

tagupdate

NEWS ON TAG'S PROGRESS IN THE FIGHT AGAINST AIDS

HIV Research Catalyst Forum

A HIGHLIGHT OF 2010 EMPOWERS NEW ACTIVISTS

The HIV Research Catalyst Forum: Treatment, Prevention, Advocacy was a unique conference focusing on community advocacy in HIV treatment and prevention research—from identifying research priorities to overcoming research barriers. TAG collaborated with several partners and allies to host the HIV Research Catalyst Forum in Baltimore, Maryland, in April 2010. The four-day workshop brought together new and experienced activists from around the United States to focus on issues such as AIDS and aging, policy and a cure for HIV. As Lei Chou, Hepatitis/HIV Project coordinator for TAG and one of the conference organizers commented, “The conference was based on TAG’s model of advocacy—empowering

individuals most affected by the disease to understand the issues and know what needs to be done to advance the agenda and amplify the voice of the community.” And amplify we did! The community blog for the conference was active with daily reports from the workshops, including video blogs and musings on how to build advocacy momentum. Postconference, some attendees continued to write for POZ’s blog and to use their newly gained skills to join existing advocacy campaigns. “Having community voices be heard and the intergenerational learning was a high point,” said Coco Jervis of TAG’s policy program. “It was very satisfying to have a part in creating a new cohort of treatment activists.” ●

DEAR FRIENDS OF TAG,

The year 2010 has proven to be another successful and fruitful one at TAG, one of the highlights of which was the HIV Research Catalyst Forum that brought together new activists from around the country to hone their skills and engage in new activism to accelerate HIV research and advocate more intensely for a cure. You can read about TAG program highlights in this issue of *tagupdate*; you’ll find it was a busy year, full of accomplishments. In addition to program success, two new board members, Robert Monteleone and Frank Rappa, have brought talent and passion to the mission of TAG.

I want to thank you for your support and loyalty through-out the years and for ensuring that TAG can continue its core work to advocate for a vaccine and a cure to end the epidemic. You have my commitment that the talent and passion of TAG’s staff will continue the fight against HIV/AIDS on which TAG has built its reputation. Thank you for your continued support.

Barbara Hughes
President, Board of Directors

TAG Remembers Judy Peabody

Judith D. Peabody, New York socialite, and long time supporter of people with AIDS and activist died this year at the age of 80. Judy supported TAG since its inception and was one of the first high-profile people outside the gay community to embrace hands-on AIDS activism.

In the early 1980s when AIDS hysteria was still common, Judy became a care partner at Gay Men’s Health Crisis and cared for dozens of men during their last days. It was for Judy the beginning of a long history of caring for AIDS patients, fund raising, and personally supporting AIDS causes across the country. She did not fear the AIDS stigma of the time and often showed up for her care partner appointments in her signature Chanel suit. Judy’s compassion, grace, and caring were rare in the early days of the epidemic. TAG and its comrades in the fight to end AIDS will never forget Judy Peabody, the many many lives she touched, and her enormous contribution to AIDS activism. ●

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IN BRIEF WHAT'S GOING ON

Hepatitis/HIV Project

It's been an active and exciting year for Tracy Swan, TAG's Hepatitis/HIV Project director. There are dozens of new hepatitis C drugs in development that have the potential to change the way the disease is treated. "People have been waiting for more than a decade for oral HCV drugs, and to see if it is possible to cure hepatitis C without interferon. We are getting closer to the answers. Soon most people will not need a full year of HCV treatment, and cure rates will increase."

Tracy has been working with a new group, the Hepatitis C Community Advisory Board (H-CAB), comprised of U.S. and European activists from the hepatitis C and HIV communities. "HCAB works to see that drug development focuses on 'real world' issues and drugs are studied as soon as it is safe to do so in the people who need hepatitis C treatment most"

Tracy's work has paid off: in 2010, two trials in people who are coinfecting with HIV and hepatitis C were launched—in part due to pressure from TAG. Now coinfecting people won't have to wait years and years to know if new drugs will work for them. But the standard of care for hepatitis C will become more complicated for patients and medical providers. "As with HIV drugs, these new treatments must be used properly or they will not be effective," notes Tracy. "Hepatitis C treatment education is more important than ever. TAG covers the waterfront; we produce materials for people living with hepatitis C and HIV/hepatitis C coinfection, clinicians, service providers, researchers and policy makers. We offer people lifesaving information so that they can make informed decisions about their own health care and advocate for themselves and their communities."

TAG's work on hepatitis B coinfection was challenging for the second year in a row due to the lack of drugs in the development pipeline. As Hepatitis/

HIV Project coordinator Lei Chou notes, "It's only a matter of time before drug resistance develops to the currently available treatments—and there will be nothing in the pipeline to address this in the near future." On the policy side, the news was much better in 2010 as community organizations, including TAG, advanced prevention and screening for hepatitis B coinfection.

In 2010, the hepatitis portion of TAG's website was the most heavily trafficked with over 58,000 page views about patient information on HIV coinfection for viral hepatitis. ●

U.S and Global Health Policy

TAG's policy work had far-reaching effects in the fight against AIDS. With amfAR, TAG published the policy brief *A Sound Investment: The Multiplier Effect of AIDS Research*. Sue Perez, TAG's policy director, notes that, "we received positive feedback, and thank-yous from congressional staff, the Office of National AIDS Policy, the Office of AIDS Research, and staff at the National Institutes of Health (NIH), and heard that the policy brief was being used in government budget discussions to help make the case for greater AIDS research funding." Sue also worked to raise the issue of PEPFAR underfunding at the highest political levels by partnering with the Lantos Foundation for Human Rights and Justice to issue a statement at the International AIDS Conference in Vienna calling on the U.S. administration and Congress to honor its commitment to fully fund PEPFAR.

Coco Jervis, TAG's senior policy associate, worked to keep people with HIV at the forefront of U.S. health care reform. A big achievement is the fact that now single, childless adults with HIV are entitled to Medicare and cannot be denied care due to a preexisting condition. Coco's other big focus was the National HIV/AIDS Strategy (NHAS), which advocates have been waiting for to fix the patchwork of

ineffective and uncoordinated efforts to adequately address the AIDS epidemic in the United States. Despite progress, Coco knows there is a lot of work ahead. "The National HIV/AIDS Strategy is finally out. Now we have to work to ensure that the implementation truly addresses the needs of getting people into care and reducing new infections." Coco is cochair of the research working group of the Federal AIDS Policy Partnership, a coalition of hundreds of U.S. organizations working to end the domestic epidemic. The working group leads advocacy to increase research funding and to ensure that AIDS research is incorporated into the NHAS goals.

A highlight of the year for both Sue and Coco was collaborating with TAG's TB/HIV Project on a workshop held in Cape Town, South Africa. They worked with African TB/HIV activists to strengthen skills in identifying political targets, creating policy positions from on-the-ground evidence and analyzing legislation and policies. ●

TB/HIV Project

The year 2010 saw the culmination of many years of work by TAG's TB/HIV Project. The *Global Plan to Stop TB* was updated (see box) to include basic science and operational research—something TAG has been pushing for since 2006. To support the process of revising the plan, TAG cosponsored a fundamental science meeting with the Stop TB Partnership and the National Institute of Allergy and Infectious Diseases (NIAID) of the National Institutes of Health to identify the basic science research priorities. Claire Wingfield, assistant project director of TAG's TB/HIV Project was part of the group that defined the operational research agenda that is now included in the revised plan.

One of the most satisfying achievements of the year came about when activists whom TAG has trained and worked with over the last three years mobilized and

IN BRIEF WHAT'S GOING ON

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pressured the national TB program and the judicial authorities in Kenya to release three men who were imprisoned for not completing their TB treatment. Javid Syed, TAG's TB/HIV Project director comments, "This is but one example of what advocacy capacity-building can do to reverse injustice and ensure that people have access to appropriate treatment."

TAG's advocacy efforts with the World Health Organization (WHO) accomplished a significant milestone. National TB programs have traditionally been seen as the primary drivers of TB care and control, but TAG has long been emphasizing the need to meaningfully include communities in order to make the TB response more effective. As a result of TAG's advocacy, the WHO expanded its TB control policy to include a component focused on empowering TB patients and their communities. There was, however, no guidance on how this component was to be implemented. TAG, in partnership with the International Community of Women Living with HIV—Eastern Africa, has been documenting what it takes to build activists' capacity to address TB and TB/HIV and the outcome of their advocacy efforts on the national, regional, and global levels. This documentation led the WHO to finally recognize the need for better guidelines and the importance of having indicators to measure national TB programs' efforts to support civil society involvement in TB research and treatment. In September 2010, the WHO convened a global consultation to develop these guidelines and indicators. "Though this is a huge step, the work of keeping people most affected by TB at the center of the TB response is far from over," notes Javid.

As a result of TAG's continued advocacy and collaboration with the Centers for Disease Control and Prevention (CDC), resources have been dedicated to strengthening community engagement and feedback mechanisms within the TB Trials Consortium (TBTC). The CDC has entered into a formal agreement with

Launch of the *Global Plan to Stop TB: 2011–2015*

On October 13, 2010, the Stop TB Partnership launched the new *Global Plan to Stop TB 2011–2015*, a funding and implementation strategy to reduce the burden of TB by 2015 and set the stage for eliminating the epidemic as a public health threat by 2050. The new plan was hailed as "an advocacy win" by TAG and TB research activists, who over the course of five years advocated strongly for a revised Global Plan that set more ambitious funding targets and a comprehensive research agenda to include basic science and operational research. "Since 2006, TAG has carried out a resource-tracking report to establish a baseline for global TB research funding and measure progress against the Global Plan funding targets," said Javid Syed, TAG's TB/HIV Project director. "The annual reports found that the plan's funding targets were severely underresourced and the research agenda incomplete." With the report in hand, TAG called for expanding the TB research agenda to include basic and operational research, and increasing annual TB research costs from \$900 million to \$2 billion. Eleonora Jiménez, author of this year's TB resource tracking report adds, "We are pleased with the revision of the plan. As a result of our advocacy efforts, TAG and its allies can now focus on mobilizing resources to support the TB research agenda that—if fully funded—will help reach the global target of eliminating TB by 2050."

To learn more about the current state of global TB funding please visit <http://www.treatmentactiongroup.org/TBRD2010.aspx>.

TAG to provide technical and logistical support to the Community Research Advisory Group of the TBTC.

TAG staff met with Dr. Anthony Fauci, director of NIAID, and drew his attention to how little funding was being allocated for TB research. Because of TAG's advocacy, change is happening—the NIAID AIDS clinical trials networks will be reconfigured to include TB as a key area of research alongside HIV. This restructuring will provide millions of dollars to fund research and significantly increase TB trial capacity.

TB and TB/HIV have stepped up to a more prominent place on the global health agenda, and PEPFAR and Global Fund have increased their funding for TB programs. This is due to the efforts of advocacy networks to raise awareness, increase funding, and propose innovative ways to make current investments in TB achieve the best results possible. Though we have a long way to go to reach the goal of eradicating of TB by 2050, TAG's work continues to change the global landscape by gathering momentum on the ground and at the highest levels of policy-making institutions. ●

TAG's Basic Science, Vaccines, and Prevention Project

Richard Jefferys, coordinator of TAG's Basic Science, Vaccines, and Prevention Project, spent much of his time in 2010 focused on the cautious optimism around new science that could lead to a cure for HIV. He attended a workshop on HIV reservoirs at the Keystone Conference in Santa Fe, New Mexico, which included, an update on the Berlin patient—a man who has been free of detectable HIV in the absence of antiretroviral treatment for more than three years. (A report on this meeting appeared in the first *TAGline* for 2010, Vol. 17, no. 1.) Richard's work on the cure continued into the summer in

Vienna (see box) as a participant in the International AIDS Society workshop. In collaboration with the AIDS Policy Project, amfAR, and Project Inform, TAG is planning for a workshop in 2011 that will focus on issues related to the conduct of cure-related human studies including regulatory requirements, ethics, and study design. Richard notes that “there are serious ethical issues to consider because people with a low risk of illness may be participating in potentially risky experiments.”

Cure Workshop

In Vienna, in July, immediately preceding the XVIII International AIDS Conference, TAG cosponsored the IAS workshop “Towards a Cure: HIV Reservoirs and Strategies to Control Them.” Chaired by IAS president elect and Nobel laureate Françoise Barré-Sinoussi, the workshop was a high-profile illustration of the reinvigoration of the research effort toward curing HIV infection. TAG’s Richard Jefferys wrote the workshop report, which is now available online in the open-access *Journal of the International AIDS Society*: <http://www.jiasociety.org>. For more background and resources on cure-related research, go to www.treatmentactiongroup.org/cure.aspx.

While at the IAS conference in Vienna, Richard gave a presentation on pathogenesis to a standing-room-only crowd. “Even with the advances in treatment, it’s important to know that people still have a very high level of interest in pathogenesis,” he notes. Richard worked with Matt Sharp from Project Inform on a community immune based therapy (IBT) workshop at the Conference of Retroviruses and Opportunistic Infections (CROI) in February. Scientists and representatives from companies working on the leading

IBT candidates attended and presented.

“IBTs have always lagged behind antiretroviral treatment but now more than ever, it is important that they be thoroughly investigated,” explains Richard. A significant number of people experience persistent dysregulation of the immune system despite viral suppression, and this is associated with a greater risk for a spectrum of diseases more typically linked to old age. “Within TAG’s mission is the goal of achieving for people with HIV the same longevity as their HIV-negative counterparts,” explains Richard, “so pushing to get therapies to address immune dysregulation fits very well with TAG and what we do.” Richard also presented on the immunology of HIV and aging at the TAG-sponsored HIV Research Catalyst Forum in Baltimore, Maryland, April and is now an active participant in the Coalition for HIV & Aging Research and Policy that formed at one of the forum sessions.

Throughout the year Richard followed the emerging breakthroughs in research on treatment as prevention. “This has really come to the fore in the past year and there is a lot of dialogue in the context of not scaling back promises for treatment. Investing to ensure access now can help avert new infections and thus reduce the global need for treatment in the future.” ●



Richard Jefferys presents at IAS

TAG INTERVIEW

TAG’s two newest board members, Robert Monteleone and Frank Rappa, come to TAG from different perspectives but with a common goal—to have a positive effect on the AIDS epidemic.



Mark Harrington with TAG’s newest board members, Frank Rappa and Robert Monteleone

TAG: How did you get involved with Treatment Action Group?

Robert Monteleone: I have followed the work of the TAG staff ever since my years in ACT UP. My progression has gone from friend and supporter to donor, and then from Research in Action Awards committee member to board member.

Frank Rappa: I have always been interested in AIDS activism and then, like Robert, worked on TAG’s RIAA committee. As a committee member for the 2009 RIAA I was then asked to join the board.

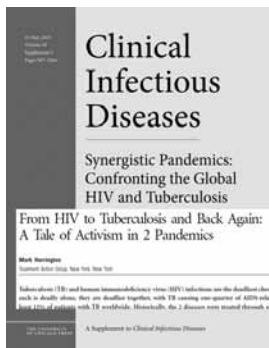
TAG: What is it about TAG that enticed both of you to join the board of directors?

RM: I’ve known many of the staff for years and believe in their dedication. Joining the board has become a natural progression for me as a new way to participate in the fight to end AIDS.

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TAG IN THE NEWS TAG EVENTS

TAG's executive director **Mark Harrington** was published in three peer-reviewed journals during 2010. In the May issue of *Clinical Infectious Diseases*, the article "From HIV to Tuberculosis and Back Again: a Tale of Activism in 2 Pandemics" was published. This article is based on a keynote presentation that Mark gave in Cape Town, South Africa, on 19 July 2009 for a TB/HIV satellite workshop on catalyzing TB/HIV research.



Mark also coauthored two articles that appeared in the *Lancet*: "Scale-up of Services and Research Priorities for Diagnosis, Management, and Control of Tuberculosis: A Call to Action" and "The HIV-associated Tuberculosis Epidemic—When Will We Act?"

TAG's Youngest Fundraiser

Iverson Xu, also known to his parents and friends as Nunu, is certainly TAG's youngest fundraiser to date! For Nunu's first birthday, his parents, **Andrew Xu** and **Tim Iverson**, decided not to have people give gifts but instead threw a big birthday bash and asked for donations for TAG. The party was an amazing success, and raised over \$10,000 for TAG. Thank you Nunu from all of us at TAG! ●

2010 was a year full of TAG fundraising and donor events.

In January, **Fred Hersch** and **Renée Fleming** performed at the luxurious Soho home of **Steven** and **Judy Gluckstern** to the delight of opera and jazz fans alike.



Renée Fleming, Fred Hersch, and Judy Gluckstern

TAG's Palm Donor Circle event was held at the home of **Robert Monteleone** and **Stephen Mack** on a stunningly beautiful evening on June 8. TAG introduced its two newest board members, Robert Montelone and **Frank Rappa**, to a standing-room-only crowd on the rooftop garden and many new friends joined the TAG family.

In June, TAG had its first fund-raiser in Los Angeles at the landmark Sowdenhouse designed by Lloyd Wright. Former "Dreamgirl" **Sheryl Lee Ralph** gave a short but moving performance and a rousing speech imploring attendees to not forget what happened 20 years ago—and that the AIDS fight is not over.



Iverson "Nunu" Xu

On September 14, TAG Board member **David Sigal** presented a benefit screening for TAG of his critically acclaimed film *Florent: Queen of the Meat Market* that included a lively, entertaining and informative Q&A after the film. In October, David again lent his talents to TAG when he held a benefit screening of the film, *Fair Game*, which he coproduced. **Valerie Plame** and **Joseph Wilson**, who were portrayed in the film, were on hand for an after-screening discussion.



David Sigal at the screening of his film Florent: Queen of the Meat Market

Finally, TAG board member **Alby Maccarone** held a beautiful cocktail party at his penthouse in San Francisco bringing together friends of TAG, old and new, to celebrate TAG's work. It was a wonderful evening, and great fun to see many of TAG's friends from the "old days" and to talk about how far we've come—and how far we have to go.

This month we are looking forward to honoring **Scott Campbell** of the Elton John AIDS Foundation, **Dr. Mehmet Oz**, renowned researcher **Dr. Steven Deeks**, and activist filmmaker **James Wentzy** on 12 December at TAG's annual Research in Action Awards. ●

TAG INTERVIEW

(continued from inside)

FR: For me, it was the mission of the organization and the passion that everyone at TAG has. They are a creative, hardworking team and passion is contagious in the TAG family.

TAG: Were you involved in AIDS activism or AIDS issues prior to joining the board?

RM: The work I participated in with ACT UP in the early 90s effected real change. We fought hard to alter perceptions and policy around HIV issues in society. From outside the room you could see these actions were effecting real change—inside the room, we were clinging to each other in the midst of a war.

FR: TAG has been my introduction to the world of AIDS activism.

TAG: As a board member, how do you hope to contribute to the mission of TAG and its programs?

RM: A good start will be to enhance my involvement and build on the success of the RIAA event! I believe it is important to take the time and recognize individuals who research, document, and educate the world about HIV and AIDS.

FR: I would love to grow the involvement of the younger community and to raise TAG's profile using social media—it's a new and interesting way to raise funds for our cause.

TAG: What would you like our supporters to know about you?

RM: As a garden designer, my work is about developing my surroundings. When I'm not on rooftops in the city, I enjoy exploring Columbia County with my partner, being with friends, and the romance of old French cars.

FR: I am a regional vice president for AX I Armani Exchange and my passion is traveling and learning as much as I can about history and different cultures. ●

TAG BE INVOLVED

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.

TAG's project areas encompass antiretroviral treatments, basic science, vaccines, prevention, viral hepatitis, and tuberculosis.

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.

TAG is a not-for-profit organization founded in 1992 and based in New York City.

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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