

TAG

FALL 2005

update

INTERVIEWWITH JAVID SYED,
TAG TB/HIV PROJECT DIRECTOR

photo: Tracy Swan

Philippine activists **Joshua Formentera** and **Nenet Ortega** with TAG's TB/HIV Project Director, **Javid Syed**, at TAG's 4th International TB/HIV workshop in Paris, October 2005.

Q. How did you get involved in AIDS work?

In the late 80s/early 90s I was a recent immigrant to the US, living in Bowling Green, OH. The queer community that the campus had to offer felt very single issue and basically racist. I started volunteering at an HIV testing site as it was clear to me that HIV was a social justice issue that highlighted the ways in which sexuality, gender, race, and poverty all came together to define who survived and who didn't. Besides the HIV testing clinic, I also volunteered at a hospice for homeless people living with HIV/AIDS, which also opened my eyes to the levels of inequity that existed in the U.S. Those experiences solidified my commitment to work on the disparities underlying HIV through a lens of health. I continue to do this work with that goal to this day.

Q. Why TAG? Why now?

I have spent most of my paid work supporting services for immigrant and queer people of color. Though I believe that service sites can be a vital space for organizing, I found that most service agencies were challenged in striking that balance in the face of government crackdowns and financial restrictions. When I moved back to New York after my last job in San Francisco, I looked

for work that was focused more on activism and less on service. I also wanted to support movements in the global south that were fighting for improved health access. HIV is a health concern that has underscored the connection between public health and human rights. The history of HIV and current state of global activism is constantly inspiring to me. TAG, with its own rich history of AIDS activism, has brought together many of the things that I was looking for in my work. I also find the prospect of enhancing impacted communities' ability to understand, demystify, and use scientific information to be better-informed advocates very exciting.

Q. What are you doing at TAG?

Currently my work encompasses three primary areas: 1) To build a base of global TB/HIV activists. We do this through our annual TB/HIV community mobilization workshop and through strengthening the networks of activists in extant organizations like the International Treatment Preparedness Coalition with a focus on TB/HIV. 2) To partner with funding organizations and research institutions to ensure that they support community advocacy projects and involve communities impacted by TB/HIV in all levels

of decision making and priority setting. Our partnerships with the Open Society Institute's TB/HIV Advocacy Grant Project and the TB Trials Consortium are examples of this work. 3) To channel the leadership from our base building work to impact policymaking bodies to inform and transform their policy platforms. The goal is to ensure that TB/HIV policies are developed with an active engagement of people most affected by the dual epidemics. In part due to TAG's initiative, the Stop TB Partnership (a global policy body with 400 + public and private partners) for the first time this year has Community Representatives on each of its Working Groups. As you can see, the project involves a diverse set of strategies, which makes it both stimulating and a good challenge.

Q. What are the big research and policy issues?

There are quite a few major research issues in the field of TB. After a long lull, there is currently new energy in research focused on TB treatment and diagnostics. The most commonly used TB diagnostics, the sputum smear test, only detects 45-60% of the cases on an average. In people living with HIV/AIDS, this number is even lower due to higher rates of sputum smear negative or extra pulmonary TB, which doesn't get detected by the sputum test. Addressing the current crisis in diagnostics through the development of new tools is one of the highest research priorities. TB treatment is also burdensome, requiring treatment regimens of at least 6 months. Shortening this regimen will enhance health systems' capacity to serve a greater number of people, and the shortened duration will increase communities' ability to effectively complete the treatment. There are many sub-issues under each of these macro research priorities. For instance the need to detect people with latent TB that are most likely to progress to active TB is a crucial diagnostic need. Information on how best to manage concurrent TB and HIV treatments and the role of community participation in supporting treatment adherence and ensuring adequate funding for health programs themselves is another operational research question. Each of these research priorities has significant policy implication on how best to fund, implement,

and evaluate TB programs, with an eye towards a broader vision and plan to strengthen overall health systems in resource-constrained countries. The resource gap that exists in all these areas of research, and the underlying lack of political will, are two policy priorities that need to be addressed for the field to move forward. In the long run, it is my hope that supporting and enhancing the role of community activists will also lead to our increased capacity to address the underlying issues of poverty, race, and gender inequities that are fueling the TB/HIV health crises.

Pictures from TAG's 4th International TB/HIV Community Workshop, October 2005



TAG's Mark Harrington and Dr. Helene Gayle, M.D., Ph.D., of the Bill & Melinda Gates Foundation, welcome guests at the Foundation's reception honoring the activists at TAG's 4th TB/HIV Community Workshop. The Foundation's Renee Ridzon listens in.



Dr. Haileyesus Getahun (WHO, Switzerland), Eugene Schiff (Agua Buena Human Rights, Dominican Republic), Zackie Achmat (Treatment Action Campaign, South Africa), and Polly Clayden (i-Base, UK) at TAG's 4th TB/HIV Workshop.

OUT & EQUAL WORKPLACE ADVOCATES HONOR RICH LYNN

THANK YOU, MARK O'DONNELL!

This fall, long-time TAG board member Rich Lynn, Ph.D., was nominated for an Out & Equal Workplace Award, given to individuals and organizations that are leaders in advancing equality for lesbian, gay, bisexual, and transgender (LGBT) employees in America's workplaces. In addition to his volunteer work for TAG, Rich was instrumental in gaining a state-of-the-art domestic partner benefits program at his employer, Pfizer Inc. He also established the Out Pfizer Employee Network (OPEN), an extremely active LGBT employee organization that serves as a model for other employee LGBT groups. Congratulations, Rich, on a well-deserved honor!

On 8 September 2005, TAG Board member Mark O'Donnell opened his art-filled downtown loft to members of the host committee for the 2005 Research in Action Awards (RIAA), to be held on 11 December 2005 at Artists' Space in SoHo (see <http://www.aidsinfonyc.org/tag/riaa/event.html>). The event was a wonderful kickoff to RIAA 2005, which will honor long-time AIDS activists New York State Senator Thomas Duane, Cornell University associate professor of public health and former TAG board member Bruce R. Schackman, and artist/film-maker/provocateur John Waters. Thank you to the RIAA 2005 host committee and to you, Mark, for your generous hospitality.

TAG IN THE NEWS

"The Invention of Patient Zero"

New York Magazine, May 2, 2005

...On closer examination, almost everything about this case seems murky. An investigation by the Department of Health turned up no evidence that the New York man passed the virus to anybody. And on March 29, the department put out a press release saying that the patient was responding well to his medications. "The virus that ate New York," as Richard Jefferys, basic-science project director for Treatment Action Group, put it, "is just one case."

"AIDS-Preventative Test Halted By Cameroon Amid Protests"

The Wall Street Journal, February 8, 2005

A study of a promising AIDS-prevention pill was halted by the government of Cameroon after French AIDS activists charged that volunteers got too little information and care for their participation... American AIDS activist Mark Harrington, director of the New York-based Treatment Action Group, charged Act Up Paris with "ethical imperialism" in scuttling the trial. "It's not going to reduce HIV to stop this trial, or provide health care to a single one of those sex workers in Cameroon," said Mr. Harrington. Although FHI could improve its communication with volunteers, he added that stopping the trial "could delay discovery of a powerful prevention tool – if we could ever find out it works."

"Report: Prevention Can Reduce AIDS Costs"

The Associated Press, July 4, 2005

TB is one of the leading causes of death among HIV-positive people, especially in the developing world," said Javid Syed from New York-based Treatment Action Group. Yet governments have typically looked at TB as a low-tech disease of the past, and cut spending. Ignoring the problem also proved costly in the United States. A delay in addressing the HIV/TB threat in New York cost the city \$1 billion as hard to treat, multi-drug resistant strains of TB infected HIV positive people, he said.

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JOIN TAG'S BOARD

TAG is always looking for good 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 at TAG. She can be reached at 212.253.7922 or at barbarah@projectrenewal.org. Don't delay!

ABOUT TAG

Founded in 1992, the Treatment Action Group, or TAG, fights to find a cure for AIDS and to ensure that all people living with HIV receive the necessary treatment, care, and information they need to save their lives. TAG focuses on the AIDS research effort, both public and private, the drug development process, and health care delivery systems. We meet with researchers, pharmaceutical companies, and government officials to encourage exploration of understudied areas in AIDS research and speed up drug development, approval, and access. We work with the World Health Organization and community organizations globally, and strive to develop the scientific and political expertise needed to transform policy. TAG is committed to working for and with all communities affected by HIV.

CURRENT TAG REPORTS

What's in the Pipeline: New HIV Drugs, Vaccines, Microbicides, HCV and TB Treatments in Clinical Trials by Rob Camp, Richard Jefferys, Tracy Swan & Javid Syed, edited by Mark Harrington & Bob Huff, published in July 2005, is available on the TAG website at <http://www.aidsinfonyc.org/tag/tx/pipelineIntro.html>

Fall 2005 Antiretroviral Pipeline with links to CROI 2005 Abstracts and IAS 2005, updated 11/5/2005, Rob Camp's comprehensive, regularly updated guide to new anti-HIV drugs in development, <http://www.aidsinfonyc.org/tag/tx/pipeline2005b.html>

Basic Science & Vaccines Weblog, by Richard Jefferys, with regular updates on key issues in AIDS research, immunology, and the search for a vaccine, http://tagbasicscienceproject.typepad.com/tags_basic_science_vaccin/

Towards a Revolution in Tuberculosis (TB) Prevention, Care and Treatment, statement released at the 36th World Congress on Lung Health, 23 October 2005, Paris, France. In English, French, Spanish, Russian & Chinese, endorsed by activists from around the world, <http://www.aidsinfonyc.org/tag/tbhiv/revolutionTB.html>

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