Dear Friend of TAG –

My name is Sara Rafsky. My dad, Bob Rafsky, was a founding member of Treatment Action Group (TAG) when it formed out of ACT UP New York’s Treatment & Data (T & D) Committee in January 1992.

If you’ve seen David France’s recent acclaimed documentary, How to Survive a Plague, you will remember my father interrupting then–presidential candidate Bill Clinton and pointedly questioning him about what his AIDS platform would be, or his fiery funeral oration at the political funeral of ACT UP/New York’s Mark Fisher the night before the 1992 presidential election. But my dad was acutely aware that it would take more than speeches and politics to curb the AIDS epidemic. Along with ACT UP’s activism, he knew that tackling, let alone ending, the crisis would require massive and smart research investments for the long haul. He also knew that no one was better equipped to set the research agenda than his activist comrades, and that TAG would ensure that the right research took place.

What most impresses me about the history of AIDS activism is how a community of mostly young people facing a terrifying new disease with a universally grim prognosis chose not to act as passive victims, but rather to stand up and fight back. Even more improbably, they became self-educated experts in the science of the disease. What most impresses me about TAG and its leadership 20 year later is that, after achieving their initial goal of finding the drugs that turned AIDS into a chronic, rather than fatal, condition, they did not rest on their laurels, but chose to continue the fight for others.

My dad did not survive long enough to witness TAG’s amazing successes over the past 20 years, but he would be incredibly proud of what they’ve done and that the movement endures. I know I am.

I’m writing today to thank you for all your past years of support for TAG’s work, and to tell you why it’s now more important than ever to keep on supporting TAG.

TAG developed proposals that reformed the entire AIDS research system of the U.S. National Institutes of Health (NIH) and were signed by President Clinton in 1993, creating the first national HIV research strategy linked with strong budget increases.

TAG developed proposals to fast-track HIV protease inhibitors, leading to their launch in 1996 as highly active combination antiretroviral therapy (HAART), which has saved more than 14 million years of life since it was introduced, reducing HIV death rates in the United States by over two-thirds.

Since TAG was founded, the U.S. Food and Drug Administration has approved over 32 drugs to treat HIV.

TAG has worked with the U.S. government, the World Health Organization (WHO), UNAIDS, and the Global Fund to Fight AIDS, Tuberculosis, and Malaria. Today, thanks to these efforts, more than 8 million people worldwide are receiving HIV treatment.

TAG works to accelerate research on new treatments, better prevention, and a cure and a vaccine for HIV, and to speed up cures for HIV’s two deadliest companion diseases, hepatitis C virus (HCV) infection and tuberculosis (TB).
But TAG’s work is now needed more than ever.

• Globally, while 8 million people are on treatment, 25 million more aren’t, and at least 7 million need treatment now.

• The United States has failed to bring down new HIV infection rates since 1990—long before HAART—and has 50,000 new infections a year.

• Only 25% of HIV-positive people in the United States are in care, on treatment, and with an undetectable viral load.

• The Affordable Care Act (ACA) offers a framework for increasing U.S. HIV prevention, care, and treatment, but activism is needed to ensure that it is implemented in a way that will help, not hinder, care for HIV.

• The current federal budget negotiations threaten drastic cuts in funding for U.S. and global HIV programs, as well as for research.

• The U.S. government needs to create a more ambitious domestic AIDS strategy that puts the epidemic into irreversible decline using combination prevention and treatment interventions based on the best and latest science.

• The U.S. needs to continue supporting the Global Fund and the President’s Emergency Plan for AIDS Relief (PEPFAR) and its visionary Blueprint for an AIDS-Free Generation.

• One person has been cured of HIV infection. Now we need to discover cures that can be scaled up globally.

• We still don’t have a vaccine to prevent HIV.

TAG is a globally respected leader in research and treatment activism. We’re in this fight to the finish. Thanks to the past two decades of research, activism, investment, and implementation, we have begun to turn the tide on the AIDS pandemic.

We need your help to ensure that we get there as fast as humanly possible.

I know my father would be very grateful for your efforts—and for TAG’s—to save lives. I certainly am. I am now of the same age as TAG’s founders when they started this fight, and want to make sure my generation and future generations continue to build on all they have accomplished. We owe it to them.

Let’s end this epidemic together. Act Up. Fight Back. Fight AIDS.

Yours in the struggle,

Sara Rafsky
DEAR FRIENDS OF TAG,

Twenty years ago this year, a group of brave, hard-working, passionate, smart, and—in retrospect—incredibly young activists broke off from ACT UP/New York to form Treatment Action Group (TAG). Thanks to your support and their tireless labors, this year saw the approval in the United States of the 32nd drug to treat HIV; the endorsement by the U.S. government of an AIDS-free generation as an official goal of U.S. policy; and the announcement by UNAIDS that over 8 million people living with HIV around the world are receiving lifesaving anti-HIV treatment.

I’m incredibly proud to have been TAG’s board president for 15 of the past 20 years, and to share with you the 2012 TAG Update. As you will read below, TAG’s staff continues to define a legacy of immense accomplishment fighting for better treatments, a cure, and an end to the pandemics of HIV and its two deadliest coinfections—hepatitis C virus (HCV) and tuberculosis (TB).

You too should be proud of the work your tireless support has enabled TAG to accomplish. I and the rest of the TAG board and staff thank you and ask you once again to help us continue our work to end this pandemic.

Yours in the struggle,

Barbara Hughes
President, Board of Directors

ACT UP/NY and TAG’s accomplishments featured in prize-winning documentary

In September 2012, David France’s documentary How to Survive a Plague opened in New York City, Los Angeles, and San Francisco, after six months on the festival circuit. The film focuses on the work of ACT UP’s Treatment & Data (T & D) Committee and that of TAG in breaking down the bureaucratic and scientific barriers to effective treatment for HIV between 1987 and 1996. Featuring TAG cofounder Peter Staley, and with a supporting cast including several other TAG cofounders including Garance Franke-Ruta, Gregg Gonsalves, and Mark Harrington, and ACT UP’s pioneering pharmacologist Iris Long, PhD, and playwright Jim Eigo, the film—crafted from over 700 hours of archival AIDS activist documentary footage by over 30 film- and video makers—shows how a group of New Yorkers, pushed to the limits by the inaction of the Reagan and first Bush administrations, created a local, then a national, and finally a global community activist response to the pandemic, and pioneered a groundbreaking form of scientific evidence-based research and treatment activism, which led to the advent of highly active antiretroviral therapy (HAART). It’s a must-see for anyone who wants to understand the history of AIDS activism: www.surviveaplague.com.
D.C. garden party commemorates TAG’s 20th anniversary

In May 2012, Ellen Sigal, founder of Friends of Cancer Research, and Gerald Sigal—parents of filmmaker and TAG board member David I. Sigal—hosted a garden party in Washington, D.C., to commemorate TAG’s 20th anniversary. Speakers included Dr. Anthony S. Fauci, Director of the National Institute of Allergy and Infectious Diseases, National Institutes of Health (NIH), and Dr. Margaret A. Hamburg, Commissioner of the Food and Drug Administration (FDA). The event gathered together many of the researchers, policy makers, and activists who spearheaded reforms at the FDA and NIH that resulted in much faster approval of drugs to treat HIV and related opportunistic infections and cancers. Dr. Fauci saluted TAG’s accomplishment, while noting, “It wasn’t always easy” (perhaps thinking of ACT UP’s “Storm the NIH” demonstration in May 1990). Dr. Hamburg spoke of how AIDS activists transformed the way the FDA regulates drug testing and approval. TAG thanks the Sigals for their generosity. 

Longtime TAG supporter Dr. Michael Giordano hosts reception honoring TAG’s Accelerating Research to Cure AIDS Campaign

On June 20, 2012, longtime TAG supporter and NYC AIDS clinician Michael Giordano, MD, hosted a reception honoring TAG’s Accelerating Research to Cure AIDS Campaign. TAG board member and Cornell University Medical School Professor of Infectious Disease Roy “Trip” Gulick gave an update to Cure Campaign supporters about progress in HIV cure research. TAG thanks Drs. Giordano and Gulick for helping move the cure agenda forward. 

Summer Fire Island Pines benefit honors TAG

On August 18, TAG board members Frank Rappa and Monte Steinman hosted a benefit honoring TAG’s work at Club 570 in Fire Island’s Pines. Special thanks go to Club 570 hosts Anthony Bellapigna, Michael Rizzi, Marc Berman and John Yakubik, and Bobby Mistretta; A|X Armani Exchange; Sip•n•Twirl; DJ Justin Dawson; bartender Robert; entertainers Justin and Oscar; and all those who came to support TAG!
TAG, with allies, pushes for a cure for AIDS, zero TB deaths, and global access to hepatitis C treatment at International AIDS Conference


TAG welcomes Colleen Daniels, Melanie Havelin, Tim Horn, Karyn Kaplan, Erica Lessem, and Lindsay McKenna

2012 was a year of growth for TAG. We welcome incoming TB/HIV Project Director Colleen Daniels; TB/HIV Project Assistant Director Erica Lessem, MPH; Karyn Kaplan, Director, International Hepatitis/HIV Policy & Advocacy; Tim Horn, HIV Project Director; and Melanie Havelin, Deputy Director. Previously, Colleen coordinated the global TB/HIV Working Group of the Stop TB Partnership; Erica worked at the Global Alliance for TB Drug Development and obtained her masters in public health at the Johns Hopkins University; Karyn worked for the International Gay and Lesbian Human Rights Commission before cofounding the Thai AIDS Treatment Action Group (TTAG) and the Thai Drug Users’ Network (TDN); Tim worked at AIDSmeds.com and POZ magazine (and in the mid-1990s wrote TAG’s Wasting Report); and Melanie was executive director of the John M. Lloyd Foundation, a longtime supporter of AIDS policy advocacy. TAG also brought on board Lindsay McKenna, an MPH candidate at SUNY-Stony Brook, as TB/HIV Assistant Project Officer.

TAG thanks Scott Morgan, Javid Syed, Claire Wingfield, and Jamie Saakvitne

In mid-2011 TAG’s previous deputy director, Scott Morgan, took a policy advocacy position at AIDS-Free World. In November 2011, TB/HIV Project Assistant Director Claire Wingfield took a position at PATH in Washington, D.C. TAG’s first TB/HIV Project Director, Javid Syed, moved to American Jewish World Service in February 2012. TAG also thanks longtime board of directors member Jamie Saakvitne, who stepped down in mid-2012 due to the demands of his job. TAG is grateful to Scott, Claire, Javid, and Jamie for their many years of dedicated work with TAG and wishes them great success in their new endeavors.
Q & A with HIV Project Director Tim Horn

Q: Tell us about yourself. What lead you to AIDS activism?
Like so many others, I tested positive for HIV during the “dark ages” of HIV research, and the darkest days of death and despair. Science was undeniably the way forward, and I knew I wanted to be a part of the advocacy efforts to move the needed research along.

Q: You’ve spent the last twenty years fighting HIV, mostly as a treatment educator and writer. What do you see as the major challenges facing the AIDS movement currently?
We need more advocates! The push for an effective, safe, and widely accessible cure is going to be intense—and we still need to continue moving forward with HIV disease-management research, not to mention full-spectrum HIV care access. One goal I have is to bring more people into the TAG fold, through improved usability and dissemination of the organization’s publications, as well as science literacy and advocacy trainings.

Q: What else will you be focusing on at TAG?
I’ll have irons in several fires. In addition to antiretroviral R&D, I’ll help lead advocacy for research into various HIV-related health complications and the push for the science required to fully implement the National HIV/AIDS Strategy and the Affordable Care Act.

Q & A with Karyn Kaplan, Director, International Hepatitis/HIV Policy & Advocacy

Q: Tell us about yourself. What lead you to AIDS activism?
My mom was very involved in anti-apartheid activism and political theater as I was growing up, and I was raised with an awareness of inequality and human rights from the beginning. In 1988, after graduating from college, I was teaching English in northern Thailand, and volunteering at a local sex-worker rights organization, EMPOWER. Chiang Mai, where I lived, was near the Burma and Laos borders, and the epicenter of the HIV/AIDS epidemic. Thousands of poor, young women were getting sick and dying. It was impossible to ignore the constellation of economic, social, and other factors that led to this crisis: the underlying issues of poverty, gender inequality, and the denial of basic rights were what compelled me to act. Eventually my involvement took on a more personal dimension, as I watched friends and colleagues die. My partner of 11 years is living with HIV/AIDS is also an activist, and my main inspiration.

Q: What do you see as the major challenges facing the HIV and hepatitis movement currently?
A lack of awareness about the disease(s) and one’s own status, the cost of the diagnostics and treatment, the legal and social status of people who inject drugs (who are the group most disproportionately affected by coinfection), and the general lack of political will to address the right to health are some big ones that come to mind. Excitingly, we are building a global movement to change all that!

Q: What else will you be focusing on at TAG?
Helping to create the tools for activists everywhere to develop informed and effective campaigns to push for comprehensive and equitable treatment access; hepatitis C can be cured, and the treatments are radically improving, but access will be a massive challenge.
Q & A with TB/HIV Project Director Colleen A. Daniels

Q: Tell us about yourself. What lead you to HIV/TB activism?
I started working in HIV when I saw the enormous effect it was having on people in my hometown of Durban, South Africa. We had won the war against apartheid, yet we were losing the fight against HIV. Once people were on treatment, it felt like we were finally making a difference; people’s lives were changing. Then I realized that the biggest cause of death among people with HIV was TB. I was shocked—here was a preventable, curable disease, and more than 5,000 people still died of TB every single day around the world. This facilitated a new direction, and I found myself working on HIV/TB.

Q: What do you see as the major challenges facing the HIV/TB movement currently?
The biggest challenge is a lack of political will to fund a response that will eliminate TB. Adequate funding for much-needed research and development (R&D) for new TB drugs and diagnostics is minimal. The Global Strategy to Stop TB 2011–2015 states that $2 billion annually is needed for R&D; today this figure is around $649 million. Most parts of the world still use microscopy, a tool that is 120 years old, to detect TB, and we have not had a new TB drug in 40 years—this must change if we are to eliminate TB.

Q: What else will you be focusing on at TAG?
I will be focusing on the need for activists to engage with TB diagnostics developers to ensure that our voices are heard. We need to ensure that we contribute to the preparation of target product profiles (TPPs). There are huge unmet diagnostics needs—we need better and more affordable tools, and we need competition to increase affordability and diversity of options.

Q & A with TB/HIV Project Assistant Director Erica Lessem

Q: Tell us about yourself. What lead you to HIV/TB activism?
I’ve always been interested in promoting human rights, equality and dignity, but began to find my niche when I started to work on the NYC Condom Campaign. It was an exciting introduction to working in HIV, but I soon found the disparities in access at the global level and among marginalized populations even more pressing. I went on to mobilize women’s health groups in Nepal and the Republic of Georgia, and to conduct HIV research in Baltimore and New York City. TAG’s HIV/TB project offered the opportunity to integrate my interests in research, policy and activism. Having always rooted for the underdog and strived to hold people in power accountable for their actions, getting to use my voice to help others express theirs is a rewarding job.

Q: What do you see as the major challenges facing the HIV and TB movement currently?
Political will appears to be waning in HIV, and near nonexistent for TB. Part of this is a lack of momentum coming from communities. As a younger activist coming into this field, watching How to Survive a Plague was eye-opening—not only because of the horror of those early days, but also because of the urgency and inspiration. The HIV movement has lost much of that, and TB—an older, slower, progressive disease that primarily affects poor people—has never really had it. But it’s building, and activists are maximizing their impact. And policy makers will notice.

Q: What else will you be focusing on at TAG?
I'd like to bring more to the forefront of the conversations about HIV and TB issues involving women, children, people who use drugs, and people whose employment makes them more susceptible. These important populations are shockingly neglected, especially in research, and it’s unacceptable.
Hepatitis/HIV Project

2012 was an exciting year for TAG’s Hepatitis/HIV Project. Proof-of-concept has been established: Three months of pills can cure hepatitis C virus (HCV), a disease that 170 million people are living with, and 350,000 die from each year. Global momentum for HCV treatment access is building, and a movement is beginning.

TAG was able to broaden support for HCV activism when Karyn Kaplan became Director of International Hepatitis/HIV Policy and Advocacy in mid-2012. In July, Karyn cosponsored a groundbreaking meeting at the 19th International AIDS Conference, Advocating Access to HCV Diagnostics, Treatment, and Care for All attended by activists from more than 15 countries, which led to the Washington Call for Access to HCV Diagnostics, Treatment and Care for All, an international activist platform of principles and demands for increased access to HCV treatment (available online at www.hepcoali- tion.org), which she coauthored. Since then, Karyn has created and disseminated an activist survey to assess education and advocacy capacity-building needs in lower- and middle-income countries, and she continues to work closely with activists from around the world to integrate HCV into their global advocacy work.

TAG’s Hepatitis/HIV Project continues to fight for “real life” clinical trials in people with the most urgent need for treatment, instead of in those who are easiest to treat. Tracy Swan, TAG’s Hepatitis/HIV Project Director, continued bringing her technical expertise and dedication to social justice to the table, working both locally and internationally. She participated in the development of World Health Organization guidelines for HCV prevention and treatment, co-organized and presented at crucial meetings on global HCV treatment access, drug development in HIV/HCV coinfection, and compassionate use programs. Locally, Tracy and Karyn co-conducted a workshop in Brooklyn with VOCAL-NY, providing community leaders with the information they need to inform advocacy campaigns for access to high-quality HCV prevention, testing, care and treatment for low-income and uninsured people in New York City.

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

TAG’s BSVP project continued to play an important role in covering HIV cure research and participated in multiple collaborative advocacy efforts related to this emerging field. Along with the AIDS Treatment Activist Coalition and Project Inform, TAG cosponsored a daylong community cure research workshop that was held March 4 in Seattle, immediately preceding the Conference on Retroviruses and Opportunistic Infections. The workshop attracted 61 attendees including representatives from the drug and biologics divisions of the FDA, a regulator from Health Canada, representatives from the International AIDS Society (IAS) and several pharmaceutical companies, academic researchers, and many community advocates (both American and international). TAG also cosponsored the second IAS-led Towards an HIV Cure workshop before the International AIDS Conference in Washington, D.C., in July 2012 (AIDS 2012). BSVP coordinator Richard Jefferys organized a cure research literacy workshop for community advocates at the event. Richard also presented at two AIDS 2012 satellite meetings, an educational forum sponsored by the Black AIDS Institute, and a session on the Strategies for the Management of Antiretroviral Therapy (SMART) trial hosted by the INSIGHT research network.

The BSVP contributed a chapter on preventive technologies, research toward a cure and immune-based/gene therapies to the annual TAG pipeline report. Ongoing coverage of relevant conferences and scientific articles was provided throughout the year in TAgline, on the TAG website, and via the project blog and twitter feed. At the end of 2012, Richard Jefferys was recognized as an important contributor to cure research advocacy in the annual POZ 100 list.

TB/HIV Project

In 2012, TAG entered into collaboration with Partners In Health, the Harvard Medical School, and the Stop TB Partnership to launch a new campaign calling for zero TB deaths, zero new TB infections, and zero suffering and stigma from TB. This bold call was the brainchild of advocates, clinicians, researchers, implementers, funders, policy makers, and affected communities. The current Global Plan to Stop TB 2011–2015 is uninspired in its goals, and we believe that it is necessary to have a bigger, bolder vision post-2015.

This campaign has been embraced at a global level at a rapid pace. Over 317 individuals and 146 organizations have now signed on to the declaration, and at the recent Stop TB Partnership coordinating board meeting, the campaign was endorsed as part of the three-year operational strategy that outlines how the Partnership will deliver the Global Plan to Stop TB 2011–2015.
The Global TB Community Advisory Board (TB CAB) is a group of activists from nine countries, working tirelessly to call for countries such as South Africa to begin compassionate use programs for a new TB drug called bedaquiline. Together with TAG staff members, they have fostered connections between countries such as the United States and Botswana to get access to bedaquiline.

TAG also focused on pediatric TB this year, calling for it to be included in statistical data collected by the World Health Organization. In January, TAG held a federal advocacy meeting on childhood TB, worked with advocates at the international level to develop a roadmap for advocacy, and co-hosted a congressional TB briefing at the end of March to highlight childhood TB advocacy. On World TB Day, TAG launched a series of stories documenting the global problem of pediatric drug-resistant TB. The team continues to collect these stories and aspires to collect them from as many countries as possible.

Earlier this year, Coco organized TAG’s first federal advocacy meeting on childhood TB. The advocacy meeting brought together over 50 TB/HIV and maternal- and child health advocates along with researchers, clinicians, and implementers from around the U.S. to advance the discussion and advocacy agenda on childhood TB research needs and priorities.

A highlight of this year was putting together the first ever TB/HIV networking zone at an international AIDS Conference. The zone hosted 20 separate panels, small discussions, workshops, film screenings, game shows, and other activities throughout IAC, creating increased visibility, and spurring new interest in advocacy for important TB/HIV coinfection issues. Finally, Coco led global TB community members in the drafting and publication of the Civil Society Declaration on Tuberculosis: Zero TB Deaths during the 2012 Union World Conference on Lung Health in Kuala Lumpur.

U.S. and Global Policy Project

Budgetary cuts and the looming threat of sequestration continue to threaten the fragile safety-net infrastructure for people living with HIV in the U.S. Over the past year, Coco Jervis has advocated for the creation of the first-ever TB congressional caucus, and presented at three congressional briefings.

As co-chair of the Research Working Group, Coco fought for the federal AIDS research funding portfolio, and advocated for the National HIV/AIDS Strategy, the rollout of health care reform, as well as strategic planning with allies on Ryan White and PEPFAR reauthorization, set for next year.

In Memoriam

PETER FRANKLIN DIFFLY
September 16, 1954–August 2, 2012

Excerpted from the eulogy given by Richard Cardillo

Anyone who knew Pete, knew how outspoken he was about many justice issues. When it came to poverty, he was vociferous about supporting the direct poor by modifying our consumer lifestyle accordingly. Regarding gay rights, Peter promoted organizations, candidates, and movements that reflected his unique perspective. Most recently, his activism took direct aim at health care reform.

Peter knew that as a result of his HIV status and his misfortunes with mental health, he had no choice but to be a thorn in the side of powerful health care companies that he monitored closely.

As his mental illness took over in the last three or four years, he was subjected to pretty harsh environments in a number of different psychiatric institutions. Yet, in the midst of the harshness, Peter would reflect to me: “Do you realize... I’m one of the few people here who hasn’t spent time in prison or got caught up in the criminal justice system. I’m one of the only people in my support groups who never had to confront homelessness along with my mental illness. I am fortunate that I haven’t had to battle the demons of substance abuse along with my depression.”

These reflections weren’t at all out of sync with the Peter Diffly who was born and raised in Selma, Alabama, at a time when civil rights, human dignity, and equality for all were major concerns. So, how do we appropriately memorialize Peter? Perhaps, then, it’s worth it to keep it simple, as Peter tended to prefer, and just do the next thing. And, as Peter’s particular, unique, brilliant gift allowed him to do, just go and plant something.

The family is requesting that donations be sent to one of Peter’s favorite charities, Treatment Action Group.
A note from TAG supporter Jim Aquino, who raised nearly $4,000 for TAG via pledges toward his planned run in the New York City Marathon

One of the first words that comes to mind when I think of TAG is commitment. And now it’s been an unbelievable 20 unwavering years of that spirit that continues to inspire me.

When I decided to run the New York City Marathon, I knew I wanted it to benefit TAG’s continuing efforts to accelerate a cure for AIDS. So I trained hard and asked my family and friends to help, and they did not disappoint. They knew how much this meant to me and how important it is to support TAG’s campaign. I will be forever grateful to them. Over the 18 weeks that I trained, I had plenty of time to think about the past, about dear friends that are no longer here, and about the hope of a not-too-distant future when there will be a cure. And knowing my run would benefit TAG kept the wind at my back the entire way.

Ultimately, the fact that the Marathon was cancelled due to Hurricane Sandy doesn’t change the inspiration that motivated me to train for it in the first place. And in the end, I was just happy that the hard work still resulted in a nice donation to TAG. Every little bit helps....and now I’m working on new ideas to keep it coming!