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## Treatment Action Group (TAG): an interview with Tracy Swan

By Saina Behnejad

**A personal perspective on how Treatment Action Groups (TAG) help improve access to life saving drugs for Hepatitis C positive patients, but still more needs to be done.**

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Tracy Swan has been a HIV/AIDS and hepatitis C virus treatment advocate since 1990. "I wanted to find something important to do with my life."

She told BBV Review about her early days in the movement, "One of the first jobs I had was to walk around Boston in an area where there were a lot of young sex workers. We handed out condoms, and when we could get them, because it wasn't technically legal at the time, we'd hand out syringes."

She is now with the Treatment Action Group (TAG), an organization that emerged from the AIDS activist organization AIDS Coalition to Unleash Power's (ACT-UP) Treatment and Data Committee in January of 1992. "There's a great film that was made about it, called How to Survive a Plague that I really recommend," says Tracy.

"It was basically a group of people being devastated by HIV/AIDS and there was no government response or a coordinated effort to address the virus. They demanded that it be addressed, and that they be included in designing and reviewing clinical trials."

When several effective antiretroviral drugs were approved in 1995, TAG pressured the government and the pharmaceutical industry to conduct research on these new drugs and their long-term effects.

"They really versed themselves on trial design, statistics, drug development and every aspect of HIV to make sure people living with the virus had an influence and a voice in the development of a cure and treatment. It was a revolutionary model that was and is trying to be replicated in other areas of medicine. Doctor's worked with patients in more of a partnership. It's pretty special."

TAG does global work too. Tracy emphasizes that TAG doesn't tell activists across the world how to approach this issue in their own countries, instead preferring to provide support and work with them. "With HIV, low-income regions and countries have mounted an incredible response. In Africa, the Treatment Action Campaign (TAC) has done incredible work. Their organization has saved hundreds of thousands of lives through their work."

Tracy says HIV clinical trials, which research possible cures, treatments, how a person's immune system is impacted by the virus and other issues, are not adequately funded. "There have been threats to cut AIDS research, too. It's such a shame because there's been so much progress."

Hepatitis C, another issue that Tracy tackles, also faces difficulties. "There are huge gaps in awareness and education. Unfortunately, the message most people get is that there are new treatments, but no one is going to pay for them because they're too expensive."

"I think it's likely that a lot of people were uninsured until fairly recently, until Obamacare kicked in. So you're dealing with people who aren't so familiar with navigating our healthcare system, and might not understand why the doctor can be gruff and impatient with them, not realizing that they're using a broken healthcare system, not that there's something about them that is making the doctor behave that way."

An issue that is left out of the mainstream conversation on HIV/AIDS and hepatitis C is co-infection. "HIV seems to accelerate hepatitis C progression. It also tends to increase the risk that someone will develop a serious liver disease. But the great news is that if people get treatment, they are just as likely to get cured as HIV-negative people. Before the new drugs were available, the only chance people had was to use interferon which was far less effective. HIV positive had really harsh side effects, making it hard for people to complete the treatment."

Drawing a comparison between those affected with HIV/AIDS and those affected with hepatitis C, she points out that the social stigmas are different. HIV/AIDS affected people have made communities that provide strong support, while those affected with hepatitis C still tend to hide. It is an interesting difference of dynamics, since one is curable while the other currently is not.

If treated with the new drugs, hepatitis C on average can be cured in 12 weeks, although this can vary from person to person. With interferon-based treatment, the treatment course could be 6-12 months or even longer. The side effects are also much more adverse.

One main criticism she has is that the government has not directed an adequate amount of resources to combat hepatitis C, or to do the research, "Pretty much, at this point, the drug development is all left to pharmaceutical companies. High drug prices have also led carers to restrict treatment access using a range of non-evidence based criteria. They refuse to pay for it. Imagine the healthcare experience it gives someone, say a Medicaid beneficiary, to find out they are not sick enough to receive treatment, and they have this infectious disease that can progress. The healthcare system is completely letting them down."

She further explains this non-evidence based criteria, "It can include drug testing, or in some cases, a period of abstinence from drugs before they're treated. Which is completely unnecessary. The cure rates of drug users and non-drug users are the same. There's no valid scientific reason to do this, it's just discrimination."

"We have the opportunity to eliminate hepatitis C and it would be appalling if we don't do it because it wasn't affordable. Or we wait years and years and watch people get sick and die from something that is easy to cure." She went further, calling drug prices "extortionist". Her criticisms are not new. Drug prices have been in the spotlight in recent years, with the extraordinary Sovaldi case in 2013, the drug was priced at \$1,000 a pill, or \$84,000 list price for a 12-week course.

When asked about her predictions for the future in the fight against HIV/AIDS and Hepatitis C, she expressed hope and excitement. "With HIV it's an interesting time. We know so much more about how it can be prevented. With hepatitis C we need a real revolution about drug pricing, because no matter how good the drugs are, people can't afford them. There's a lot of advocates around the country fighting for broader access, but until the prices come down, there won't be broader access."

## **About Tracy Swan**

Tracy is Hepatitis /HIV programme director at TAG. She is going to move to MSF communications department soon where she is going to work on Access Campaign Project. The campaign focuses on access to treatments for HIV, viral hepatitis, TB and other diseases.

Find out more about TAG: [treatmentactiongroup.org](http://treatmentactiongroup.org)

<http://bbvreview.com/hepatitis-c/treatment-action-groups-tag>