

# update

a publication of the Treatment Action Group

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**TAG**



## **Interview with TAG's first-ever full-time Basic Science Project Director, Richard Jefferys**

*Q: Tell us a little bit about yourself and what you see as your most important accomplishments?*

A: Setting up the Access Project database at the AIDS Treatment Data Network was perhaps my first achievement. The database included information on every state Medicaid and AIDS Drug Assistance Program (ADAP) in the U.S. I had only been living in the states a couple of years when I started work on the project and didn't quite grasp how big a country it was! I also became involved in projecting ADAP budget needs for the ADAP working group for a few years, and this effort helped maintain ADAP funding levels, although increasing drug prices and increasing demand is now again placing this system under severe stress. I'm also proud to have played a very small role in the establishment of the Health GAP Coalition, which has since gone on to do incredible work in the area of international treatment access.

*Q: How and why did you get involved in the fight against AIDS?*

A: In early 1994, a friend was diagnosed with CMV retinitis and I wanted to obtain the latest treatment information and to try to contribute something to the larger fight. I began volunteering at the AIDS Treatment Data Network, primarily thanks to my friend Joel Beard who was working there at the time.

*Q: Tell us about your work with TAG.*

A: I will be directing the Basic Science Project, which involves advocating for better and faster research into the pathogenesis of HIV infection and the interactions between the virus and the immune system. The goal is to identify the impediments to progress in basic research and make recommendations for addressing them, since ultimately progress in this area will be essential for the development of new treatments and an effective vaccine. An equally important aim is to inform the wider community about the state of basic science and vaccine research.

*Q: What would you like to accomplish at TAG?*

A: To speed the development of new and less toxic treatments (including immune-based therapies), a vaccine, and hopefully a cure. I think TAG can help foster important and productive collaborations between the research fields of HIV immunology and HIV virology, which have historically often been at odds. I'd also like to help keep others abreast of developments in basic science research and help create a broader base of basic science advocates through coalitions such as ATAC (the AIDS Treatment Activists Coalition). One of my first goals is to produce a report on the current state of pathogenesis research, addressing some of the new and potentially important developments that have occurred since the 1996 International AIDS Conference in Vancouver.

*Q: What do you see as your greatest obstacle in achieving these goals?*

A: The basic science research effort is vast, but also scattered and poorly coordinated – fostering collaboration and instilling an appropriate sense of urgency is inherently challenging. Thankfully TAG and other activist groups such as GMHC and Project Inform have already provided critical leadership in this area. Fostering an environment that supports innovation – and just as importantly, can ensure that innovations rapidly translate into advances in clinical care – is difficult for many reasons, including political inertia, economics, conflicts of interest that favor the status quo, dominating scientific egos, and control of the U.S. HIV research agenda by relatively few people. I very much hope to contribute to TAG's ongoing efforts to address these problems and catalyze progress in HIV research.

## volunteer profile



TAG Board Member  
MARK O'DONNELL

I come from one of the most beautiful cities in the world, Perth, Australia. It's home to 2 million people and is a gloriously clean, friendly place with an absolutely perfect climate and the most beautiful beaches in the world. It's also the most remote city in the world. To give you an idea: Sydney is a six-hour flight. Indonesia is actually closer to Perth than any Australian city. You feel a bit shut off from the rest of the world – being in Perth. So, when I was 25 and given a professional opportunity to come to New York, I jumped at the chance. I didn't even own a winter coat. Twelve years later, I now consider myself a New Yorker – with a full winter wardrobe.

I am a good friend of Sally Morrison, who has been associated with TAG for a number of years. I can remember the conversation quite vividly. I told Sally I had some time on my hands and wanted to use it to do something for the community. Sally said, "I've got the perfect group for you!" Sally was right. The size and scope of TAG suits my personality and interests. The boards of some non-profits become terribly social or power trips for their members. I feel that the TAG board is still committed to the original mission of the organization, and it's about getting things done – not the color of the napkins at the fundraisers. As a gay man, I'm also sensitive to the issues of those with HIV or AIDS and now that's it no longer a "trendy" disease, there is even more need to stay focused.

My experience with TAG has been extremely positive, and I think that's because I've connected with an issue and people who interest me. I think it could be very easy to hit on the wrong organization and become frustrated with their politics or bureaucracy. Like in business, you need to do your homework and meet the people – research them the same way if you were interviewing for a new job. Clearly it helps if you have a personal connection to the organization (like I did with Sally), but I knew fairly quickly that I was going to feel committed to TAG. It just felt right. The chemistry was right.

## TAG 2001 Research in Action Award Recipients



*Arthur J. Ammann, M.D., with his wife Marilyn*



*TAG co-founder and GMHC Director of Treatment and Prevention Advocacy Gregg Gonsalves*



*Author and activist Michael Cunningham with TAG founding member Joy Episalla*

## ARTHUR J. AMMANN, M.D.

Arthur J. Ammann MD is President of Global Strategies for HIV Prevention. He also holds an appointment of Clinical Professor of Pediatrics at the Center for AIDS Prevention of the University of California. Founded in 1998, Global Strategies for HIV prevention is a non-profit organization dedicated to HIV prevention and responding to the needs of HIV-infected women and children world-wide.

From 1971 to 1985, Dr. Ammann was Director of Pediatric Immunology and Clinical Research Center at the University of California Medical Center, San Francisco. During that time he established the pediatric bone marrow transplant program and developed innovative therapy for immunodeficiency diseases. He discovered several new immunodeficiency disorders including a previously undescribed enzyme deficiency. In 1982 he described the first cases of transmission of AIDS from mother to infant and the first blood transfusion AIDS patients.

He is past president of the American Foundation for AIDS Research. From 1992 to 1996 he served as the Chairman of the Health Advisory Board and Director of Research Programs for the Pediatric AIDS Foundation. From 1985 to 1992, he was Director of Clinical Research at Genentech, Inc.

Among his many awards and honors, Dr. Ammann has received the United States Surgeon General Award for Research, the United States Public Health Service Fellowship Award and an Honorary Doctorate from the Chinese National Academy of Medicine. Dr. Ammann has authored or co-authored over 325 scientific papers.

## GREGG GONSALVES

From 1992 to January 2001, Gregg Gonsalves served as Policy Director of the Treatment Action Group (TAG). He is currently Director of Treatment and Prevention Advocacy at GMHC and the co-chair of the National Organizations Responding to AIDS Research Working Group.

At TAG, he authored three reports on research on HIV infection and contributed to other reports. He has also written for numerous other publications. Mr. Gonsalves was the driving force behind the first research conference ever on long-term survivors of HIV infection and major conferences on eradicating HIV and developing novel drugs against HIV, as well as a meeting to spur the development of cheaper and easier to use virological and immunological monitoring tools for the clinical management of HIV infection in developing countries.

He has served as a consultant to the Antiviral Drugs Advisory Committee of the Food and Drug Administration and on numerous advisory committees for the NIH, where he is currently a member of the OAR Advisory Council. He has also served on the Public Policy Committee of the Board of Directors of the AIDS Action Council, and he is currently a member of the Board of Directors of the Alliance for Microbicides. He is a founding member of the Executive Committee of the National AIDS Treatment Advocates' Forum. In November 2000, Mr. Gonsalves conceived and participated in a series of training workshops on AIDS research and treatment issues in the Republic of South Africa in partnership with that country's Treatment Action Campaign. He also organized and participated in a similar training for HIV+ women and their advocates in Uganda.

## MICHAEL CUNNINGHAM

Author and activist Michael Cunningham was born in 1952 in Cincinnati, Ohio, and was raised in Pasadena, California. He received his Bachelor of Arts degree in English literature at Stanford University and later received a Master of Fine Arts from the University of Iowa. He was an active member of the AIDS Coalition to Unleash Power (ACT UP)/New York in the early 1990s when his first novel, *A Home at the End of the World*, was published by FSG in 1990. Michael was also active in the ACT UP affinity group The Marys, which included many early TAG members. His novel *Flesh and Blood* appeared in 1995. Michael's work has appeared in *The Atlantic Monthly*, *Redbook*, *Esquire*, *The Paris Review*, *The New Yorker*, *Vogue*, and *Metropolitan Home*. His story "White Angel" was chosen for Best American Short Stories 1989. Michael received the 1999 Pulitzer Prize for Fiction and the PEN/Faulkner Award, both for *The Hours*, and a Guggenheim Fellowship in 1993, a National Endowment for the Arts Fellowship in 1988, and a Michener Fellowship from the University of Iowa in 1982. Michael currently lives in New York City.

## TAG 2002

### *Following are our current organizational and programmatic goals:*

(1) Create research policy and treatment reports on:

- HIV Pathogenesis Update
- Update on Structured Treatment Interruptions (STI) Research
- Ten Years of NIH Reform: Office of AIDS Research Update
- HIV/Hepatitis Coinfection Report, version 2.0
- HIV/Tuberculosis Coinfection Research, version 1.0

(2) Cosponsor scientific meetings on:

- Third International Workshop on Structured Treatment Interruptions

(3) Participate in research conferences, including:

- 9th Congress on Retroviruses & Opportunistic Infections (CROI)
- 4th World TB Congress, Washington, D.C., June 2002
- XIV International AIDS Conference, Barcelona, July 2002
- ICAAC and IDSA conferences, USA, fall 2002

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# Treatment Action Group

The Treatment Action Group (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 both the public and private AIDS research effort, the drug development process and the U.S. and global health care delivery systems. TAG works with researchers, pharmaceutical companies and government officials involved in AIDS.

TAG strives to develop the scientific and political expertise needed to transform policy in this country and around the world, and is committed to working for and with all communities affected by HIV.

## TAG 2002 *continued*

(4) Train and mentor new and experienced treatment advocates through:

- AIDS Treatment Advocates Coalition (ATAC)
- National AIDS Treatment Action Forum (NATAF)
- Barcelona International Treatment Advocates Training, July 2002
- TB/HIV Coinfection Education & Community Mobilization Workshop

(5) Within the Antiviral Project, our goals and interests include:

- Development of new drugs against new HIV targets - entry, integrase, etc.
- Development of new drugs active against drug-resistant HIV strains
- Development of new drugs which are easier to take - e.g., once daily
- Development of new drugs with reduced toxicity profiles
- Development of research to optimize starting and switching regimens in chronic HIV infection

(6) Recruit and train a new full-time Policy Director and a full-time treatment advocate

## TAKING STOCK?

Interested in making a donation of stock or other securities to TAG? Here's how:

(1) Notify your broker to make a transfer to TAG's investment account, CID# 013226, DTC 226.

(2) Drop us a note to let us know that you've requested a transfer, as well as how many shares and the stock symbol(s) of the securities you are donating. Include best phone numbers for us to contact you, along with your name and address.

(3) You'll receive an acknowledgement letter from us thanking you for your donation once it's been transferred to our account.

It's that easy! And it's tax deductible!

Founded in 1992,  
TAG is the only organization in the world dedicated solely to AIDS research advocacy.

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