



## TB CAB 10th anniversary

### Chapter 1

Fade in Anonymous Key Informant Voice 16:

I do think there are some people who think it would be easier if they were gone. But Gosh, I shudder to think about the horrible ethical violations that would occur in the absence of the Global TB CAB, and you know, 20 years from now what people would be writing or saying. I think they keep us honest.

Bactrin Killingo:

What is the Global TB CAB and who are they keeping honest?

I'm Bactrin Killingo, a palliative care physician, long-time HIV and TB activist, and founding member of the Global TB CAB.

I'll be joined by Mark Harrington, co-founder and Executive Director of Treatment Action Group. Together, we'll answer these and other questions in this three-part podcast. We will explore the ins and outs of the Global TB CAB, from its origins in 2011 and impact over the last 10 years to its future plans -- and the important role communities play in shaping & moving science and access to innovations forward.

Much of what we will cover is based on the findings of an evaluation undertaken by Andrea DeLuca, the founder of Research for Impact. The full evaluation report is available at [www.treatmentactiongroup.org](http://www.treatmentactiongroup.org).

Andrea interviewed 40 people including activists, researchers, pharmaceutical company representatives and other global health actors who have worked with the TB CAB at various points since its inception. Their perspectives on the past,

present and future of the TB CAB are woven throughout this podcast series, with direct quotes de-identified to preserve their anonymity.

We hope you enjoy the series.

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#### Bactrin Killingo:

In 2020, 10 million people -- 1.1 million of them children -- fell ill from a pandemic respiratory disease. 1.5 million died. But we're not talking about COVID-19 -- we are talking about tuberculosis -- what we refer to as "TB".

Unlike the novel coronavirus, TB is thousands of years old. It has killed more people than any other pathogen in human history. Before 2020, it was the deadliest infectious disease on Earth. After COVID-19, it now holds the number 2 slot.

Astonishingly, we're still fighting TB today but with yesterday's tools -- the only semi-effective vaccine is over a hundred years old, and existing treatments are toxic and difficult to tolerate. Compared to the unprecedented mobilization of scientific resources against COVID-19, the lack of progress against TB may be hard to understand. How is it possible that this age-old disease continues to wreak such havoc today? And why has so little been done about it?

The answer lies in political will: while government, scientists and civil society groups rose to take action against COVID-19, TB simply hasn't inspired the same urgency. People with AIDS and their allies knew their survival depended on effective research and treatment, which wouldn't come about without institutional support -- so they resolved to build it themselves.

One of those activists was Mark Harrington, whose experiences fighting for more effective HIV treatments led him to co-found Treatment Action Group, or T. A. G.; TAG.

#### Mark Harrington:

I moved to New York City back in 1986, when I was 26 years old. By then, AIDS had already claimed nearly 50,000 lives in the United States. Over 250,000 Americans were already infected with HIV. Many were young gay men like me, and I was seeing friends get sick and die. But the response from people in power was indifference, ignorance, and inaction. Racism and homophobia were rampant. The war on drugs was putting tens of thousands of young Black and Latino men behind bars. The Reagan administration was slashing funds for public health, research, and medical care.

Those of us living among communities of people living with HIV knew there was no time to waste – government bureaucrats, clinical researchers, and pharmaceutical companies weren't doing enough or moving fast enough to save lives.

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Bactrin Killingo:

There wasn't exactly a playbook for how to make these entities do more or move faster. Mark and other people affected by AIDS would have to write their own: they banded together and came up with tactics that would force institutions to prioritize AIDS and change the lives of people living with it.

Protests, media stunts, teach-ins, civil disobedience.

AUDIO CLIP OF ACT UP DEMONSTRATION:

This beautiful day started with trouble in lower Manhattan where more than a hundred people were arrested during a protest. Demonstrators were demanding more money in the war against AIDS. They brought rush hour traffic to a standstill. Tim Minton has details.

*Demonstrators chanting as background sound – “Act up, fight back, fight AIDS.”*

The early show on Broadway today was packed. Thousands of financial center workers leaving subways and hundreds more in cars were nowhere to go were

caught by the performance. The message was blunt. Spend more for research, treatment, and education on AIDS.

Bactrin Killingo:

Chapters began sprouting up across the country, calling themselves ACT UP: The AIDS Coalition to Unleash Power.

Different members focused on different issues. ACT UP members would go on to win concessions as broad ranging as supportive housing policies for people living with HIV, to establishing needle exchange programs for people who inject drugs. For his part, Mark threw himself into the science, leading a working group that strove to improve and accelerate HIV/AIDS treatment and data – called, well? Treatment and Data. They were nicknamed “Science Club”, devouring research about HIV/AIDS in academic journals, and ultimately untangling how science works in the real world: whose research gets funded, how scientists even decide what to study, or how drug developers run clinical trials. All the questions had different answers but shared one very important one: people directly affected by AIDS were never at the table.

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Mark Harrington:

AIDS activists learnt how to use a combination of spectacular direct actions and demonstrations, alongside expert reports and testimony -- an inside and outside strategy -- to force our way into rooms where decisions were made on what to test, who to test, and how to test new drugs. Starting in 1990, our massive "Storm the NIH" demonstration at the U.S. National Institutes of Health headquarters in Bethesda, Maryland began to upend norms for how research was done.

AUDIO CLIP FROM STORM THE NIH DEMONSTRATION:

What else can I tell you about NIH? The NIH constantly, consistently excludes people and uses a lot of fancy ways of doing it. They talk about inclusion, they talk

about exclusion criteria, they base it on your liver values, they locate treatment centers away from where you are and they locate them where the disease isn't.

Mark Harrington:

We fought to have people living with HIV involved in every step of the clinical trial process – on every protocol team, research committee, peer review committee, and data safety monitoring board -- and we won! AIDS treatment activism created local, national and drug company community advisory boards. This activism helped change the way that drugs were studied and approved for AIDS in the United States and around the world. Among the key changes were allowing surrogate markers like changes in HIV levels in the blood, or viral load, to stand in as a basis for preliminary U.S. Food and Drug Administration, or FDA, accelerated approval, which paved the way for the advent of effective combination HIV treatment, starting in 1996.

This advance steered the field in a new direction, and helped bring in more federal research dollars, drug discovery efforts and better treatment. In just two years after the rollout of combination HIV treatment, AIDS deaths in the United States dropped by 67%. Today, with proper care and treatment, HIV has become a chronic and manageable condition.

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Bactrin Killingo:

And as for Science Club? They founded their own organization in 1992, called Treatment Action Group. In the years that followed the ART breakthrough, patients privileged enough to get treatment went on to live relatively normal lives. But things for people living with HIV were far from perfect. Globally, where 95% of people with HIV live, the drugs were too costly.

Less privileged people – like my patients in Kenya -- still lacked meaningful access to the lifesaving innovations that activists in wealthier countries had won.

Knowing that effective treatments existed, but that people in Africa were still dying of HIV – inspired me to become an activist too. I got involved in the fights waged by comrades at the Treatment Action Campaign (TAC) and Médecins sans Frontières (MSF) Khayelitsha that ultimately brought access to HIV medicines to Southern and Eastern Africa. Activists in Brazil, Kenya, Thailand and elsewhere mobilized as well, forcing global leaders to act.

#### AUDIO CLIP FROM TREATMENT ACTION CAMPAIGN VIDEO:

In 2000, South Africa hosted the World AIDS Conference.

*Welcome to the 13<sup>th</sup> International World AIDS Conference.*

The number of people living with HIV in South Africa increased to nearly 4.5 million in 2000. Sub-Saharan Africa had become the epicenter of the epidemic. Yet, antiretroviral treatment was unaffordable for most in our region. The TAC organized a mass march for treatment access. The march mobilized global opinion in support of the call that patents and profits should not be allowed to prevent access to lifesaving medicines. In a crucial opening address to the conference, judge Edmund Cameron placed the issue of access to treatment on the agenda.

*I'm here, I'm able to be talking to you, I'm able to engage with you, I'm able to speak with you about this important topic because I'm on antiretroviral therapy. There are people throughout Africa, 25 million people in Africa, and 34 million people in our whole world who are at this moment dying. And they are dying because they don't have the privilege that I have of purchasing my health.*

#### Bactrin Killingo:

So people would have the knowledge to take advantage of these critical new medicines, we followed the example of the Treatment Action Campaign and designed HIV and treatment literacy materials and campaigns with the International Treatment Preparedness Coalition – rolling these out in scores of countries around the world. And seeing just how powerful activism can be, we founded the World CAB – a mechanism to bring together global HIV activists to

engage with governments and pharmaceutical companies – a model that the TB CAB would draw on years later.

Today over 25 million people with HIV are receiving life-saving combination HIV treatment. But as fewer and fewer people were dying of AIDS in Kenya, I began to notice something else: that our patients, colleagues, and friends, who were brought up from deathbeds, were returning to those very same deathbeds because of TB.

Mark Harrington:

And it wasn't just in Kenya. A troubling pattern had emerged throughout the AIDS pandemic: the most vulnerable people affected by HIV were also at astoundingly high risk of another life-threatening co-infection, tuberculosis.

As we know, TB had been around since ancient times – but went through a resurgence beginning in the 1980s driven largely by the global AIDS crisis that allowed the TB organism to take advantage of weakened immune systems and weakened health systems. By 2000, tuberculosis had become the leading cause of death for people with AIDS around the world, and at least one-third of people living with HIV were already co-infected with TB. So, it was a threat to all of us. Nearly two million people were dying of tuberculosis each year – around the same number of people that were dying of AIDS. So that when people with HIV around the globe finally gained access to effective and safe HIV treatment, they realized that they may be able to live with HIV only to die from tuberculosis. And the most marginalized people were in the gravest danger. So, activists around the world began to get angry. Very angry. Like Ezio Tavora, a founding member of the Global TB CAB from Brazil:

Ezio Tavora:

I'm Ezio Tavora, I'm Brazilian, born and living in Rio de Janeiro. I was diagnosed with HIV back in 85, when HIV was still called HTLV three. And I had TB twice in

the 2000s. I am a lawyer by formation. I have a master's in international relations. I have a PhD in health policies. But above all, I'm an advocate. I'm an AIDS and TB advocate.

As I am a longtime survivor of HIV and AIDS, I started my AIDS treatment back in 1990. I have to highlight that I had TB twice. There was a coincidence because I had my first TB condition the year I started doing TB work. That was back in 2000, at the end of 2002.

I am a middle-class person in Brazil, working in the health area with researchers, with advocates, so I knew what to do, where to go, etc. and Brazil has the universal health system. And we, I knew the specialists, etc. so, I don't struggle for food or housing conditions, but majority of people who are affected by TB are people living in poverty. So, I had my TB condition because I'm a person living with HIV. But most people affected by TB are people living in poverty in bad conditions. TB treatment is cruel to these people.

Bactrin Killingo:

But very little was being done to make it less cruel. For every dollar spent on HIV/AIDS research, a measly 5 cents went to TB. In the early 2000s, an estimated 8.8 million people were sick with TB but only 1.2 million, 26% of them were being treated for it. The best available treatment had tons of side effects and hadn't been improved since the 1960s. The only marginally effective vaccine – which is cheap and widely implemented but only effective in childhood – dated back to the early 1920s! Diagnostic tests hadn't improved since the 1800s and were so slow with such limited sensitivity, especially among people living with HIV, that many people died of TB waiting for their results.

In other words, the TB field desperately needed a push, like those that remade the HIV world so dramatically years before. People living with HIV had demanded better diagnostics, prevention methods and treatment for years, and had successfully shifted the course of the HIV pandemic.



So, it was the right moment to apply HIV activist's knowledge and know-how to create a similar shift in the political will and tools available to fight the TB pandemic.

Mark Harrington:

TAG began to include tuberculosis in our work in the year 2000, when we began working with treatment activists in South Africa to force their government to provide free combination HIV treatments and seeing first-hand how they were fighting both AIDS and TB at the same time in the same communities and in the same bodies. Back then, there was very little activism centered on TB itself. We began to hold workshops on TB and HIV at the International Union World Lung Health Conference in Montreal back in 2002... and at the outset it was very lonely work.

But bit by bit, people affected by TB around the world began to find each other, connect, and collaborate – many people who'd cut their teeth in HIV advocacy, people from civil society groups whose work touched on TB, and survivors of TB and their family members. Like Wim Vandeveld, another founding member and chair of the TB CAB from 2011 until 2018.

Wim Vandeveld:

My name is Wim Vandeveld. I am a Belgian living in South Africa. I work for the Global Network of People Living with HIV, GNP+, and as the liaison officer for the communities' delegation on the board of UNITAID. And I'm also the former and first chair of the TB CAB.

I can distinctly remember the drive around Rio de Janeiro in Brazil. I believe it was an HIV conference. We were sharing a cab with Mark Harrington and Nikos Dedes from the European AIDS treatment group. And Mark was trying very hard to, to convince the HIV activists which we were at the time, the European activist to get involved in TB, and there was very little interest. But his pitch made a big

impression on me. And that was really the moment when I started looking at TB a bit more closely.

Bactrin Killingo:

The emerging cadre of TB activists also included physicians like me, who were infuriated to see so many patients dying of a curable disease. Mark, Ezio, Wim, me and other early TB CAB members were all from very different walks of life, but we had one powerful thing in common: we refused to tolerate the inaction of governments, health systems and drug developers in the face of so much needless suffering.

Mark Harrington:

And so, our growing group of TB and HIV activists slowly embarked on a similar strategy as Treatment and Data had earlier. Developing a deep understanding of the dire state TB research, diagnosis, treatment, and prevention, and how it had to change.

Our conclusions were damning. We discovered that TB programs around the world and policymakers at the World Health Organization were promoting and implementing policies that left millions of people with TB excluded from effective diagnosis, care, treatment, and prevention. TB treatment had barely changed since the mid-1960s, but the TB organism itself continued to evolve - exploiting collapsing health systems, the rise of HIV, and increasing mutations which made many of the most commonly used first- and second-line TB drugs ineffective in the face of these new drug resistant organisms.

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Bactrin Killingo:

It was clear that TB needed a fight of its own, so we stepped up to wage one. We marched with TAC against MDR and XDR-TB in Cape Town in 2007, and at an

AIDS conference in the same city in 2009, we did a ton of activism on TB and HIV. We basically got really pissed off and made a scene and said “enough is enough.” But as exciting as it was to finally see some activist action focused on TB and its effects on major TB institutions like the United Nations Stop TB Partnership, we still had no formal mechanism to elevate TB community demands, and to pressure entities involved in TB research and programs to prioritize the issues and needs most relevant to people and communities directly affected by the disease. So the next step was to build our own: with funding support from the Bill and Melinda Gates Foundation, TAG convened the first meeting of the Global TB CAB with a vision that it would become an integral part of the research and development of new TB tools and technologies.

And so it was that on November 7<sup>th</sup> 2011, nine people from seven countries convened in Virginia to form the world’s first CAB focused on TB – and, honestly, we got straight to work. During our first meeting we invited allied experts to train us on TB research and regulatory science, reviewed the most current information on compounds and regimens being evaluated in clinical studies, and met with the TB Alliance, Otsuka, and Tibotec (now Janssen) to discuss their short- and long-term strategies for developing TB drugs and regimens.

Mark Harrington:

It reminded me of the early days of Treatment and Data and TAG. We gathered information about what was happening, to show just how big of a problem TB really was and how little was being done about it. We held well-informed conversations and built our activist agenda based on roadblocks we identified in research, regulatory agencies, uptake and access to newer and more effective diagnostics tests and treatment regimens. We questioned the status quo by challenging policy makers, programs, research institutions, product developers, regulatory agencies, and governments... we needed more to be done, and we demanded significant change.

The TB CAB used activist tactics that we knew would work: learn the science, build coalitions, establish inside and outside strategies, name and shame, employ civil disobedience and direct action. TB activists started doing things never seen before in the TB field in over 150 years! And all those actions had a real, palpable impact.

Here's Wim again:

Wim Vandeveldel:

One of the early impactful actions that stand out for me was when we stormed the stage at the Paris Union Conference in 2013, I believe. And Bactrin Killingo took the mic and called out the Indian government representatives who were sitting in the front row and called out their lies on the terrible situation in India. And this action really put us on the map I believe.

Bactrin Killingo:

I was charged with, essentially, shaming the Indian Health Minister. Because India was manufacturing medicines and exporting them to other countries, but our research had proven that they were ignoring people with TB in their own country – and lying about it. So, I interrupted the conference to deliver the TB CAB's message in front of 1000 people. It was an out-of-body experience.

AUDIO CLIP FROM UNION CONFERENCE 2013 ACTION

It is time to be serious and practical and to put aside rhetoric. We will never achieve zero if we don't look at the gaps that exist in our countries. One thousand people die in India everyday of tuberculosis.

*Chanting of shame in the background.*

Every day, including children. Why? Because, for instance, there are stock outs. There are stocks of anti-TB medicines for children, drug sensitive, drug resistant,

that have been flagged by civil society for almost a year and a half. And the Indian government continues to deny that there are any stockouts.

*Chanting of shame in the background.*

There has to be a stop to these kinds of things that cause people to die unnecessarily. Innocent children are dying when people are continuing to say there are no stockouts. We have evidence. We have evidence that last year the Joint Monitoring Committee made suggestions about what needs to be done to anticipate stockouts. India supplies most of the drugs to most of the countries from where I come from in Africa. But people in India are dying because they are not getting their meds and, whatever meds they get, are substandard. We, global advocates, say “no” to this. It must stop, and it must stop now.

*Chanting of shame in the background and cheering/ clapping.*

Bactrin Killingo:

I'm sure the Minister was very unhappy with me! But that very day, TB policies began to shift in India. There is still a long way to go with many gaps in the National Program in India, some of which you will hear about in later episodes. But after this action in Paris, now with the knowledge that the international community was watching and criticizing what they were doing –there was a sense of increased urgency and attention to TB within the Indian government. And I don't think that the transformation we've witnessed in TB over the last two decades could have happened without activist pressure. Here is how Ezio put it:

Ezio Tavora:

I remember situations in where government representatives would leave the room, or developers would feel very uncomfortable and tension were part of the thing and sometimes it creates a bit of a distance. But you don't do the omelet without breaking the eggs. I mean, you have to change the context.

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Mark Harrington:

If you're listening to this podcast, you may know this story. Perhaps you've been a part of the Global TB CAB, or been directly or indirectly affected by its work. With the TB CAB first decade already behind us – an anniversary that we're marking in the midst of yet another global pandemic – tuberculosis is still tragically neglected by global health leaders, struggling for lack of investment and largely reliant on antiquated, outdated technology. And yet, due to the activism and the research of the last 20 years, the outlook is brighter than it ever has been for TB – with a promising research and development pipeline and major new discoveries in TB prevention, diagnosis, and treatment, which now have to be implemented around the world.

I'm Mark Harrington with Bactrin Killingo. Now that we've explained the origins of the Global TB CAB, it's time to ask a few big questions: What did we do? What have we won, how have we fallen short, and how can we make the most out of the decade to come? Tune in to Episode 2 to find out.

**VOICE ACTOR:**

This podcast is produced by Treatment Action Group, with the support of Laia Ruiz Mingote and Alex Orozco.

The informant quotes were voiced by TAG staff.