

tagline

NEWS ON THE FIGHT TO END HIV/AIDS, HEPATITIS C, AND TUBERCULOSIS

TAG AT 30



TOWARDS PANDEMIC EQUITY: LESSONS FROM 30 YEARS OF SYNDEMIC ACTIVISM

By Mike Frick and Mark Harrington

The articles in this 30th anniversary issue of *TAGline* grapple with “pandemic equity,” an increasingly common catchphrase in global health. COVID-19 has shown that “equity,” like its cousins “justice,” “fairness,” and “equality,” is one of those words whose use rises in proportion to its absence in practice. If it feels easier to define its opposite, inequity, that is because inequities have more often been the lasting outcome of pandemic responses — whether to HIV in 1981 or to COVID-19 in 2020.

The inequities that have defined COVID-19 were predictable to communities of people who have weathered the harshest effects of HIV, TB, and HCV.

TAG’s home of New York City has afforded many opportunities to consider pandemic equity, both historically and within our lifetimes. NYC has frequently found itself at the epicenter of pandemic outbreaks, including multiple bouts of cholera in the nineteenth century, smallpox in 1947 (to which the city responded by immunizing 6 million people in five weeks — a striking example of having the right tools in the right quantities at the right time), HIV in the 1980s, multidrug-resistant TB in the early 1990s, COVID-19 in March 2020, and now monkeypox in 2022.

As the articles that follow show, understanding pandemic equity requires looking backward as well as forward to consider both inequities within pandemics and inequities among pandemics and over time. Take, as a

starting point, differences between the exceptional response to COVID-19 and the three diseases at the heart of TAG’s work: HIV, tuberculosis (TB), and hepatitis C virus (HCV). As of August 8, 2022, the World Health Organization (WHO) had recorded 6,410,961 deaths from COVID-19 and estimated the full death toll of the pandemic — considering both direct and indirect mortality — at 15 million. Over the nineteenth and twentieth centuries, TB claimed [one billion lives](#) — more than smallpox, malaria, cholera, and the relative newcomer: HIV, which has killed 40 million people since the first cases of AIDS-defining illness were reported in 1981. Untold millions have died from HCV before and since its discovery in 1989. That some diseases spark tremendous resolve to bring about their end (COVID-19) while others last for millennia (TB) signifies the greater inequalities plaguing global health.

After three decades of activism at the intersection of HIV, TB, and HCV, we know that pandemic equity cannot be limited to ending COVID-19 or anticipating Pathogen X. Pandemic equity requires addressing pandemics that predated COVID-19 and applying lessons from these ongoing struggles to achieve health for all. The inequities that have defined COVID-19 were predictable to communities of people who have weathered the harshest effects of HIV, TB, and HCV.

- The global vaccine apartheid seen in COVID-19 came as no surprise to HIV activists, who early on recognized vaccine hoarding by wealthy nations in the Global North as a recurrence of the treatment access disparities that marked the years following the advent of antiretroviral therapy in 1996 and have led to millions of preventable deaths from AIDS. Even today, ten million of the world’s 38.5 million people living with HIV are not receiving life-saving combination antiretroviral therapy.
- TB activists could have told us that early scientific triumphs against COVID-19, most notably the development of mRNA vaccines and oral antiviral

therapy with nirmatrelvir/ritonavir (Paxlovid), would not be enough to end the pandemic for everyone. After all, TB research drove some of the biggest advances in twentieth century medical science — the use of serial *in vitro* passaging to create the BCG vaccine, the invention of randomized controlled trials to study TB treatment, and the antibiotic revolution that followed — yet TB continues to kill more people each year than any other infectious disease, second only to COVID-19.

- And hepatitis C activists, for their part, could have foretold that offering expensive treatment without providing access to diagnosis would leave many vulnerable people without care, as is the case today where millions with HCV lack access to an easy-to-take, two-month, all-oral cure.

In short, activists who have fought for equity in earlier (still present) pandemics have a lot to teach us about current ones.

The articles that follow coincide with the 30th anniversary of TAG's founding and draw on the past as they look to the future. Dorrit Walsh and Mark Harrington's closing retrospective (p. 12) covers major TAG milestones over its history.

Cheriko Boone, Abraham Johnson, and Richard Jefferys reflect on the past 40 years of advocacy to make HIV research inclusive and representative of the people living with and affected by HIV in all of their diversity (p. 7). They tally what's been achieved, how efforts have fallen short, and what's still needed to ensure that the communities most affected by the HIV epidemic can participate in and benefit from scientific progress — as both study participants and investigators.

Lindsay McKenna's contribution (p. 4) introduces the 1/4/6x24 campaign, aimed at building the political will to implement one-month or once-a-week TB preventive treatment, four-month drug-sensitive TB treatment, and six-month treatment for drug-resistant TB worldwide. While these shorter treatment regimens have been scientifically validated and recommended by WHO, it's up to advocates to demand the "staff, stuff, space, systems and support" required to make them available to people with TB by 2024. The 1/4/6x24 campaign, devised by TAG, Partners in Health, and other close allies in honor of the late physician-anthropologist Paul Farmer, harkens back to the earlier 3x5 initiative, which jumpstarted the global scale-up of antiretroviral treatment for HIV.

The "staff, stuff, space, systems, and support" at the heart of 1/4/6x24 add up to what Farmer called "a prescription for global health equity." Among the "stuff" needed to secure global health are diagnostic tools and essential medicines, discussed in an interview with David Branigan and Joelle Dountio Ofimboudem (p. 10). They analyze the barriers preventing scientific breakthroughs from being used to improve lives and consider future strategies to combat the corporate power and government reluctance that bars access to these technologies. They imagine a world in which rapid, accurate diagnosis is available, affordable, and convenient for all people.

"If everyone has a right 'to share in scientific advancement and its benefits,' where are our programmatic efforts to improve the spread of these advances?"

– Paul Farmer,
Pathologies of Power: Rethinking
Health and Human Rights,
AJPH 1999

Writing in 1999, Farmer laid out a dilemma we're still contending with as we seek to envision and enact equitable responses to pandemics. He observed that "even as our biomedical interventions become more effective, our capacity to distribute them equitably is further eroded."

"If everyone has a right 'to share in scientific advancement and its benefits,'" Farmer asked, "where are our pragmatic efforts to improve the spread of these advances?"

We hope this issue of *TAGline* provides modest yet powerful examples of such pragmatic efforts, gleaned from our 30 years fighting HIV, TB, and HCV.

INTRODUCING 1/4/6x24

A CAMPAIGN THAT DRAWS INSPIRATION FROM THE PAST TO CHANGE THE TRAJECTORY OF THE FUTURE FIGHT TO END TUBERCULOSIS

By Lindsay McKenna, Mike Frick, and Mark Harrington

At the 24th International AIDS Conference in Montreal this summer, TAG, Partners In Health (PIH), and Médecins Sans Frontières (MSF) launched the 1/4/6x24 Campaign to accelerate equitable global uptake of newly discovered safer, shorter regimens to cure all forms of tuberculosis (TB). The “1,” “4,” and “6” represent the shortest available regimens for TB: one month or once-weekly preventive TB treatment (TPT), four months for drug-sensitive TB, and six months for drug-resistant TB. The “24” sets a deadline — the year 2024.

For the first time since 2005, the number of TB deaths each year is rising. It's against this backdrop and with an eye toward the next UN High-Level Meeting on TB in 2023 that we move forward with the 1/4/6x24 Campaign.

When TAG first added TB to its mission in 2000, global and national health actors faced strong inertia and were making little progress against the world's oldest pandemic. Over two decades later, there has been substantial scientific advancement, and we finally have evidence-based and World Health Organization (WHO) recommended short-course regimens for the prevention and treatment of TB. And yet, far too few people who could benefit from these regimens have access to them. The 1/4/6x24 Campaign is a rallying cry to change that, in memory of Dr. Paul Farmer's lifelong fight to extend the highest attainable standard of care and health to marginalized people across the world.

The coalition championing 1/4/6x24 urges global health actors to fulfill existing promises: In 2018, political leaders gathered during the United Nations General Assembly and committed, by 2022, to put at least 30 million people on TPT and to treat 40 million people with drug sensitive TB, including 3.5 million children, and 1.5 million people with drug-resistant TB, including 115,000 children. Four years later, and now just a few months before the end of 2022, we are not on track to meet a single target. In fact, the combined effects of the COVID-19 pandemic and other concurrent global health, economic, environmental, and political crises have reversed a generation's worth of progress. For the first time since 2005, the number of TB deaths each year is rising. It's against this backdrop and with an eye toward the next UN High-Level Meeting on TB in 2023 that we move forward with the 1/4/6x24 Campaign.

By rallying around the 1-month and once weekly short-course TPT regimens, the 4-month drug-sensitive TB regimens, and the 6-month drug-resistant TB regimens in a joint demand to governments and duty bearers, we aspire to reenergize the TB movement. As Dr. Farmer emphasized, ensuring universal access to scientific advances like the shorter TB regimens at the core of the 1/4/6x24 Campaign requires a few essential ingredients he dubbed “the five Ss”: staff, stuff, space, systems, and support.

“Paul used the five Ss: the first S is the space. Do you have a dignified space to receive that patient? Do you have enough staff to take care of that patient and make sure that staff have the knowledge they need? Do we have enough stuff —not only the drugs but also the diagnostics. Do we have the system? [...] And the last, which is the most powerful, is the social support [...] As Paul taught us, this campaign must deliver these regimens within a comprehensive model of care. Today we need — we must — invest in those 5 Ss.”

— Patrick Ulysse, Chief Operating Officer, PIH.

"Rather than creating these long, laborious consultative processes. If there's been an evidence review by WHO, then there needs to be in country a process for rapid adoption for WHO-recommended regimens. ... We need targets for all those who are eligible [for 1/4/6] and those need to be incorporated in our national strategic plan."

— Norbert Ndjeka, Chief Director TB Control and Management, National Department of Health in South Africa and Harry Hausler, Chief Executive Officer, TB HIV Care, South Africa.

"We need to call for national guidelines to reflect 1/4/6 by the end of 2022 ... and for national strategic plans to reflect 1/4/6 goals. We need the Global Fund to show the way and to pay for it. ... And can we find funding for national advocacy for crying out loud."

— Sharonann Lynch, O'Neill Institute for National and Global Health Law, Georgetown University.

"Today the science is on our side. This campaign could not have come at any better time than now."

— Vuyiseka Dubula, Stellenbosch University, Africa Centre for HIV/AIDS Management, former TAC General Secretary.

"We're not going to debate about whether we're going to do this campaign. We're going to debate how we do it."

— Madhukar Pai, Canada Research Chair in Epidemiology & Global Health at McGill University.

"The fulcrum is the 5S's — staff, stuff, space, systems, support. That would move the targets up [and our progress against them] where they are meant to be."

— Carole Mitnick, Global Health and Social Medicine, Harvard Medical School.

"Because they're [children, pregnant women, other 'vulnerable' populations] not included in studies of innovations, we become paralyzed. So, when it comes to rolling out innovation, we continue to exclude people with a very perverted notion of protecting them."

— Jennifer Furin, Global Health and Social Medicine, Harvard Medical School.

"We are facing lack of staff ... We need integrated teams for TB care, with a MD [medical doctor], nurse, psychologist, nutritionist, and social worker."

— Rosa Herrera, TB Controller in Baja California, Mexico, and member of the Global TB Community Advisory Board (TB CAB), Americas TB Coalition, and the Mexico TB Social Observatory.

"Prevention is still the best key to unlock the door to TB elimination by 2030."

— Ketholelie Angami, head of the Access to Rights and Knowledge Foundation, Spokesperson of Action TB India, and member of the Global TB Community Advisory Board (TB CAB).

"[referring to short-course prevention and treatment regimens] this is not a dream, these are solutions that exist and, as the TB community, we have a right to demand and access them."

— Gloriam Kerubo Moses, National Empowerment Network of People living with HIV/AIDS in Kenya (NEPHAK) and member of the Global TB Community Advisory Board (TB CAB).

COMMUNITY REPRESENTATION IN HIV RESEARCH: FROM STUDY VOLUNTEERS TO INVESTIGATORS

By Cheriko A. Boone, Abraham Johnson, and Richard Jefferys

In a 1989 article by Dr. Anthony Fauci, “AIDS—Challenges to Basic and Clinical Biomedical Research”—which preceded Treatment Action Group’s founding by just a few years—he described NIH/NIAID’s work on establishing the Community Programs for Clinical Research on AIDS, and he called for more minority patients, researchers, and physicians to be engaged in clinical trials of HIV and AIDS therapies. “We envision this as a national program that will broaden the base of our clinical research efforts,” Dr. Fauci wrote, “It is hoped that these research efforts will be innovative and responsive to community needs while also meeting the criteria for sound scientific research.”¹ As one of the earliest accounts from a U.S. federal official regarding the need for increasing involvement of racial/ethnic minorities in clinical trials for development of treatments for HIV and AIDS, Dr. Fauci acknowledged two crucial points that for the most part remain true to this day: clinical research on HIV and other diseases must be diverse and representative in recognition of persistent disparities in the most heavily affected groups, and because it’s critical to determine how interventions can be equitably rolled out to different communities.

Despite Dr. Fauci’s pronouncements, it took activism to force the NIH to deliver on that promise. In 1990, the AIDS Coalition to Unleash Power (ACT UP) organized the now famous “Storm the NIH” protest at the agency’s Bethesda headquarters, where some 1000 demonstrators (including TAG Executive Director Mark Harrington) demanded more inclusion of women and people of color in research and more involvement of affected communities at every step of the process. The action became a sort of watershed moment in HIV/AIDS research, which did become more open and inclusive thereafter.

Such laudable examples show that we’ve indeed come a long way in terms of ensuring racial, ethnic, and gender diversity in research since the early days of the HIV epidemic. But we still have a long way to go — and engagement and leadership of marginalized communities is key to getting us there.

In the decades preceding Dr. Fauci’s aforementioned article, the general public reported increasingly positive views toward biomedical science and experimental therapies and rising numbers of privileged Americans were taking part in clinical trials — but participation among racialized and ethnic minorities remained limited.² One reason was poor outreach: women and people of color were less likely³ to learn about HIV trials in the first place, and early AIDS Clinical Trial Group sites cared for fewer people of color relative to disease burden. Racial disparities have also been partially due to medical mistrust stemming from abuses of Black people and the poor in medical experimentation, demonstrations, and for surgical purposes early in the development of the American healthcare system.^{4,5} People who use drugs were also excluded from most study protocols, as clinicians worried they’d be unreliable participants.⁶ These exclusions blunted scientific knowledge about the needs and particularities of key populations. As one researcher put it in 1997, “Failure to include adequate numbers of women and persons of color may limit the generalizability and usefulness of study results for clinical practice.”

As much as the situation has improved, underrepresentation still presents key points for continued advocacy. For example, underrepresentation of women, including the exclusion of individuals of child-bearing potential, remains a critical issue in HIV biomedical research, such as HIV cure-related research.^{7,8,9,10} In response to the absence of cisgender women and other individuals assigned female at birth from clinical trials that resulted in approval of emtricitabine/tenofovir alafenamide for HIV pre-exposure prophylaxis (PrEP), TAG lambasted the lack of their inclusion and demanded more research examining the medication’s efficacy for preventing HIV through vaginal exposure.¹¹

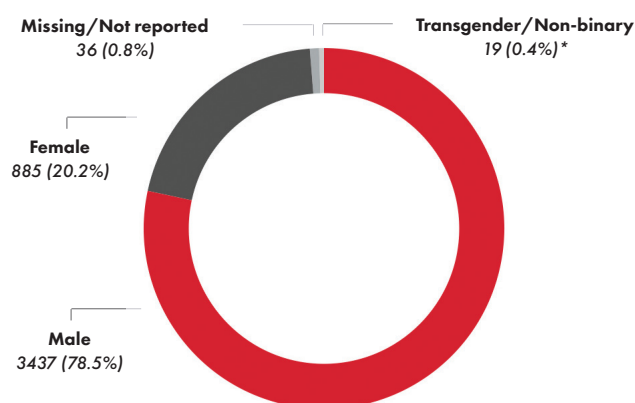
Treatment Action Group’s work to advance racial equity in research will be necessary for the foreseeable future. Our work is grounded in the perspective that access to opportunities to participate throughout the research process falls within a Right to Science framework, which emphasizes that such

HIV Cure Research Demographic

Demographics of participation in HIV cure-related clinical studies with results presented or published from 2018 to October 2022. Total of 122 clinical trials or observational studies (115 adult, seven pediatric/adolescent), with five providing no sex, gender or race/ethnicity information and 36 providing no race/ethnicity information. Total number of participants: 4475.

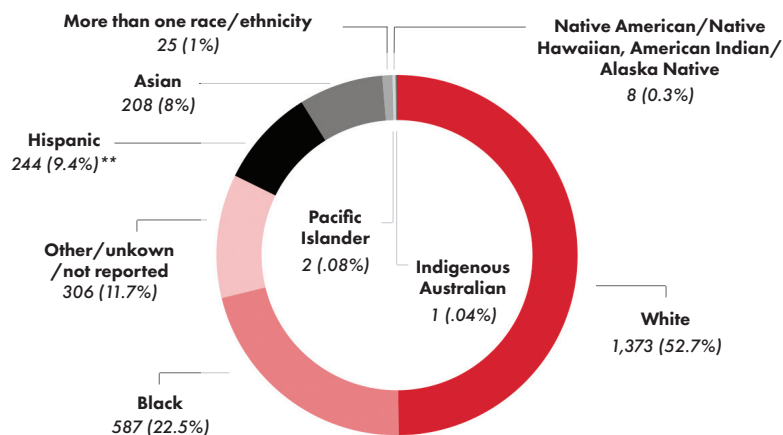
Total from studies reporting sex and gender

(Total=4375)



Total from studies reporting race/ethnicity

(Total=2607)



*Includes two transgender participants reported additively to data presented on sex

**Includes 147 participants of Hispanic ethnicity reported additively to data on race (with their race not specified)

opportunities constitute a human right—not only a right to receive benefits of the applications of scientific progress but also a right to participate in scientific progress.¹²

Over the years, through partnerships such as the Federal AIDS Policy Partnership's (FAPP) Research Working Group and collaborations with the HIV Vaccine Trials Network, Black AIDS Institute, and the Southern AIDS Coalition, TAG has advocated for meaningful involvement of persons living with HIV (PLWH) and historically underrepresented groups in the implementation of clinical research studies, as well as translation of science for research advocates. We commend the FDA's guidance around increasing diversity in clinical trials^{13,14} and NIH's commitment to addressing structural racism,¹⁵ which includes engagement and career advancement of principal investigators from historically underrepresented groups.

It's not enough to focus solely on diversity among research study participants. We also need to ensure that meaningful and inclusive community engagement drives all aspects of research endeavors, with intentional investments in maximizing diversity among researchers and clinical staff. There are persistent gaps in this regard that need to be filled. For example, Historical Black Colleges and Universities (HBCUs)

aren't prioritized enough with respect to NIH funding for HIV biomedical prevention research, despite their reputation as trusted sources for their communities. The U.S South still has the highest incidence of HIV, which unfortunately remains insufficiently reflected in advocacy efforts and funding.

Furthermore, most U.S. investigators in the HIV Prevention Trials Network (HPTN) have been of majority race/ethnicity and sexual orientation.¹⁶ To that end, HPTN developed a special initiative, the HPTN Scholars Program, to recruit, engage, train, and mentor young racial/ethnic minority investigators within a large HIV prevention clinical trials collaborative group, which includes support for short-term projects for medical students. Currently, of all the scholars who have completed the program thus far, 22% are Black/African American and 4% are Hispanic/Latino/Latina. It's essential to increase investments in and scale up such programs in order to reach as many researchers and advocates as possible from underrepresented communities.

Another heartening recent development is the advent of the We the People Research Cohort (WTPRC), a joint project of the Fred Hutchinson Cancer Research Center, Treatment Action Group, Southern AIDS Coalition, and the Black AIDS Institute. This unique partnership developed an innovative curriculum

for HIV advocates and trained individuals in research advocacy through a 16-week certification program. The WTPRC project utilizes the framework of Community Based Participatory Research. In development of the training modules and curriculum, we applied Good Participatory Practice Guidelines,¹⁷ which involved an iterative process between staff members from partner organizations and community stakeholders. An additional lesson for increasing diversity and inclusion in clinical research comes from the COVID-19 Prevention Trials Network (CoVPN). Clinical research sites that were a part of the CoVPN successfully enrolled 47% of COVID-19 vaccine trial participants who identified as Black, Indigenous, and People of Color (BIPOC). The increased enrollment of BIPOC in the CoVPN trials further builds the case that equitable enrollment of BIPOC communities is achievable

when there are adequate resources and an established commitment to doing so.¹⁸

As we look toward achieving the goal of ending HIV, we realize this cannot be done without clear recommendations and policies to ensure that diversity and inclusion is at the center of HIV biomedical prevention research and advocacy. As Dafina Ward, executive director of the Southern AIDS Coalition, poignantly notes: *“Ending HIV . . . will require us to lean in and learn from those closest to the epidemic. We need data that tells the whole story — research that captures the full spectrum of experiences and communities impacted by HIV. We have to make things more accessible and remove the mystery around people gaining access to research, resources, and opportunities.”*

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POLITICAL NEGLECT AND CORPORATE GREED

A Panel Discussion on Finding and Treating the #MissingMillions with TB + HCV

By David Branigan, Joelle Dountio Ofimboudem, and Natalie Shure

TAG was founded in 1992 with the aim of accelerating the availability of effective HIV treatments through science-based advocacy at every step of the research, development, and implementation process. These strategies helped deliver antiretroviral treatment regimens in 1996 but have required sustained action from activists, civil society, and governments to get them to the tens of millions of people around the world whose lives have been saved by these revolutionary drugs. Nonetheless, there are still hundreds of thousands of preventable AIDS deaths each year, many of which are caused by TB and HCV — two prominent HIV coinfections that TAG added to its mission in 2000 and 2012, respectively. Like HIV, both the TB and HCV pandemics disproportionately affect marginalized communities and have been worsened by political neglect, inadequate funding, and corporate greed. In a roundtable discussion moderated by Communications Coordinator Natalie Shure, HCV Acting Project Director Joelle Dountio Ofimboudem and TB Project Officer David Branigan discuss key opportunities for expanding access to care and cures moving forward:

NS: HCV and TB are both curable, but there are access problems at every level of care. What are the current challenges and future opportunities for scaling up access to key innovations that could accelerate the end of the pandemics?

JDO: For HCV we do have curative originator and generic treatments, but in a lot of countries these treatments are not accessible. HCV is not prioritized by most national health programs and millions of people with HCV remain undiagnosed. As a result, demand for treatment remains very low, rendering the market unattractive to generic developers. Moreover, the HCV diagnosis pathway in many countries remains very complex, requiring several steps, and resulting in people being lost to follow-up. One key opportunity is to simplify diagnostics to make it easier to test and treat HCV. Also, Children aged three years upwards diagnosed with HCV should be treated per the [World Health Organization \(WHO\) updated recommendations](#).

DB: As with HCV, much more must be done to find people with active TB. Countries have been very slow to scale up TB technologies — we see this in both treatment and diagnostics. Smear microscopy — a nineteenth century technology — persists in many places to diagnose TB, even though the WHO has recommended rapid molecular testing as the initial TB diagnostic test since 2013. To make matters worse, Cepheid held a decade-long monopoly on rapid molecular diagnostics for TB. Due to COVID-19 related lockdowns and health system disruptions, the TB diagnostic gap widened from 2.9 million people in 2019 to 4.2 million people in 2020 (out of the 10 million people estimated to develop active TB each year). Still, we're hopeful that new tools developed for COVID-19 will have applications for TB moving forward.

NS: So what are some of the main ways of addressing these barriers? And what role will TAG play within that broader strategy?

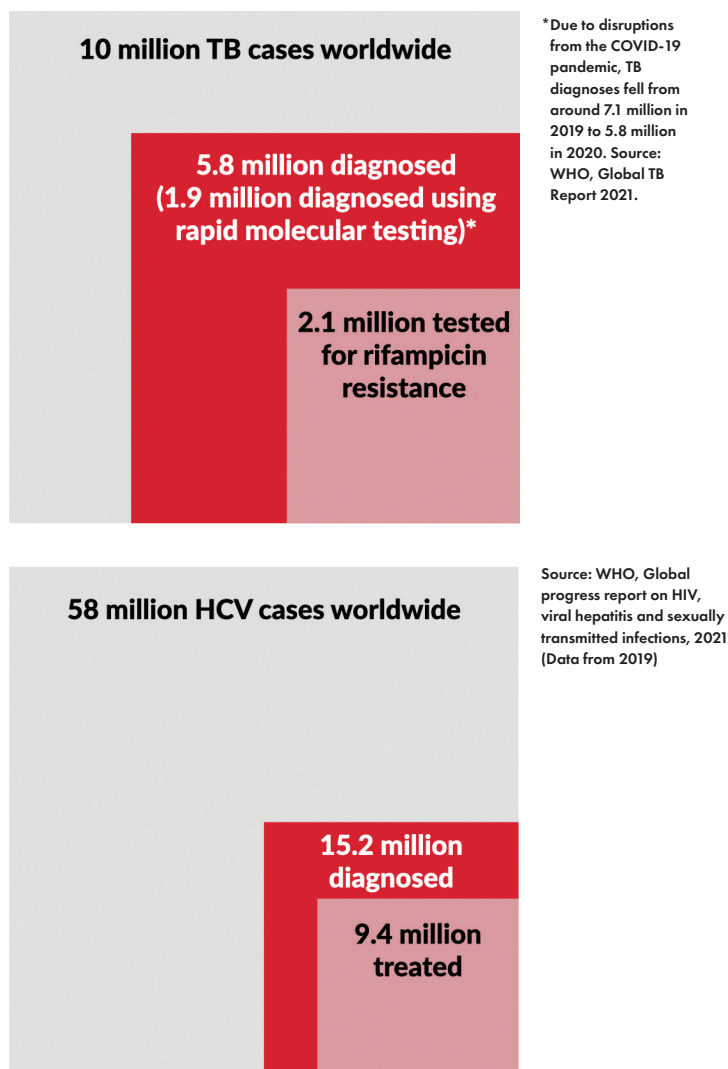
DB: The fact that Cepheid continues to be the dominant supplier of rapid molecular diagnostics for TB and other infectious diseases has resulted in limited leverage in negotiations with the company and a lack of sufficient consequences for Cepheid's nontransparent high pricing and inadequate service and maintenance (often leading to unacceptably long downtime between repairs). High prices of tests, equipment, and warranties have in turn contributed to slow scale-up by countries. To address these challenges, TAG joined with allied communities and civil society organizations to form the Time for \$5 Coalition, which aims to push Cepheid to lower its test prices and improve service and maintenance across diseases. The Coalition also calls for donors and other global health actors to break down disease silos and pool procurement volumes across diseases to maximize bargaining power with Cepheid and other suppliers while investing in competing technologies (in addition to Molbio's Truenat) to break the Cepheid monopoly and bring TB testing closer to the point of care.

JDO: In terms of barriers for hepatitis C, governments need to start by ensuring that HCV national elimination plans include people at high risk; namely, people who use drugs, men who have sex with men, people in incarceration, immigrants, etc. Civil society needs to continue to push for decentralization of care to ensure delivery of HCV testing and treatment at community-based facilities; integration of HCV testing and treatment with existing care services at peripheral health facilities; and task sharing to ensure delivery of HCV testing, care, and treatment by trained non-specialist doctors and nurses to scale up HCV diagnosis and expand treatment access. To this end, through the Hep C PACT, TAG together with other partners is working with stakeholders in select countries to help foster an enabling environment for improved availability of HCV diagnostics and treatment in high burden low- and middle-income countries. We know that around 58 million people around the world are living with HCV, and close to 80% of these people do not know they are infected, so we must scale up diagnostics to find and treat the “missing millions” just as in TB. But without dedicated global funding for HCV elimination, direct acting antiviral (DAA) manufacturers and health ministries are less likely to act. TAG provides technical support to civil society to build community pressure as a force for change — for example, through platforms like [mapCrowd](#) and [hepCoalition](#), codeveloped with other partners — that enable advocates to crowdsource and share key data and resources to inform their advocacy work.

NS: As the COVID-19 pandemic wore on, the international push to suspend intellectual property rights to achieve global vaccine equity has not had the success that advocates hoped. How should that experience inform treatment activists’ work moving forward? How should these crises of access change the approach of civil society?

DB: For diagnostics, intellectual property isn’t currently the main barrier to access. Rather, it’s the need for increased investment in research and development and local manufacturing capacity to introduce more competition and further undermine Cepheid’s monopoly, which is also key for global vaccine equity. During the pandemic, Cepheid developed and marketed a COVID-19 test, but prioritized orders from high-income countries and undersupplied low- and middle-income countries, essentially selling to the highest bidder. This is in spite of the fact that Cepheid received over \$250 million in public investment to develop GeneXpert technology, including the COVID-19 test. A similar pattern is seen across health technologies, including COVID-19 vaccines — the public invests in the development of new technologies but has limited ability to secure affordable pricing and equitable access. COVID-19 vaccine hoarding by high income

Key Diagnosis and Care Gaps for TB and HCV



countries and Cepheid’s refusal to implement lower pricing for diagnostic assays or prioritize orders for COVID-19 tests from low- and middle-income countries point to a common problem as well as a key opportunity moving forward: activists should push for the inclusion of access conditions on public funding for new technologies — conditions such as requiring transparency for evidence-based equitable pricing, volume-based price reductions, and, where appropriate, the obligation to fulfill orders from low- and middle-income countries, which was a huge problem during COVID-19. By including these conditions on funding, our hope is that this will create a healthier market that is able to meet global public health needs. To ensure that community voices most affected by infectious diseases have a seat at the table, global health donors should invest in community engagement in research and financially support civil society organizations in high-

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TAG AT 30: MILESTONES

By Dorrit Walsh and Mark Harrington

Since 1992, Treatment Action Group has been advocating for those affected by and struggling with HIV. Since then, we've expanded our mission to include tuberculosis (TB) — the leading cause of death by infectious disease worldwide — and hepatitis C (HCV).

It's impossible to cover a full 30 years of history in a short retrospective, but for this issue of TAGline, we think it's important to cover some major milestones. This is in no way meant to be a complete history of TAG.

TAG played a major role in compelling the pharmaceutical companies developing protease inhibitors to study these drugs and provide information on how to use them.

1992–2002

Fight for Survival

In 1992, AIDS activists were suffering from growing pains, burnout, and a continuing failed government response to the disease. ACT UP/NY, which was the largest group at the time, was rife with infighting, and at the same time many of its leaders and members were dead or getting sick. In January of 1992, some members of the ACT UP Treatment and Data Committee (many already infected) formed a new nonprofit organization focused on accelerating treatment research. Initially, TAG's first action targeted drug companies whose prices were considered too high and therefore prohibitive. The group's first media story, "AIDS Hit Squad Seeks More Than Attention," written by Catherine Woodard, was published in *Newsday*.

In mid-1992, to focus policymakers' attention on making AIDS research more strategic and better-funded, in July TAG cofounders Mark Harrington and Gregg Gonsalves presented "AIDS Research at the NIH: A Critical Review" at the 8th International Conference on AIDS in Amsterdam. TAG's recommendations to reform the NIH AIDS research program were signed into law by President Clinton in June 1993.

TAG's activities in its first decade continued to center on getting government and drug companies to finally listen to our concerns. TAG played a major role in compelling the pharmaceutical companies developing protease inhibitors to study these drugs faster and provide information on how to use them. TAG sped up research into opportunistic infections and cancers that at the time were leading killers of people with HIV. Triple combinations of highly active antiretroviral therapy (HAART) were introduced in 1996, and brought down the AIDS death rate by two-thirds in rich countries, creating a revolution.

TAG worked relentlessly to achieve broader access to HIV treatment in developed and developing countries. We worked with South Africa's Treatment Action Campaign (TAC) to conduct a series of three-day treatment literacy workshops in November 2000, spearheading work that led to their government finally providing life-saving HIV treatment to over 5 million South Africans.

2002–2012

Mission Expansion

TAG's second decade (2002 – 2012) centered on broadening and deepening the methods of treatment activism TAG had pioneered in its first ten years. We added TB and HCV to our agenda and worked on getting better prevention, treatments, and vaccines for those two epidemics. We broadened our partnerships to more closely include the communities most affected by these diseases. We worked closely with organizations that worked in Africa, Asia, Latin America, and the former Soviet Union. Our work with HCV made it essential to get involved with groups concerned with prisoners, sex workers, and drug users.

TAG concentrated on getting better drugs and more access to HIV drugs — not only in the United States, but around the world. The pinnacle of our efforts in the second decade was

the 19th International AIDS Conference in Washington, DC, in 2012. This was the first time the conference had been held in the U.S. since 1990. (This was due to the U.S. government's decision in 1987 to mandate HIV screening for all visitors over the age of 14. This ban stayed in effect until Congress lifted it in 2009, which paved the way for the conference to once again return to the United States.) It was also during this conference that Mark Harrington along with leaders from other U.S.-based activist groups participating in a global march on the White House were arrested. By chance, Mark was put in the same van as his friend and ally Charles King, executive director of Housing Works. It was in that van that they came up with a plan to use New York State and New York City as a test case to create a program that could help end AIDS as an epidemic in New York.

2012–2022

Equitable Access

In the past decade (2012–2022), TAG has continued to fight for equitable access to treatment for HIV, HCV, and TB, and for accelerating research for better treatment and prevention.

With Housing Works, we launched a statewide coalition of activists, people with HIV, and providers and persuaded New York State and City to endorse an ambitious effort to end AIDS in New York by providing effective treatment and prevention to all. Despite many obstacles — including COVID-19 — we are on track to making AIDS history in New York, and other jurisdictions are now beginning their own such efforts.

Back when we began working on TB, it took a long time to cure and many of the drugs came with their own horrible side effects. But in the past ten years, treatment of this disease has been shortened and radically simplified.

HCV has a similar story. Treatment for this disease went from ineffective and very toxic to 99% curative two-drug, two-month regimens. We also worked successfully to make HCV treatment more affordable in the U.S. and around the world. Theoretically, we could eliminate HCV, if only countries would implement affordable access to treatment.

Despite many obstacles — including COVID-19 — we are on track to making AIDS history in New York, and other jurisdictions are now beginning their own such efforts.

Into the Future

Thirty years is a long time, and so much has changed since twenty angry treatment activists left ACT UP in 1992 and set out on their own mission. We've had successes and we've had failures. 40 million people have died from HIV since the pandemic began; in the past two centuries, a billion people have died from tuberculosis and millions from HCV. We're closer to ending these epidemics, but not close enough. With your support, we can continue the progress that began 30 years ago.

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burden countries to engage communities in treatment and diagnostics literacy and advance advocacy to generate demand for new tools.

JDO: Global inequities in COVID-19 diagnostic tools, vaccines, and treatment access simply spurred the decades-long broader access to medicines and health technologies movement more generally and made it clear that the World Trade Organization is not the right forum to address these challenges. Ultimately, there's a great need to rethink the global trade regime, and governments need to understand

that. Apart from these international efforts that were basically initiated and led by civil society organizations and very few countries, governments individually also need to play their part in making use of available flexibilities included in the Trade Related Aspects of Intellectual Property Rights (TRIPS) Agreement, national intellectual property laws, and trade secret laws. So, there is a great need for civil society organizations to engage with, and push for reform with policymakers not just at the global level, but also at the local and country levels.

SAVE THE DATE!

Research in Action Awards

November 14, 2022

New York City + Live Stream

Tickets, event info, and more: treatmentactiongroup.org/riaa

SUPPORT TAG

TAG has been a leader in ending HIV/AIDS since our founding in 1992. Now, in our 30th year, we continue to make strides toward improving research, access, and treatment toward ending HIV, tuberculosis, and hepatitis C. But there's more work to be done, and our ability to continue to fight relies on your support. Please give today and help us continue to save lives in 2022.

Make a donation today: treatmentactiongroup.org/support-us/donate

ABOUT TAG

Treatment Action Group (TAG) is an independent, activist, and community-based research and policy think tank committed to racial, gender, and LGBTQ+ equity; social justice; and liberation, fighting to end HIV, tuberculosis (TB), and hepatitis C virus (HCV).

TAG catalyzes open collective action by affected communities, scientists, and policymakers to ensure that all people living with or impacted by HIV, TB, or HCV — especially communities of color and other marginalized communities experiencing inequities — receive life-saving prevention, diagnosis, treatment, care, and information.

We are science-based activists working to expand and accelerate vital research and effective community engagement with research and policy institutions for an end to the HIV, TB, and HCV pandemics.

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