, HIV/hepatitis project coordinator. Swan plunged into HIV issues in 1990 and began focusing on hepatitis C in 1998. "A couple years ago, a friend of mine asked, 'Did you think you were going to be doing [AIDS work] for 15 years?' And I said, 'No, of course not. So many smart people are really working on HIV—they'll figure out a way to cure it, and we can all go home and do something else.'" Like Harrington, Syed and Wingfield, Swan is a treatment-data dervish. "I would not be comfortable being in this world and enjoying all the wonderful things about it if I were not doing something to make it a better place," she says. "And this is the thing I picked. I'm definitely not a martyr, but I love my work and I'm very passionate about it. There are a million other things I'd love to be passionate about. Hopefully I'll have a chance in this life to do those, too. Cat breeding? Wine sales?"

Swan's background is in direct services—HIV clinics, syringe exchange programs, homeless shelters—so she comes to TAG with a slightly different skill set from the usual treatment guru. "I saw people coming in every day with the same problem. I thought, 'This is terrible, they really shouldn't have to be going through this.' And I'd rather try to do a big fix than try to do dozens and dozens of small fixes for something that's just not working. That sounds really grand, and I don't mean it to sound that way. But [TAG] is an opportunity to work on the big fix."

She sees kindred spirits in her coworkers. “My colleagues would not be thrilled at my saying this, but you have to be sort of a nerd to want to do this work.” Swan fits the bill, certainly, with an added touch of goth glamour. She never dreamt she’d be a science and policy geek, but “science can be a unique tool to advocate for social justice, and my primary interest is social justice,” she says. “I was not a very good science student. In fact, I barely scraped through. But activism is a great motivator.”

Swan describes how the TAG model of peer-to-peer science sharing can yield results. “Our work is organic,” she says. “We kind of get the ideas and make them happen. I was working with colleagues in Thailand, TTAG [Thai Aids TAG]. We’d been talking for a while about the problem of viral hepatitis, both B and C, and the need to get tenofovir as a first-line antiviral for both coinfected and people with HIV alone.” Swan and Chou, who were there helping assess the needs of different groups of drug users, “rolled out the curriculum—‘trainer training,’” Swan says. “By the last day people were sort of like, ‘Hey, we don’t need you guys anymore. This is our material, and we know what we want to do with it and how it will work for people in our communities.’ Which thrilled me, because the ultimate success is not being needed [any] more.”

Swan and her colleagues, alas, will likely continue to be very much needed for many years. But focusing on hepatitis and TB may be easier for now than focusing on a cure for HIV. Apart from incremental improvements in ARVs, advances in HIV treatment are an endless source of frustration. (Don’t start Harrington on the V word: “Developing a vaccine has been a nightmare,” he says.)

But one new idea positively lights him up: treatment as prevention (TAP), whereby the suppression of viral loads in infected populations effectively halts the virus’s spread. Researchers in Vancouver are studying the effect of greater access to testing and treatment among high-risk populations. “The authors of the study don’t believe they even need universal access,” Harrington says, “their goal is 50 percent.” He points out that another study, this one in the Bronx, New York, and Washington, DC, among African-American men who have sex with men, is offering universal testing and specific targeted care, hoping to gauge under those circumstances how many men go on treatment, stay on treatment and stay undetectable. TAP, Harrington says, “brings everything together—we can integrate treatment, prevention and testing. We need to show we can turn the epidemic around, and this may be the best way.”

A tantalizing idea, but one surrounded by questions (and controversy). For example, does TAP address universal access? Harrington mulls this over. “In a utopian world, where you could test everyone…,” he begins. “Let’s say all 33 million people were treated as soon as they’re tested. Treat all of them for life—that’s 30 years of treatment on average, so”—the MacArthur winner is suddenly very much in evidence; you can almost hear his brain whirring—“that’s 990 million patient years of HAART, at $300 a year for the newer first-line meds we’re moving toward, and $1,000 a year for second-line drugs.” It would cost less than a trillion dollars, he calculates. And if you think that number is astronomical, he’s quick to point out that the U.S. government found billions to bail out AIG.

Ultimately, Harrington says, it's not a question of whether we have the money, it's a question of whether we have the political will to fight HIV/AIDS. "The U.S. President's Emergency Plan for AIDS Relief—PEPFAR—and the Global Fund were created under the regime of Chirac, Blair, Bush [former leaders of France, England and the United States]," he says, adding that today's leaders—Sarkozy, Brown and Obama—pass over AIDS, focusing instead on global health provision systems. "Ten million people, or 40 percent of the people who need HAART under the old treatment guidelines, which recommended starting meds under 200 [CD4s], can now get it. But under the new guidelines—I think it's 350—that number rises to 15 to 20 million people," or up to twice as many people to cover. And just as political momentum has waned we've been hit with a global recession. "For every two people who get treatment, another five become infected," Harrington says. "The virus is not getting tired."

So how is it that the TAG team never seems to get tired? "Until we can tip the epidemic into reverse, I still consider this work critical," Harrington says. "There are a lot of different ways to be an activist. An activist is any person who believes in the power of an individual to have an impact. You have to be an optimist to be an activist."

The European AIDS Treatment Group's Wim Vandevelde, chair of the European Community Advisory Board in Brussels, has frequently partnered with TAG on TB issues. "TAG people are among the best activist friends and allies I have come to know. I meet frequently with them on various continents," Vandevelde says. "Skype and conference calls are useful. But they will never replace the after-hours bonding over caipirinhas or margaritas." Ah, the secret ingredient. And TAG still serves it up.

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