

# tagupdate

TAG'S PROGRESS ON THE FIGHT TO END HIV/AIDS, VIRAL HEPATITIS, AND TUBERCULOSIS

Dear Friends of TAG,

Over the past year, Treatment Action Group (TAG) has catalyzed a new dialogue in the United States—building on the rollout of the Affordable Care Act (ACA) and recent medical research advances—to instigate bolder leadership from the U.S. government in the domestic and global struggle against AIDS.

Just one year ago, the Obama administration released its plan for a global “AIDS-Free Generation.” TAG started working to assemble scientists, activists, and policy makers to design a domestic initiative to revitalize the National HIV/AIDS Strategy, develop priority research questions for how to ensure that the maximum number of people with HIV enter high-quality care and achieve treatment success, preserving their own health and life and preventing onward transmission.

TAG's work has led to a national discussion, and work at many state and local levels, to assemble the tools we now have to develop a Plan to End AIDS in the United States, while pursuing the further research needed to develop better treatments, a cure, and a vaccine.

Thirty years ago, no one would ever have believed we would be able to concretely discuss how to end AIDS. It has been a long journey to get to this point, where millions of people worldwide are on lifesaving therapy. We know that HIV treatment as prevention works and that preexposure prophylaxis can prevent infections in high-risk individuals. So while the future looks more promising, there is still a tremendous amount of work to do before we can truly get to “The End of AIDS.”

Over 9.7 million people in low- and middle-income countries are receiving antiretroviral treatment, but that is only 34 percent of the people eligible for treatment under the 2013 World Health Organization guidelines. Here at home, we are seeing an explosion in new infections among young men who have sex with men. The annual number of new infections in the U.S., instead of declining, has stubbornly remained at roughly 50,000 for the past two decades.

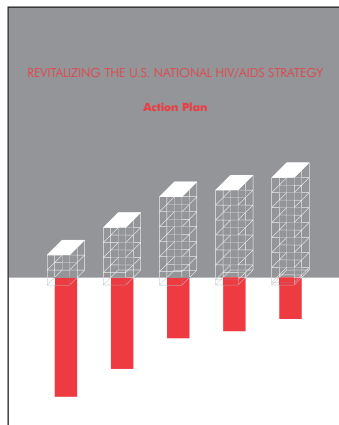
In this edition of *TAG Update*, you'll read about the work and activism carried out by TAG staff to change the trajectory of the HIV epidemic and its most deadly coinfections, hepatitis C and tuberculosis. TAG staff and its allies will not rest until there are better treatments, a vaccine, and a cure for HIV, hepatitis C, and tuberculosis.

I'm very proud to have been the president of TAG's board of directors for the past 16 years. To see all that TAG has accomplished, through your support, is remarkable. We could not have made the progress we have without you. We ask you to continue your personal and financial support as we move beyond 2013 and closer to the end of AIDS.



TAG's Executive Director Mark Harrington was arrested along with N.Y.S. Senator Brad Hoylman and 14 other leaders of the AIDS community outside United Nations on September 18, 2013, as they marched with the Robin Hood Tax Campaign.

Yours,  
Barbara Hughes  
President, Board of Directors



## TAG's Progress Toward Revitalizing the National HIV/AIDS Strategy

By Mark Harrington

In December 2012, TAG convened an urgent national consultation bringing together government officials, researchers, service providers, and activists to discuss how to incorporate the latest science and build on the upcoming implementation of the Affordable Care Act (ACA) and accompanying Medicaid expansion to revitalize the U.S. National HIV/AIDS Strategy (NHAS; <http://aids.gov/federal-resources/national-hiv-aids-strategy/nhas.pdf>). Recommendations from the meeting were forwarded to the U.S. Office of National AIDS Policy in April 2013.

In January and May 2013, TAG, along with Housing Works, convened two consultations hosted by Columbia University to explore the same issues at the state and local levels, with the goal of instigating the development of a New York State Plan to End AIDS.

In June 2013, TAG and the Foundation for AIDS Research (amfAR) hosted a meeting with the aim of defining a community-driven implementation science agenda to fill the gaps in the HIV continuum of care (also known as the treatment cascade).

On July 15, 2013, President Obama issued an executive order (<http://www.whitehouse.gov/the-press-office/2013/07/15/executive-order-hiv-care-continuum-initiative>) directing federal agencies to develop a plan to improve outcomes throughout the treatment cascade and report back to him by December. This order was a major step forward and amounted to endorsing a much more ambitious set of treatment targets as part of the NHAS—in other words, asking the government to develop a strategy to maximize treatment success, retention in care, and viral suppression for as many people as possible.

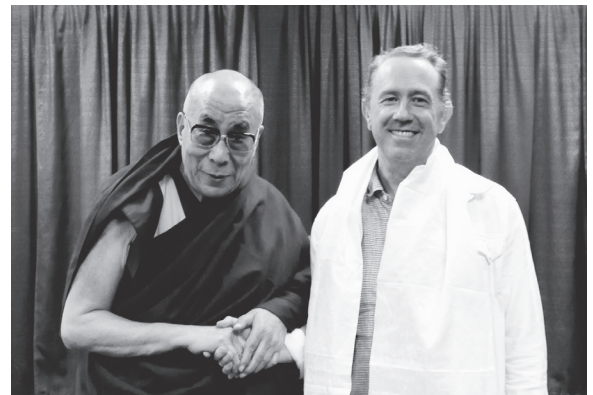
In August 2013, the New York State AIDS Institute requested input from TAG and Housing Works on what the elements of a New York State Plan to End AIDS should be (<http://www.treatmentactiongroup.org/tagline/2013/fall/toward-plan-end-aids-new-york-state>). Now the state government is reviewing the proposal for that plan. TAG and its allies hope New York will once again take leadership nationally and internationally in defining the end of the AIDS pandemic as an overarching strategic goal for the state—and for New York City, which remains the epicenter of the U.S. epidemic.

TAG's next steps in these interlocking campaigns include issuing recommendations for the implementation science agenda; developing proposals for comprehensive twenty-first-century HIV surveillance and prevention; broadening the use of high-quality generic antiretroviral drugs and combinations where appropriate; and working with activists, researchers, providers, and state and local health authorities to create a scalable model of a statewide plan to end AIDS that can be used throughout the United States. •

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### Working to Improve TB Care and Treatment among the Tibetan Community in Dharamsala, India

On May 14, 2013, at the behest of Dr. Zorba Paster of the University of Wisconsin–Madison, TAG's executive director, Mark Harrington, had the extraordinary privilege of meeting the 14th Dalai Lama, who was in the United States to present Buddhist teachings and participate in a panel on the science of human happiness. The Dalai Lama wanted to discuss how TAG's TB/HIV Project could help the Tibetan diaspora community in Dharamsala, India, to provide better diagnosis and treatment for the high rates of drug-resistant TB (DR-TB) there. TAG is now working with Dr. Tsetan Sadutshang of the Tibetan community, the Global Drug Facility, and others to ensure that the TB program in Dharamsala has access to the highest-quality DR-TB drugs at the best possible prices.



# REPORTS FROM THE FRONT

## HIV Project Update

In addition to its continued advocacy to advance antiretroviral drug development and evidence-based HIV disease-management practices, TAG's HIV Project spent much of 2013 helping to drive the development and execution of a community-focused research and policy agenda to achieve (and ultimately surpass) the goals of the National HIV/AIDS Strategy (NHAS).

Following an initial NHAS revitalization meeting with key opinion leaders in December 2012, TAG and the Foundation for AIDS Research (amfAR) cohosted a meeting in June with activists, service providers, researchers, and government officials to develop a community-based agenda to improve implementation of effective service-delivery approaches and identify research priorities for improved management of HIV treatment as prevention, with a particular focus on filling the gaps in the U.S. continuum of care (testing, linkage to care, retention in care, and viral-load suppression).

On July 15, President Obama issued an executive order establishing the HIV Care Continuum Initiative, mandating tight collaboration between various federal agencies to achieve the goals of the NHAS. Many of the recommendations included in proceedings from TAG's NHAS revitalization meetings are reflected in the HIV Care Continuum Initiative and its associated programs. •

## Hepatitis/HIV Project Update

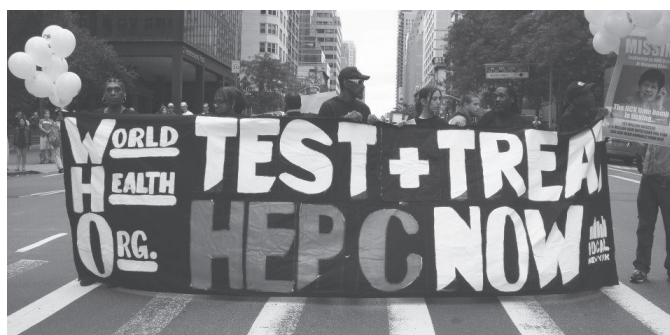
In 2013, TAG's Hepatitis/HIV Project worked to increase access to, and quality of, hepatitis C virus (HCV) treatment. HCV can lead to liver failure and liver cancer; each year, over 350,000 people die from these complications. In HIV-positive people, HCV-related liver disease is now a leading cause of death, despite antiretroviral therapy. But HCV is curable, and a treatment revolution is under way. Over 30 drugs are in development, and the first all-oral HCV treatment is expected by the end of 2013.

TAG is working across many fronts to leverage these amazing therapeutic advances: we develop materials for activists and people living with, and at risk for, HCV and HIV so that they are abreast of relevant research; provide advice on the HCV treatment landscape; present at scientific meetings; participate in treatment guidelines panels; and work with regulatory agencies.

Most people do not have access to HCV treatment. Inspired by victories in HIV treatment access, TAG mobilized a global movement of grassroots HCV activists

in 2013. Through this network, we share information, develop campaigns and strategies, and advocate for policies to create and broaden HCV treatment access, especially for people who inject drugs and people living with HIV/AIDS.

In 2013, with allies from around the world, TAG urged that HCV be given higher priority by the World Health Organization (WHO); coordinated a successful campaign to add HCV treatment to the WHO's Essential Medicines List, and advocated for early access to potentially lifesaving HCV treatments. •



## TB/HIV Project Update

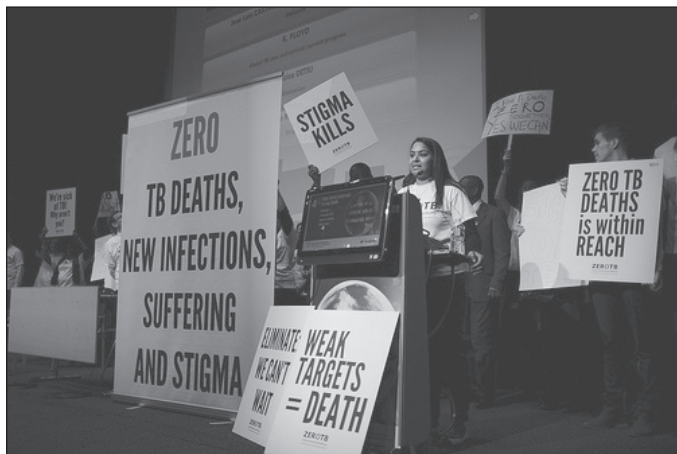
The highlight for the TB/HIV team this year was a trip to India to support the work of activists, which resulted in the establishment of a TB Community Advisory Board (CAB) in India. The CAB's advocacy work has been more effective in India, in particular calling on its government to investigate drug stock-outs. Advocacy has continued based on the findings of the meeting of the TB CAB, the National TB Program, and a workshop for activists working on HIV and TB from around India. TAG also visited the Central Tibetan Administration TB program in Dharamsala.

TAG worked on promoting the neglected issue of pediatric TB. In collaboration with the Sentinel Project, TAG produced and published *We Can Heal: Prevention, Diagnosis, Treatment, Care, and Support: Addressing Drug-Resistant Tuberculosis in Children*, which highlighted the challenges for diagnosing and treating children with MDR-TB. TAG also wrote an article, "Novel Pediatric Delivery Systems for Second-Line Anti-tuberculosis Medications: A Case Study," which was published in the *International Lung Union Journal*, and together with UNICEF, the WHO, the Stop TB Partnership, and the International Union Against Tuberculosis and Lung Disease, developed and launched a *Roadmap for Childhood Tuberculosis*, which was picked up by over 60 media outlets including the BBC and Reuters.

This year, TAG and the TB CAB focused on addressing issues in TB diagnostics. The TB CAB sent open letters to Qiagen and Immunoshop (two manufacturers producing IGRAs, a type of TB diagnostic), who are aggressively marketing these tests in India. The letters called on the companies to stop unethical marketing and off-label use of their two assays. The TB/HIV team influenced the materials that Immunoshop produces and has since heard that the Indian government is now in discussions about banning the use of IGRAs. Working with Doctors Without Borders/Médecins Sans Frontières, TAG raised awareness and pushed for transparency with the UNITAID board and the EXPANDx TB steering committee about the doubling in price of the Hain MTBDR<sub>plus</sub> diagnostic system.

Other advocacy work on drugs included a campaign in conjunction with the National TB Controllers Association to reduce the price of rifapentine, resulting in national media attention and an open letter to the company from multiple stakeholders. A successful federal meeting on domestic drug stock-outs was held, which resulted in discussions with the Centers for Disease Control and Prevention on how to address the issue. TAG produced *An Activist Guide to Bedaquiline*, which provides information on the first new TB drug in forty years. The European Medical Association refused approval of another new TB drug, delamanid; the team responded immediately with a press release and will continue to push for delamanid's approval.

Finally, the vision and goals of the Zeroes Campaign (launched in 2012), which calls for zero new TB deaths, new infections, suffering, and stigma, are being taken up by international organizations and reflected in the WHO's proposed global plan for 2015 and onward. •



TB activists stormed the stage at the World Health Organization (WHO) sponsored Stop TB Symposium during the 44th Union World Conference on Lung Health.

## Politics Is a Major Hurdle in HIV Treatment

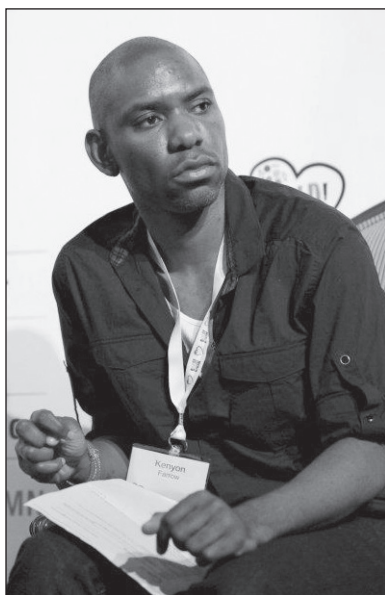
By Kenyon Farrow, U.S. & Global Health Policy Director

We are increasingly living in an environment where biomedical interventions are advancing in terms not only of treatment, but also of prevention. But it is not just the discovery that antiretrovirals are as useful at preventing HIV as they are at treating it. Through the relatively new research field of implementation science, we are learning more about how to measure what prevention and treatment policies we need and what it will cost to reduce the number of new infections and provide people with HIV the opportunity to be healthy.

Two recent policy developments give us a good start toward these goals, but fall short of enabling us to achieve them. The National HIV/AIDS Strategy (NHAS) was long fought for by AIDS activists and provides us with a governmental framework for policy priorities; the geographic areas and demographic groups we should invest the most resources in; and the goals we're attempting to reach by 2015. With only two years to go, it remains unclear whether many of the goals of the NHAS will be achieved. Many of those goals have been undermined by a lack of political will to fund the policies and the scale-up of research that the strategy calls for.

The open enrollment provision of the Affordable Care Act (ACA) went into effect just a few weeks ago. While the ACA will greatly expand access to health care for many Americans, a 2012 Supreme Court decision gutted several of its key provisions, particularly the expansion of Medicaid to all states. The expansion is designed to give more Americans greater health coverage, encourage people to be engaged in preventive care, and reduce the use of emergency rooms, which proves costly, as people without insurance often wait until their condition is so severe they have no other option. But 26 states, most of them in the South, that rank high in poverty and HIV rates have decided not to expand Medicaid coverage under the provisions of the ACA. Federal funding would pay the states nearly 100 percent of the cost of coverage, freeing up many states' budgets and creating new jobs necessary to carry out the expansion.

It is no exaggeration to call this a travesty and an injustice. A recent report by the Kaiser Family Foundation finds that nearly six in 10 African Americans who would have qualified for Medicaid under ACA expansion live in states that are not moving forward with the program. And while cities like Washington, D.C., have recently shown massive reductions in new HIV infections, we will lose this momentum if we can't expand access to health care to more people nationwide.



Following the recent federal government shutdown and the semiannual self-imposed budget crisis, social safety net programs like the Supplemental Nutritional Assistance Program (SNAP) that feed thousands of people with HIV annually, as well as research being planned or conducted by the National Institutes of Health, have become weapons in budget battles while people in need are caught in the crossfire.

It's not just domestic HIV prevention and treatment that are under threat. Under the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), there has been a massive scale-up of people being treated for HIV in sub-Saharan Africa. In consequence of this, among other efforts, many African countries this year are showing double-digit reductions in mortality from HIV-related illnesses and similar reductions in new infections. This could be a major game-changer for the continent. However, we are in a fight to keep PEPFAR and the Global Fund fully funded to meet the needs that they serve. The huge across-the-board cuts caused by sequestration in the United States along with austerity measures in Europe threaten a much-needed infrastructure that has been built over the last decade. Are we ready to throw that away?

I say no.

We are at a critical moment in treatment advocacy globally. Not because we don't understand what to do, but because political and economic restraints are making it more difficult to do what's necessary. Effective strategies to fund, implement, and evaluate policies are critical. And so is marshaling the global community to act together, and to once again build public consensus for action. •

## Q & A with TB/HIV Project Officer Mike Frick

**What attracted you to TAG?** The opportunity to conduct science-based advocacy drew me to TAG. Before joining TAG, I was working on health and human-rights advocacy in East and Southeast Asia. In the course of this work, I realized the urgent need for rights activists to engage directly with scientists, research institutions, and public-health agencies and to carry a strong understanding of the science underlying their area of disease focus into these engagements. I feel very committed to TAG's mission of conducting advocacy at the intersection of science, government, and the public. As a resident of China for several years, and as the grandson of Kentucky tobacco farmers, I feel a particular commitment to advocacy promoting lung health. TAG's work on TB really reflects these professional and personal interests.



**What are the key focus areas of your team?** The TB/HIV project at TAG has two broad areas of focus: advocacy for research and development of new tools to fight TB and, once these are developed, advocacy to ensure that TB-affected communities have access to these new tools. Within the TB/HIV project, I am focusing on research and development advocacy for new TB vaccines. The current vaccine against TB—known as BCG—was introduced in 1921 and offers limited protection against pulmonary TB to adolescents and adults. A safe, more effective vaccine would bring us a lot closer to achieving zero TB deaths, new infections, and suffering. I also coordinate the Community Research Advisors Group to the U.S. CDC's Tuberculosis Trials Consortium, which gives me the opportunity to work directly with strong TB activists from around the world on issues related to TB drug development.

**What are the biggest issues facing TB at this point in the epidemic?** TB programmers are using twentieth-century technologies to address a pathogen that has embraced twenty-first-century globalization and continues to evolve resistance to our existing arsenal of drugs. Not only are the tools available to fight TB out of date, but the framework in which they are employed ignores the needs and voices of people with TB. There is an urgent need to introduce patient-centered care into TB treatment so that it becomes more flexible and responsive to the complexities of TB disease. Listening to people with TB will go a long way toward building the levels of political will necessary to achieve scientific breakthroughs and avert the nearly nine million new cases and 1.4 million deaths due to TB each year. •



## **Q & A with HIV Prevention Research & Policy Coordinator Jeremiah Johnson**

### **What attracted you to TAG?**

I took a class called Global AIDS Policy during my last semester at Columbia where I learned about a number

of key HIV/AIDS activist organizations and how they essentially changed the entire practice of public health. One of the organizations I studied was TAG. I remember being so inspired by these amazing HIV-positive activists who didn't simply rely on so-called experts to develop lifesaving treatments; they became the experts themselves and showed everyone the way forward. When I saw that TAG was hiring, I knew that I wanted to be a part of that legacy; I wanted to work alongside all these amazing expert-activists.

### **How did you get into HIV activism?**

I've been interested in working on HIV-related issues for most of my adult life, but my real dedication to HIV activism came after my own diagnosis in 2008. At the time, I was serving as a Peace Corps volunteer in Ukraine, and, unfortunately, the Peace Corps' policy at the time was to dismiss volunteers who tested positive. Fortunately, the American Civil Liberties Union took up my case, and together we were able to get the Peace Corps to change its official stance on HIV-positive volunteers. Now, if a volunteer tests positive, that person can finish his or her service without interruption. Ever since that time, I've been obsessed with trying to address misconceptions about the virus, those living with it, and those most at risk for it. There is a lot of injustice associated with HIV in the United States and around the globe, and I want to do what I can to change that.

### **You will be focused primarily on HIV prevention. What do you think are the critical priorities, domestically, at this point in the epidemic?**

There are so many critical priorities. I think that as a nation we've really done a poor job of protecting a number of key populations from getting HIV, and we have a lot of catching up to do. We need to work toward

the development of a broadly accepted, responsibly funded, strategic plan for HIV prevention in this country. At present, many of us working in HIV prevention are well aware of the HIV crises going on in several communities in the United States, but we're unsure of how to move forward for a number of reasons. For one, with the advent of preexposure prophylaxis, postexposure prophylaxis, and treatment as prevention, we have new technologies to prevent new HIV infections. However, how do we incorporate these innovations into programs that historically have focused on behavioral interventions, condom use, safer injection practices, HIV testing, et cetera? How do we take programs that currently exist for HIV-negative individuals and include prevention for people who are positive? In essence, what should comprehensive prevention programs look like? How do we effectively match interventions with individuals? Specific interventions will not be equally effective for all people—we need to know what prevention products are being demanded, where the products are needed, and then supply them accordingly.

Right now HIV prevention is woefully underfunded in comparison with treatment, with only 3.7% of the CDC's 2012 HIV/AIDS budget dedicated to preventing new infections. We need to ensure that the funding matches up with the evidence—the right interventions need to be funded with a focus on high-prevalence areas.

Finally, as a sociologist at heart, I believe that the number one priority is, and always will be, eradicating stigma. We can have all the great prevention tools in the world, but if people are too afraid to seek them out for fear of judgment or discrimination, then we are doomed to fail. We absolutely must include effective interventions for HIV-related stigma as a central element in all of our prevention efforts. •

## **Q & A with Board Member Earl L. Plante**

### **What appealed to you about TAG as an organization?**

TAG's reputation as a groundbreaking, unwavering treatment and research advocacy organization was something that was very appealing, and something that I have tried to emulate in my personal advocacy work over the years.

### **You bring a wealth of experience in the LGBT community with you. Do you see the current LGBT agenda and TAG's mission as complementary?**

My core advocacy passions have been civil rights and women's rights along with LGBT and HIV concerns. These have been very useful in terms of building bridges across



disciplines and issues that have arisen over the years. However, I am deeply concerned about the underacknowledged schism that has developed between the HIV and LGBT communities. To be blunt, HIV is no longer a priority issue for the mainstream LGBT movement. The reasons are understandable: increased competition for scarce money in an economic climate

that is still reeling from a global recession, and the undeniable success of the HIV movement, which has led to a complacency that is literally killing thousands every year. A response to this situation was a sign-on letter that was released publicly in June of this year that re-commits the LGBT community to fighting HIV. I find it laudable that 35 signatories were attempting to reprioritize HIV within the LGBT movement—an attempt that is long overdue—affirming that they felt the need to do it as a sign of HIV’s declining influence. It is troubling, however, that none of the individuals listed on the letter were openly HIV-positive.

As we all know, people with HIV bring unique expertise to informing where and how our programmatic activities can be strengthened and improved. People living with HIV need to be involved in all aspects of HIV/AIDS policy, project design, and implementation—alas, three decades into the global pandemic, little more than lip service is paid to this perspective. This is an unacceptable breach of the historic 1983 Denver Principles, which highlighted the importance of the empowerment and emancipation of people living with HIV.

### **What do you think are the biggest issues in the HIV epidemic today?**

We are at a critical crossroads in the global HIV movement: stigma, discrimination, isolation, lack of resources, complacency, criminalization, and human- and civil rights deficiencies are all holding us back from our collective goal of ending AIDS, and from allowing individuals living with HIV to move from a survival position to a new and thriving one that reclaims our personal dignity and strengthens our holistic health. •



### **Q & A with Board Member Frank Bua**

**You have been an LGBT activist for a long time. What appealed to you about TAG?**

I had just turned twelve when HIV reared its ugly head. There was so much societal and medical uncertainty during such a critical stage of my development that I determined it was best not to act on my sexual impulses. And watching boyhood idols like Rock Hudson and Freddy Mercury succumb to the mysterious disease helped keep the closet door firmly shut even longer. Looking back, it was probably no small coincidence that I came to terms with my sexuality around the same time that the AIDS enigma started to unravel. Only then—after more than a decade—was I able to claim my place in life as a gay man. I remain saddened and painfully aware that so many people just a few years older than me never got to live their lives, and am frustrated that the same disease that stole a generation continues to exist so prolifically. So I vowed to become involved in the original rallying call for our movement, the fight to treat those that have HIV, and to ultimately cure those who have AIDS, and all roads led to Treatment Action Group. TAG has the organization, infrastructure, and staff to help remove the vacuum of awareness that continues to surround this disease, to drive scientific research and governmental agencies to work in tandem, and to affect tangible on-the-ground change. I do not want the youngest generation of gays hiding in the closet the way I did, but I do believe there needs to be a reeducation about the power and pervasiveness of the virus. A treatment isn’t a cure, and until there is a cure, there is TAG.

**You bring significant board experience to TAG. Do you have a particular skill or area of expertise that interests you most when working on a board?**

One of the things that make TAG unique among the nonprofit organizations I've worked closely with is that it is more progressive think tank than traditional nonprofit organization. In that context, I hope to do my small part to move the organization's agenda forward: ensuring that all people with HIV have access to treatment, making treatment as progressive and affordable as possible, and finding the elusive cure. I have long believed in the power of the group dynamic to affect change. TAG has such an impressive collection of minds, and it is truly a privilege to be a part of the organization.

**You and your partner have twins. How do you balance all of your activism and work with raising a family?**

My family is the *raison d'être* for my activism. I wake up every morning amazed that I live in a society where two dads can raise a family, but concerned that the progress that we have made pales compared with all that is left to accomplish. It is my hope that, in some small way, my work with the LGBT community can help educate the broader community, change hearts and minds, and facilitate the types of conversations necessary to make the world a better place for Holden and Zoe. •

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## SUPPORT TAG

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Supporting TAG is a wise investment in AIDS treatment advocacy. Every donation brings us one step closer to better treatments, a vaccine, and a cure for AIDS. Donate online: [www.treatmentactiongroup.org/donate](http://www.treatmentactiongroup.org/donate).

Does your company have a matching gifts program? If so, you can double or even triple your donation. Just complete the program's matching gift form and send it in with your donation to TAG.

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## ABOUT TAG

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Treatment Action Group is an independent AIDS research and policy think tank fighting for better treatment, a vaccine, and a cure for AIDS.

TAG works to ensure that all people with HIV receive lifesaving treatment, care, and information. We are science-based treatment activists working to expand and accelerate vital research and effective community engagement with research and policy institutions.

TAG catalyzes open collective action by all affected communities, scientists, and policy makers to end AIDS.

**TAG**  
Treatment Action Group

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