







LHL International





Partnership

















ACTIVISTS URGE NATIONAL TB PROGRAMS AND TREATMENT PROVIDERS TO DISCONTINUE USE OF HARMFUL INJECTABLE AGENTS IN TB TREATMENT

In a symbolic display, activists invited conference participants to discard the injectable agents and commit to rapidly scaling up access to safer, more effective medicines

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The Hague, Netherlands – October 25, 2018 –Activists from around the world called on National TB Programs to discontinue routine use of harmful injectable agents in treatment regimens for drug-resistant tuberculosis, in favor of newer, safer World Health Organization (WHO)-recommended treatments.

At the closing of a symposium at the 49th Union World Conference on Lung Health titled "Toward Zero Hearing Loss: Access to New TB Drugs and the Human Right to Enjoy the Benefits of Scientific Progress," activists from Treatment Action Group (TAG), Médecins Sans Frontières (MSF), TB Proof, the Global Coalition of TB Activists (GCTA), AIDS-Free World, AIDS and Rights Alliance for Southern Africa (ARASA), Kenya Legal and Ethical Issues Network on HIV and AIDS (KELIN), LHL International, Health GAP, International Indigenous Working Group on HIV & AIDS, Stop TB Partnership, Stop TB Partnership – Kenya, TALAKU Community, Global TB Community Advisory Board (TB CAB), Tunisian Center for Public Health, Wote Youth and Development Projects, and Zimbabwe National Network of People Living with HIV (ZNNP+) "capped the jabs" by discarding syringes into the trash bin of history, which was labeled with a biohazard sign.



"People no longer have to choose between death and permanent disability," commented Phumeza Tisile, an extensively drug-resistant TB (XDR-TB) survivor and TB advocate from TB Proof. "The newer medicines for drug-resistant TB—bedaquiline, linezolid, and delamanid—can save people's lives and their hearing."

Second-line injectable agents (kanamycin, capreomycin, and amikacin)—previously considered essential medicines for the treatment of multidrug-resistant TB (MDR-TB)—have poor efficacy against TB and high toxicity, including irreversible hearing loss. Giving these medicines to people with MDR-TB exposes them to unnecessary pain and risk of disability—in the case of kanamycin and capreomycin, without any benefit. In a rapid communication released in August 2018, the WHO recommended bedaquiline be used alongside linezolid and either levofloxacin or moxifloxacin as the preferred core of treatment regimens for rifampicin-resistant and multidrug-resistant-TB. Kanamycin and capreomycin are no longer recommended at all; amikacin should only be used when a regimen cannot be otherwise constructed.

"Every person with TB has the right to the best available treatment. As a community, we demand our right to participate in decisions about care, and commit to holding our governments accountable for ensuring access to the best standard of care," said Blessina Kumar, CEO of GCTA.

"For patients that can be treated with safer, more effective alternatives, in particular using bedaquiline, the continued use of toxic injectables is unethical," said Lindsay McKenna, Co-Director of the TB Project at TAG. "National TB Program managers must act with a sense of urgency—the urgency with which they would act if their own hearing were at risk—and rapidly scale-up access to all-oral, bedaquiline-based treatment regimens."

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About AIDS-Free World: AIDS-Free World is an international advocacy organization that exposes injustice, abuse and inequality, the social ills that underpin and continue to sustain HIV. We apply high-level advocacy, targeted legal strategies and creative communication to work for a more just world. We believe that national governments and the international institutions that were created to make the world more just, peaceful, healthy and humane should do just that. When they lose sight of their purpose, we hold them accountable and call on them to serve the world as intended, working together toward a world free of violence, discrimination and exclusion.

About the AIDS and Rights Alliance for Southern Africa (ARASA): Established in 2002, the AIDS and Rights Alliance for Southern Africa (ARASA) is a regional partnership of 115 non-governmental organisations working collaboratively in 18 countries in southern and east Africa to promote human rights in the context of HIV, tuberculosis (TB), and sexual and reproductive health and rights (SRHR). The ARASA partnership promotes inclusivity of all communities (in their diversity) in advocating for enabling national legal and policy environments to advance equitable and equal access to affordable health services.

About the Global Coalition of TB Activists (GCTA): The GCTA is a global platform of people affected by TB to advocate for a people-centered, rights-based approach to TB response. GCTA strives to encourage, establish, mentor and bring together regional and national TB coalitions to globally collaborate on addressing issues of TB-affected communities on policy, treatment and access, leveraging complementary strengths to achieve greater and wider advocacy impact. The GCTA became a legally registered entity in 2018 and currently has over 300 members from around the globe. The GCTA envisions a 'World Free of Tuberculosis' with a mission to ensure that voices of TB-affected communities influence the global TB and health agenda.

About Health Global Access Project (Health GAP): Health GAP is an organization of AIDS and human rights activists, people living with HIV/AIDS, public health experts, fair trade advocates and concerned individuals who campaign against policies of neglect and avarice that deny treatment to millions and fuel the spread of HIV. We are dedicated to eliminating barriers to universal access to affordable life-sustaining medicines for people living with HIV/AIDS as key to a comprehensive strategy to confront and ultimately stop the AIDS pandemic. We believe that the human right to life and to health must prevail over the pharmaceutical industry's excessive profits and expanding patent rights.

About Kenya Legal and Ethical Issues Network on HIV and AIDS (KELIN): KELIN is a human rights NGO working to protect and promote health-related human rights in Kenya. We do this by: providing legal services and support, training professionals on human rights, engaging in advocacy campaigns that promote awareness of human rights issues, conducting research and influencing policy that promotes evidence-based change. KELIN's current programme areas are around: promoting justice for widows and orphans, campaigning for funding for health services, ensuring the government effectively supports the rights of TB patients and persuading people in Kenya to know and use their human rights. Our vison is the full enjoyment of health-related human rights for all.

About LHL International: LHL International was established as a foundation 01.01.2013 by the Norwegian Heart and Lung Patient organization (LHL). LHL was founded in 1943 as a special interest group for people with TB. The organization fought against prejudice, and promoted TB patients' right to work and social security. LHL International's aid work, which started in the 1980s, builds on this history. Today, LHL International has partners and projects in Malawi, Tanzania, Sudan, Zambia, Russia, Romania and Norway, mostly funded through grants from the Norwegian government.

About Médecins Sans Frontières (MSF): MSF is an international, independent medical humanitarian organization that provides medical assistance to people affected by conflict, epidemics, disasters, or exclusion from healthcare. MSF's teams are made up of tens of thousands of health professionals, logistic and administrative staff - bound together by MSF's charter. MSF's actions are guided by medical ethics and the principles of impartiality, independence and neutrality. MSF is a non-profit, self-governed, member-based organization. MSF was founded in 1971 in Paris by a group of journalists and doctors. Today, MSF is a worldwide movement of more than 42,000 people.

About International Indigenous Working Group on HIV & AIDS (IIWGHA): IIWGHA's mission is to create an international voice and structure that links Indigenous peoples with their Indigenous leadership, varying levels of governments, AIDS service organizations, cooperatives, and others in a global collective action to lower the disproportionate impact of HIV and AIDS experienced by Indigenous peoples.

About the Stop TB Partnership (STBP): The Stop TB Partnership's mission is to serve every person who is vulnerable to TB and ensure that quality diagnosis, treatment, and care are available to all who need it. The Stop TB Partnership's 1500 partners include international and technical organizations, government programs, research and funding agencies, foundations, NGOs, civil society and community groups and the private sector. The Stop TB Partnership is governed by a Coordinating Board and operates through a secretariat hosted by UNOPS in Geneva, Switzerland and seven working groups whose role is to accelerate progress on access to TB diagnosis and treatment; research and development for new TB diagnostics, drugs and vaccines; and tackling drug resistant- and HIV-associated TB.

About Stop TB Partnership – **Kenya:** The STOP TB Partnership – Kenya is a movement of individuals and organizations from the Government of Kenya, corporate community, patient community and the people of Kenya who are dedicated to eliminating tuberculosis (TB) and reduction of poverty-related diseases in Kenya. The movement mirrors the Global Stop TB Partnership, which comprises of donors, national and international organizations, government and non-governmental organizations, affected communities and academic institutions working together to reduce the burden of TB worldwide and ultimately achieve a world free of TB.

About the Global TB Community Advisory Board (TB CAB): The TB CAB is a group of strong, research-literate community activists from HIV and TB networks in Asia, Europe, Africa, and North and South America. Founded in 2011, the TB CAB acts in an advisory capacity to: product developers and institutions conducting clinical trials of new TB drugs, regimens, diagnostics, and vaccines; and provide input on study design, early access, regulatory approval, post-marketing, and implementation strategies. The TB CAB is dedicated to increasing community involvement in TB research and access to tools to fight TB, and mobilizing political will.

About TALAKU Community: TALAKU Community is a non-profit organization, which was founded in 2012 by a former TB patient. It main goals are to educate the community on the signs and symptoms of TB, measures of preventing and caring for TB patients. The importance of treatment adherence, contact tracing for family members and tracing lost to follow up. TALAKU educates the pastoral community on adequate measure on preventing Zoonotic TB.

About TB Proof: TB Proof is a non-profit organization, founded by healthcare workers who were personally affected by TB. TB Proof's goals are to: (1) create safer healthcare environments to 'TB PROOF' healthcare workers and patients by raising awareness of TB transmission prevention; (2) de-stigmatize all forms of TB with particular emphasis on stigma arising from drug-resistant TB (DR-TB), occupational TB and HIV/TB co-infection; and (3) mobilize resources for TB prevention through community activism, education and collaboration with national and global partners.

About Treatment Action Group (TAG): TAG is an independent, activist, and community-based research and policy think tank fighting for better treatment and prevention, a vaccine, and a cure for HIV, TB, and hepatitis C virus (HCV). TAG works to ensure that all people with HIV, TB, and HCV 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.

About Tunisian Center for Public Health: The Tunisian Center for Public Health works collaboratively with academics and community partners to design and implement research and develop intervention strategies for urban and vulnerable populations. The Center utilizes research findings to provide tangible benefits to communities, reduce health care disparities, and foster public health care quality improvement.

About Wote Youth and Development Projects: Wote Youth Development Projects was established as an advocacy group for HIV/AIDS in 2002 using participatory interactive media mode. The youth use drama, skits, dance, role plays and football for ACSM. Currently we are implementing a CFCS TB project with STOP TB Partnership as Ambassadors of Hope.

About Zimbabwe National Network of People Living with HIV (ZNNP+): ZNNP+ is committed to be the leading national organization for advocating and lobbying for the rights of PLHIV to improve their quality of life. Our goal is to assist in ensuring that the infected and affected (by HIV and AIDS) have access to holistic care and support, prevention, treatment and mitigation in a transparent and accountable manner and to ensure that the infected and affected participate in decisions that affect them at all levels.