news on tag’s progress in the fight against aids

DEAR FRIENDS OF TAG,

I’m so proud to send you this 2011 TAG Update to fill you in on the amazing work TAG continues to do in the struggle to end AIDS and its deadliest coinfections, hepatitis C virus (HCV) and tuberculosis (TB). In 2011, TAG launched our new Accelerating Research to Cure AIDS Campaign, continued our global leadership in community activism against HCV and TB, and worked with scientists, government, industry, regulators, providers, and the community to ensure that all people with HIV have the information and treatment they need to live long and healthy lives. Our work has been challenged by the global economic crisis, while the promise of scientific breakthroughs to end the epidemic has never been stronger. We are deeply grateful to you and to all of TAG’s supporters who make our work possible.

Barbara Hughes
President, Board of Directors

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Accelerating Research to Cure AIDS Campaign

In April, TAG—along with the Foundation for AIDS Research (amfAR), the AIDS Policy Project, and Project Inform—cosponsored the first international workshop on HIV cure-related clinical research issues. The meeting brought together over 50 leading scientists, funders, regulators, and community activists to discuss research priorities and to identify regulatory barriers toward conducting successful HIV-cure clinical trials, and led to a report laying out a series of recommendations to all stakeholders. The report can be accessed online at: www.treatmentactiongroup.org/cure/2011-workshop-report.

TAG’s cure advocacy continued in June. Robert Monteleone and Steven Mack hosted a reception at which Dr. David D. Ho of the Aaron Diamond AIDS Research Center in New York City discussed the long journey and recent hopeful results of research aimed at curing HIV infection. That day, TAG launched its Accelerating Research to Cure AIDS Campaign, a challenge seeking donors to commit $5,000 or more each year to support TAG’s HIV-cure advocacy for the next four years. This year, TAG succeeded in raising over $100,000 for our cure advocacy work. With your help, next year we can bring a cure closer to reality.

Inspired by TAG’s Accelerating Research to Cure AIDS Campaign, board member Robert Monteleone hosted a small reception at his apartment on November 18, 2011, to honor a group of TAG supporters who teamed up to collectively pledge $5,300 a year for the next four years to support TAG’s work. Led by Jim Aquino and Bob Bronzo—veterans of ACT UP who have known TAG’s work from the beginning—this group dubbed itself UNITED for the Cure. TAG is honored by their support.

With political stalemate threatening federal funding for critical AIDS research, TAG launched the What Would You Do for the Cure? initiative—a grassroots campaign to strengthen congressional awareness of, and the need for investment in, HIV cure and aging research. Thirty-five activists from 20 states attended over 100 Senate and House visits on Capitol Hill. These activists will continue their work to identify new congressional champions and to develop bipartisan support for AIDS research at the National Institutes of Health (NIH).
Focus on Hepatitis C

In 2011, HCV research has advanced by decades in a matter of months; in addition to the approval of two new direct-acting antivirals, there are more than 50 ongoing clinical trials looking at both new drugs and treatment strategies. Companies are collaborating on studies of their drugs, and interferon-free treatment is quickly becoming a reality. In the words of one researcher, it is “HIV drug development on crack.”

TAG’s Hepatitis/HIV Project has been front and center, working with regulators, the pharmaceutical industry, other activists and community members, researchers, clinicians, and service providers on these exciting new developments. Tracy Swan, our Hepatitis/HIV Project director, spoke at the Food and Drug Administration’s new drug application hearing, where she advocated for trials to address underrepresentation of populations with high hepatitis C rates, and stressed the urgent need for treatment and for studies on interactions between new medications and commonly used drugs.

Liver disease from HCV is now a leading killer among HIV-positive people. But new HCV drug trials in people coinfected with HIV have had to wait until the drugs are first approved for people with HCV alone. As a cofounder of the Hepatitis C Community Advisory Board (HCAB), an international activist group, TAG met with six pharmaceutical companies to discuss early access and clinical trials for people who are co-infected. This year, for the first time, a 300-person, phase III trial has opened exclusively for people with HIV and hepatitis C, and interim results from smaller trials in coinfected people are available.

TAG also co-organized Sitges IV, the fourth multi-stakeholder meeting with the European AIDS Treatment Group, guiding drug makers, regulators, and researchers on how best to provide early access to experimental HCV drugs for people who are not eligible for clinical trials.

The Hepatitis/HIV Project continued to draw from the successes in HIV, and worked closely with allies to broaden access to, and improve the quality of, hepatitis C care and treatment, domestically and globally. The Project brought the latest information to the community through publications, workshops, and presentations, including a stand-alone report on HCV Drug Development, released A Guide to Clinical Trials for People with HCV, conducted a two-day workshop in San Francisco, training counselor/testers working in California’s correctional facilities, and presented at support groups, community forums, and public think-tank meetings.

Michael Palm Basic Science, Vaccines & Prevention (BSVP) Project

In addition to organizing the HIV Cure-Related Clinical Research Workshop in April, TAG’s BSVP Project and other sponsoring organizations sent a follow-up memorandum to the U.S. Food and Drug Administration and the NIH’s Office of AIDS Research (OAR) addressing cure-related regulatory and clinical research issues. The BSVP also supported and helped organize a smaller informal meeting on the same subject involving around 20 researchers and community advocates, which took place at the Conference on Retroviruses and Opportunistic Infections in Boston in March. BSVP created and maintained a cure-related research resource page on the TAG website featuring articles from the community and the popular and academic presses, and links to open clinical trials.

On the emerging issue of HIV and aging, BSVP worked with the TAG-initiated Coalition for HIV and Aging Research and Policy Advocacy (CHARPA) to recommend the creation of a working group at OAR. The group was created in early 2011, met several times during the year, and submitted research recommendations to OAR. BSVP also developed a report on the immunology of aging and HIV infection that will be published shortly. BSVP contributed a chapter on biomedical prevention, immune-based therapy, and cure-related research to the annual TAG pipeline report, which was distributed at the International AIDS Society conference in Rome in July. BSVP coordinator Richard Jefferys continued to maintain the program’s twitter feed, blog, and a web-based resource on clinical trials for individuals with poor immunologic responses to antiretroviral therapy.

TB/HIV Project

The TB/HIV Project’s third grant from the Bill and Melinda Gates Foundation began in January of 2011; it supports TAG’s efforts to strengthen the voices of activists working on global TB/HIV policy and research advocacy.

TAG organized the first advocacy workshop in July with TB activists serving on the board of the Global Fund, UNITAID, WHO’s Strategic and Technical Advisory Group for TB, and the Stop TB Partnership. As the result of this workshop, for
the first time, there will be a TB presession prior to the next Global Fund board meeting.

To ensure that global policy supports ambitious scale-up, TAG provided extensive input to the update of the WHO’s TB/HIV Collaborative Policy that will be launched in early 2012.

In November, TAG organized the first Global TB Community Advisory Board (CAB). The group was formed to meet with TB drug, diagnostics, and vaccine developers in order to provide a much needed patient-activist perspective. Critical issues of expanded access, compassionate use, the need to study drugs in combination, and the urgency of developing formulations appropriate for children were discussed. The issue of pediatric TB will also be a focus of TAG’s federal advocacy meeting in December. •

U.S. and Global Policy Project

Based in Washington, D.C., TAG’s Policy Project has been advocating for increased AIDS funding for research and treatment despite the challenging fiscal and political environment. With uncertainty over the future of health care reform and Ryan White programs, a growing ADAP waiting-lists crisis, state and federal funding cutbacks, and the derailed National HIV/AIDS Strategy implementation, TAG’s senior policy associate Coco Jervis continues to work on behalf of the needs of the HIV community, including getting people into care and reducing new infections.

As the Research Working Group cochair of the Federal AIDS Policy Partnership, Coco organized monthly strategic planning calls to fight for the NIH’s AIDS research funding portfolio. She also submitted congressional testimony in support of greater NIH funding. In collaboration with amfAR, TAG updated our well-received AIDS research funding policy brief, AIDS Research: Broad Health & Economic Benefits, which has since been distributed to hundreds of congressional offices and Obama administration staffers. Coco has also been taking a leadership role in HIV/TB appropriations advocacy, promoting better integration of TB/HIV services, addressing the multidrug-resistant TB treatment shortage in the U.S., and working toward building a greater global childhood TB advocacy community. •

TAG IN THE NEWS

Reporting from the International AIDS Society Conference in Rome, the website Medpage Today quoted TAG’s Executive Director Mark Harrington in the article Cure Comes Out of the Closet.

www.medpagetoday.com/MeetingCoverage/IAS/27628?pfc=101&spc=224

In October, Mark Harrington co-authored a commentary published in the medical journal Lancet: Time for Zero Deaths from Tuberculosis.

The New York Times published New Hope of a Cure for H.I.V. on November 28th, in which Mark called attention to the need for safeguards in cure-related clinical trials in the age of effective antiretroviral therapy.


SUMMER FUNDRAISER ON FIRE ISLAND

On August 6, 2011, TAG board members Frank Rappa and Monte Steinman cohosted a special summer fundraiser for TAG at the Fire Island Pines. The party, at the home of John Yakubik and Marc Berman, with support from A|X Armani Exchange, Chopin Vodka, and Sip•n•Twirl, raised over $4,000 for TAG’s work. In attendance were N.Y. State Senator Tom Duane and his partner Louis Webre.
TAG Remembers

Elizabeth Taylor

March 23, 2011, marked a sad day in the global fight against AIDS and for everyone whose lives were touched by the passion and genius of Elizabeth Taylor. TAG remembers her fierce advocacy for the human rights and dignity of people living with AIDS and people at risk for HIV, including the most marginalized and dispossessed. Elizabeth Taylor fought fiercely against the Clinton administration’s irrational refusal to support needle-exchange and harm-reduction programs to prevent the spread of HIV among drug users and their communities. She supported visionary, early community-based needle-exchange programs that documented their effectiveness in reducing HIV transmission among drug users to less than 1% year, setting the stage for growing adoption of these interventions by public health authorities worldwide. TAG is grateful to Elizabeth Taylor for her strong support of AIDS research advocacy. Above all, TAG remembers and will mourn Elizabeth Taylor’s profound ability to touch our lives, changing hearts and minds, and focusing our attention on our common humanity.

TAG extends our deepest condolences to Elizabeth Taylor’s family, friends, and loved ones around the world.

On October, 2011, a memorial celebration was held for Elizabeth Taylor at the Warner Brothers studio lot in Burbank, CA. TAG’s Mark Harrington and Barbara Hughes attended the event.

Winstone Zulu (1964-2011)

The first individual in Zambia to publicly acknowledge his HIV status, Winston Zulu died on 12th October 2011 at University Teaching Hospital in Lusaka. Born in 1964 in Lusaka, Zambia, Winstone was the sixth of thirteen children. After being diagnosed with HIV in 1990, he contracted TB in 1997. With access to effective medicines and treatment, he was cured of the disease [TB] within that same year.

Not only was Winstone Zulu a hero in the fight against AIDS, but he was also a pioneer in bringing AIDS activism to the hitherto barren and civil society free zone of TB prevention, treatment, and care. Winstone continued to speak bravely and with a calm passion. At Bangkok in 2004, he was inspired by meeting Nelson Mandela at a press conference where he and Mandela shared the stage; Mandela said, “We can’t fight AIDS unless we do much more to fight TB as well.” Winstone spent years traveling all over the world, speaking with activists, media, and politicians about the struggle of living with HIV and fighting the constant threat of TB. Winstone Zulu worked tirelessly to change the world, at no small cost to his own health and well-being. His legacy is a stronger link between HIV and TB activists, and his inimitable calm and passionate voice of reason will be deeply missed.
December 2011

TAG PUBLICATIONS

HIV Cure-Related Clinical Research Workshop Report

A body of recent research findings suggests that a cure for HIV infection may not only be possible, but potentially achievable in our lifetimes—a prospect that was once almost unimaginable. Based on a TAG-cosponsored workshop, this report identifies key issues that need to be addressed to facilitate and accelerate the conduct of clinical research in pursuit of this vital goal.


Guide to Clinical Trials for People with Hepatitis C

There are many new hepatitis C drugs in clinical trials. People with hepatitis C now have many options to choose from, making it difficult to decide whether to participate in a clinical trial, and how to select a trial. The risks and benefits of enrolling in a clinical trial may depend on the type and stage of hepatitis C, the drug or drugs being studied, HCV treatment history, other medical conditions, and personal considerations. This new guide from TAG is a unique resource to help people make informed choices, and includes an overview of the drug development process, with HCV-specific information.


Tuberculosis Research and Development: 2011 Report on Tuberculosis Research Funding trends, 2005-2010

For the sixth year, TAG publishes the latest data on global investments in tuberculosis (TB) research and development (R&D). The report offers year-to-year data on the leading TB research funders and analyzes funding trends across six TB research categories and four donor sectors. Most important, the report examines the state of TB research funding and underscores the urgency of adequate and sustained funding to produce the powerful new tools the world needs to eliminate TB as a public health threat by 2050.

www.treatmentactiongroup.org/tbrd2011

An Exploratory Analysis of HIV Treatment Research and Development Investments in 2009

The HIV treatment research landscape is changing. Thanks to recent treatment scale-up, prevention-science breakthroughs, and the new global treatment target of 15 million by 2015, there is real momentum to bring the epidemic under control and ultimately end it. To capitalize on these scientific gains, continued investment and innovation are necessary to prevent new infections, to ensure people currently on treatment are able to continue, and to scale up treatment to reach all those who will benefit from earlier initiation of antiretroviral therapy.


An Evaluation of Drug-Resistant TB Treatment Scale-Up

The global response to multidrug-resistant tuberculosis (MDR-TB) is underfunded and ineffective. This report from TAG, MSF, and Partners In Health looks at the programs in India, Russia, and South Africa, and finds that a lack of urgency and commitment from governments is a major stumbling block; donors are not making TB a priority; and unpredictable and expensive drug supplies are causing shortages and stock-outs, with serious consequences for patients.

TAG board member Robert Monteleone hosted a reception for UNITED for the Cure, a group of TAG donors led by Jim Aquino and Bob Bronzo, who banded together to commit $5,300 a year for four years for TAG’s Accelerating Research to Cure AIDS Campaign. From left to right: Greig Sargeant, David Levine, Karen Bronzo, Bob Bronzo, Tim Ford, Michael Beltran, John Deyling. In front: Jim Aquino, Robert Monteleone, Joe Lauretano. Members not in picture: Jefferson Rabb, Sunita Viswanath, Stephan Shaw, Jim Edwards, Drew Hodges.

TAG BE INVOLVED

Contribute

TAG welcomes donations from individuals who want to see the AIDS research agenda remain responsive to the needs of all people living with HIV. Make a tax deductible gift now.

www.treatmentactiongroup.org/support

Join TAG’s Board

TAG is always seeking new board members. If you are looking for a great place to invest your time and talents, please call Barbara Hughes, TAG Board President, to learn more about board opportunities with TAG.

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About TAG

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.