

# TAG UPDATE

## PROGRESS IN THE FIGHT TO END HIV/AIDS HEPATITIS C AND TUBERCULOSIS

December 2018

**TAG**  
Treatment Action Group

### ● TAG PROJECT UPDATES

## HIV PROJECT

With Ending the Epidemic (EtE) at the core of TAG's mission, TAG built on previous EtE successes within New York and around the country. In 2018, TAG launched a series of online modules to share best practices on developing and launching an EtE plan. Nationally, TAG continues to act as a co-convenor for the Act Now End AIDS coalition, and helped drive the drafting of a national EtE plan that launched this World AIDS Day.

Focusing on the southern United States, a disproportionately impacted region, TAG partnered with Housing Works to launch the first EtE University where representatives from across the Deep South convened to network and learn best practices for launching a city or state EtE plan. TAG's support encouraged a citywide EtE initiative in Nashville that launched on December 1, 2018, and the formation of an EtE steering committee and two state-funded community coordinator positions to be housed at Women With A Vision in Louisiana, teeing Louisiana up for inaugurating a full EtE plan in 2019.

Jeremiah Johnson led advocacy to end the Peace Corps' mishandling of HIV treatment, care, and prevention. Jeremiah's own advocacy career started when he was kicked out of the Peace Corps for testing positive for HIV in 2008, so when two current volunteers experienced the same discrimination a decade later, he worked with other national HIV policy organizations to take action. It paid off: the Peace Corps committed to expand the list of countries eligible to host HIV positive volunteers, and agreed to a continued dialogue to improve their handling of HIV-related matters. One volunteer has returned to service; the other has decided to remain in the U.S. for the time being.

TAG plays a vital leadership role in basic science, vaccines, and cure advocacy. Our HIV Cure Clinical Trials website listing, updated monthly to provide information on studies and their results, is widely cited by researchers and partners in scientific papers and in conference presentations. Richard

Jefferys also summarized cure-related trials involving interruptions of antiretroviral therapy for a research summit. A TAG issue brief highlighted the risks of and need for therapeutic interventions for poor immune reconstitution despite HIV treatment. The *Pipeline Report* illuminated progress and remaining needs in HIV research, including for PrEP, microbicides, cure, immune-based therapies, HIV vaccines, passive immunization, and antibody gene transfer.



*Jeremiah Johnson speaking to participants at the first EtE University, August 2018.*

## U.S. AND GLOBAL HEALTH POLICY WORK

TAG authored multiple sections of the previously mentioned community National End the Epidemic Plan, ensuring the inclusion of hepatitis C (HCV) and tuberculosis (TB), in addition to key HIV priorities, into the plan.

Alarmed at increasing threats to the health and human rights of foreign-born Americans, TAG took strong stances against anti-immigrant policies that would jeopardize progress towards ending the epidemics of HIV, HCV, and TB. Annette Gaudino and Erica Lessem were arrested for civil disobedience protesting a draft rule that would drastically expand what constitutes a “public charge,” rendering many people seeking basic health services ineligible for status adjustments. TAG fought the addition of a citizenship question to the Census, detailing in a public comment how it would drive vulnerable people away from healthcare and lead to an unfair distribution of federal resources.

TAG helped to develop and facilitate multiple sessions at the Affordable Medicines Now Conference, the first such convening among national access-to-medicines activists to address exorbitant prescription drug pricing and abusive patent practices.

TAG ensured its priorities were reflected in key legislative developments. To promote access and lower drug prices, Suraj Madoori and allies blocked the inclusion of the **Re-Valuing Anti-Microbial Products Act of 2018** amendment to the **Pandemics and All-Hazards Preparedness Act**, which would have allowed for transferable monopolies for developers of antimicrobials, without any access provisions for those rewarded products. The Congressional Black Caucus, Hispanic Caucus, and Asian Pacific Islander Caucus introduced their long-standing **Health Equity and Accountability Act**, which, thanks to TAG, recognizes the need to address TB as a health disparity among communities of color, and calls for strengthened programs and research. TAG worked on the **Comprehensive TB Elimination Act**, which includes a five-year authorization to fund the domestic TB response and global TB research driven by the U.S. Centers for Disease Control and Prevention (CDC).

TAG successfully advocated for the largest increase for federal TB research and programs in years, resulting in a \$15 million increase for USAID’s TB program for fiscal year 2018. Disappointingly, the House and Senate gave no increases for the CDC’s domestic TB elimination program, though they have initially made no cuts, and rejected the President’s cuts to the program for HIV and viral hepatitis.



Annette Gaudino (left) and Erica Lessem, being arrested as two of “The Delancey 14.” They participated in civil disobedience in response to a proposed rule that would force immigrant families to choose between using social programs and becoming legal permanent U.S. residents. Photo Credit: Karen Smul, 501SEE Photography.

## TB PROJECT

TAG and partners advanced a major shift in global policy for the treatment of drug-resistant tuberculosis, leading to updated World Health Organization recommendations establishing a safer, more effective standard of care. TAG is working with civil society partners to hold country programs and donors accountable for implementing this shift.

In the U.S., TAG and the National TB Controllers Association succeeded in reducing access barriers to bedaquiline, a TB drug which forms part of the

improved standard of care. Gains include an expansion of the patient assistance program to allow more patients to access bedaquiline for free, streamlined procurement, and a commitment from Janssen (the makers of bedaquiline) for more program-friendly packaging. Our ultimate goal remains a price reduction of bedaquiline in the U.S. and around the world.

Mike Frick advanced TAG’s seminal research, writing, and community mobilization on the human right to enjoy the benefits of scientific progress and its applications. TAG’s work included several submissions to United Nations bodies and culminated in a

presentation to the United Nations Committee on Economic, Social and Cultural Rights, informing the upcoming first authoritative interpretation of the right.

TAG developed the concept of a country's "fair share" of global funding for TB research, whereby each country dedicates 0.1% of its overall research spending to TB. The idea was endorsed, and shaped the prioritization of research in the first-ever United Nations High-Level Meeting on TB. Lindsay McKenna collaborated with partners to secure the inclusion of pediatric-specific commitments in the United Nations High-Level Meeting on Tuberculosis political declaration. Suraj Madoori led the U.S. civil society delegation to meetings with the U.S. mission to the United Nations to discuss priorities

for domestic and global TB elimination, including the importance of affordable access. TAG will strive to ensure that commitments are acted upon so that all children can lead TB-free lives, that governments spend their fair share on TB research, and that resulting products are affordable and accessible.



Activist takeover of a symposium at the Union Conference in The Hague, October 2018. Safiqa Khimani tells the audience how premature shifts from Global Fund funding to domestic financing risk the affordability, availability, and quality of medicines and diagnostics. Lindsay McKenna (rear, center) and Mike Frick (rear, right) also participated.

Following a rise in TB cases in 2017 in New York City after years of chronic underfunding for the TB response, Erica Lessem, Safiqa Khimani, and allies succeeded in restoring \$2.4M in funding for the New York City TB program. These funds enable clinics to remain open and key staff positions to be reinstated. In 2019, TAG will advocate for further increases to ensure that NYC's TB budget meets actual needs.

## HCV PROJECT

Recognizing that scaling up diagnosis requires awareness, increased treatment and diagnostics literacy, and advocacy skill-building, TAG launched HCV diagnostics advocacy activities to include in-country trainings in Georgia and Malaysia and technical assistance for treatment activists in Cameroon, India, Myanmar, and Vietnam. Bryn Gay is leading this work with new support from the Foundation for Innovative New Diagnostics.

TAG, with the European African Treatment Advocates Network and other migrant-focused organizations, co-convened the European African HIV & HCV Community Summit prior to the AIDS 2018 conference in Amsterdam. The Summit focused on developing strategies to ensure that optimal, affordable treatment and diagnostics are available to everyone who needs them, and that national elimination efforts include public health policies for migrant communities.

In partnership with the Center for Artistic Activism, TAG raised the visibility of HCV treatment barriers and lack of global funding at AIDS 2018 with several creative activist actions. These included a mock International Conference Registration booth to highlight the registration gap in the majority of countries in which Gilead has voluntarily licensed its HCV medicines to generic manufacturers; an interactive poll that showed that attendees were

more critical of global funders than Pharma; and a mock Gilead iced coffee stand that demonstrated the arbitrary pricing of its drugs depending on income-level of countries (e.g., \$84,000 per cup) and helped recruit for Gilead with satirical job applications in order to hire more employees for speeding up registration in countries.

To combat HCV in New York, Annette Gaudino spearheaded a successful budget and policy advocacy campaign, culminating in a first-in-the nation commitment to HCV elimination by Governor Cuomo, including a fourfold increase in program funding with a two-year commitment, and the commission of a statewide HCV Elimination Task Force to which Annette was named. TAG contributed to New York City Council advocacy, resulting in increased funding for peer HCV prevention, testing, linkage to care and treatment support.



Bryn Gay and Annette Gaudino staffing the mock International Conference Registration booth, which highlighted the registration gap in most countries where Gilead has licensed its HCV medicines to generic manufacturers. They gave out mock conference badges that read, "PHARMA LAZINESS KILLS."



## TAG's 2018 Publications

Under Dorrit Walsh's stewardship, TAG developed and disseminated a remarkable number of ground-breaking publications in 2018:

### Cross-project

- TAGline Spring 2018
- TAGline Fall 2018
- Pipeline Report

### TB

- *Know Your Rights Guide: Tuberculosis Prevention, Diagnosis, and Treatment* (now available in eight languages)
- *Issue Brief: Is Shorter Better? Understanding the Shorter Regimen for Treating Drug-Resistant Tuberculosis*
- *Issue Brief: The Vital Role of Research for TB Elimination*
- *United to End Tuberculosis: Key Asks for the U.S. from TB Stakeholders and Communities*
- *Issue Brief: Ending Exemptions from the Pediatric Research Equity Act (PREA)*
- *An Activist's Guide to Bedaquiline*
- *Reality Check: The Price of Bedaquiline*
- *Tuberculosis Research Funding Trends, 2005-2017*
- *Issue Brief: Funding for TB Research – Recent Momentum Must Inspire Bold Commitments*

### HCV

- *Training Manual for Treatment Activists, Hepatitis C Virus & Coinfection with HIV* (available in three languages)

### HIV

- *Issue Brief: Suboptimal Immune Recovery on Antiretroviral Therapy*
- *Community Recommendations for Clinical Research Involving Antiretroviral Treatment Interruptions*

## Transitions

The Board of Directors and Staff extend a warm welcome to TAG's new staff members: Jean Dorak, Christopher George, Safiqa Khimani, and Elizabeth "Lizzy" Lovinger. We're also thrilled to congratulate several longer-term staff members on their new roles at TAG: Jeremiah Johnson, Annette Gaudino, Bryn Gay, Mike Frick, Erica Lessem, and Lindsay McKenna. You can get the full details on many of these changes and promotions here: <http://www.treatmentactiongroup.org/content/exciting-changes-tag-team>.

## Events

TAG thanks its Board of Directors, donors, and friends for their critical support of TAG, including for several special events this year. These included: a special exhibition of TAG art editions at the Westbeth Gallery — enabled by generous grant support from the Marta Heflin Foundation and contributions from the artists; a spring donor event at the beautiful home of Kate Lear and Jon LaPook; and a successful fundraising challenge campaign catalyzed by long-time TAG supporter and 2017 Research in Action Award honoree Joseph Evall.

## DONATE ONLINE

<https://treatmentactiongroup.salsalabs.org/yearend2018>



*The Board and Staff of Treatment Action Group thank Alby Maccarone, Jr., and Jason Osher for their many years of dedicated service on TAG's Board of Directors.*

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