

# DECLARATION OF THE RIGHTS OF PEOPLE AFFECTED BY TUBERCULOSIS



# Declaration of the **Rights** of People Affected by Tuberculosis

*Preamble:*

**We, the global community of people affected by tuberculosis,**

**Recognizing** that the promotion and protection of the human rights of people affected by tuberculosis is a legal, ethical and moral imperative, as well as of crucial importance for the effectiveness of the response to the epidemic and the relief of suffering among affected individuals and communities;

**Acknowledging** that people affected by tuberculosis have been and continue to be subjected to human rights violations, including through the tuberculosis response itself, and that these violations impede the elimination of tuberculosis, add to the suffering caused by the disease, and undermine the trust people affected by tuberculosis have in their health care systems;

**Emphasizing** that people affected by tuberculosis, with their first-hand experience and knowledge, must, by virtue of right and good practice, be involved in all stages of planning, implementation, monitoring, review and evaluation of tuberculosis programs at the global, regional, national, and local levels;

**Bearing in mind** that a purely medical or public health approach is not sufficient for the fight against tuberculosis, and that a rights-based, people-centered, comprehensive approach to tuberculosis prevention, testing, treatment, care and support, as an integral component of universal health coverage, is essential to ending tuberculosis; and

**Asserting** that international and regional human rights law mandates and provides the content of this Declaration, which serves to apply the law's requirements and to clarify States' legal obligations in the context of the tuberculosis epidemic, including the:

- *Universal Declaration of Human Rights;*
- *International Covenant on Economic, Social and Cultural Rights;*
- *International Covenant on Civil and Political Rights;*

- *Convention on the Elimination of All forms of Discrimination against Women;*
- *International Convention on the Elimination of All Forms of Racial Discrimination;*
- *Convention on the Rights of the Child;*
- *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment;*
- *International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families;*
- *Convention on the Rights of Persons with Disabilities;* and
- *Convention Relating to the Status of Refugees;*

and at the regional level, the:

- *African Charter on Human and Peoples' Rights;*
- *African Charter on the Rights and Welfare of the Child;*
- *American Convention on Human Rights;*
- *Arab Charter on Human Rights;*
- *European Convention on Human Rights;* and
- *European Social Charter;* and

**Taking into account**, among other things, the Sustainable Development Goals of the 2030 Agenda for Sustainable Development, the Political Declaration of the High-Level Meeting of the United Nations General Assembly on the Fight against Tuberculosis, the Stop TB Partnership Global Plan to End TB, the resolutions of the World Health Assembly, the United Nations Guiding Principles on Business and Human Rights, the United Nations Declaration on the Rights of Indigenous Peoples, the reports and proclamations of the United Nations Special Rapporteur on the Right to Health and other United Nations Special Rapporteurs, and the World Health Organization End TB Strategy, endorsed by World Health Organization member states, that establishes the protection and promotion of human rights, ethics and equity, as well as strong coalitions with civil society organizations and communities, as fundamental principles essential to the tuberculosis response;

**Have developed the present Declaration of the Rights of People Affected by Tuberculosis**

## Chapter I. General Provisions

### Article I. **Definitions**

This Declaration utilizes the following definitions:

*Health care for tuberculosis* refers to integrated care with all the most effective, high quality health goods and services associated with preventing, diagnosing and treating tuberculosis infection and disease, including pulmonary, extrapulmonary, drug-susceptible and drug-resistant tuberculosis, with the least harmful side effects, including, but not limited to diagnostics, drugs, counseling and other psychosocial support services, long-term hospitalization and ongoing care for partial or permanent disability, when required, community-based care, palliative and end-of-life care, monitoring for and management of adverse events during treatment, and other therapeutic interventions and devices, including emergency care, delivered by trained health care workers in a respectful, dignified, culturally-sensitive, nondiscriminatory manner, free from coercion and stigmatization, over the entire course of infection or disease and covering the entire lifespan for people requiring continuing care.

*Person affected by tuberculosis* refers to any person with tuberculosis disease or who previously had tuberculosis disease, as well as their caregivers and immediate family members, and members of tuberculosis key and vulnerable populations, such as children, health care workers, indigenous peoples, people living with HIV, people who use drugs, prisoners, miners, mobile and migrant populations, women, and the urban and rural poor.

*Tuberculosis* refers to all forms of tuberculosis disease, including pulmonary and extrapulmonary tuberculosis, drug-susceptible tuberculosis, and all forms of drug-resistant tuberculosis.

## **Chapter 2. Rights of people affected by tuberculosis**

### **Article 2. Right to life**

Every person affected by tuberculosis has the inherent right to life.

This includes the right to life-saving health care for tuberculosis.

### **Article 3. Right to dignity**

Every person affected by tuberculosis has the right to be treated with dignity and respect.

This includes being treated as an autonomous individual with agency and inherent worth—not just a means to a public health end—and without discrimination, stigma, prejudice or coercion, including in health care and detention settings.

### **Article 4. Right to the highest attainable standard of physical and mental health (right to health)**

Every person affected by tuberculosis has the right to enjoy the highest attainable standard of physical and mental health.

This includes the right to available, accessible, acceptable and high quality health care for tuberculosis, as an integral component of universal health coverage, including child-friendly fixed dose combinations and testing and preventive therapy for tuberculosis infection for members of key and vulnerable populations, from the moment of presentation with presumptive tuberculosis, to the completion of treatment, and beyond for people requiring continuing care, delivered by trained health care workers, at the community level, when appropriate, in a respectful, dignified, manner, free from coercion and stigmatization, on a nondiscriminatory basis, regardless of age, birth, color, culture, citizenship status, disability, ethnicity, financial status, gender identity, language, legal status, political or other opinion, presence of other diseases, national or social origin, race, religion, sex, sexual orientation or any other status, including for people detained by the State or otherwise deprived of their liberty, with special attention to tuberculosis key populations.

## Article 5. **Right to freedom from torture and other cruel, inhuman or degrading treatment**

Every person affected by tuberculosis has the right to be free from torture and other cruel, inhuman or degrading treatment or punishment.

This includes the right to health care for tuberculosis on a nondiscriminatory basis, at State expense, for all people detained by the State or otherwise deprived of their liberty. It also includes the right to dignified, safe and hygienic conditions of detention, free from overcrowding, with adequate ventilation and provision of nutritious food. The right also applies to the treatment of people with tuberculosis by health care workers in public health facilities that rises to the level of torture or other cruel, inhuman or degrading treatment.

## Article 6. **Right to equality and freedom from discrimination**

Every person affected by tuberculosis is equal before the law and entitled, without any discrimination, to the equal protection of the law and to be free from all forms of discrimination on any ground, such as age, birth, color, culture, citizenship status, disability, ethnicity, financial status, gender identity, language, legal status, political or other opinion, presence of other diseases, national or social origin, race, religion, sex, sexual orientation or any other status.

This includes the right of every person affected by tuberculosis to be free from all forms of discrimination in all areas of their life, including, but not limited to, access to social security and public entitlements, child birth and motherhood, education, employment, health care, housing and marriage.

## Article 7. **Right to liberty and security of person**

Every person affected by tuberculosis has the right to liberty and security of person. No person with tuberculosis shall be deprived of their liberty except on such grounds and in accordance with such procedure as are established by law. And every person affected by

tuberculosis deprived of their liberty shall be treated with humanity and with respect for their inherent dignity.

Involuntary detention, hospitalization or isolation of a person with tuberculosis is a deprivation of liberty and violation of the security of person. Involuntary hospitalization or isolation is therefore only permissible as a measure of last resort, in narrowly defined circumstances, for the shortest duration possible, in accordance with Chapter 15 of the World Health Organization's *Ethics Guidance for the Implementation of the End TB Strategy*, when a person, based on accurate medical evidence:

- Is known to be contagious, refuses effective treatment, and all reasonable measures to ensure adherence have been attempted and proven unsuccessful;  
OR
- Is known to be contagious, has agreed to ambulatory treatment, but lacks the capacity to institute infection control in the home, and refuses inpatient care;  
OR
- Is highly likely to be contagious (based on laboratory evidence) but refuses to undergo assessment of his/her infectious status, while every effort is made to work with the person to establish a treatment plan that meets their needs.

Moreover, in accordance with the United Nations Economic and Social Council's *Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights*, the deprivation of liberty involved in the involuntary detention, hospitalization or isolation of people with tuberculosis is only justified if it is:

1. In accordance with national law in force at the time of the deprivation;
2. Based on, and proportionate to, a legitimate objective in response to a serious threat to the health of the population or individual members;
3. Strictly required by the exigencies of the situation;
4. The least restrictive means available to achieve the objective;  
AND
5. Not arbitrary, abusive or discriminatory.

If justified, detention, hospitalization or isolation of a person with tuberculosis must: occur in a medically appropriate setting, with effective infection control measures, for the shortest duration

possible, only as long as the above circumstances apply; the person must be provided health care on a voluntary basis; all other rights and freedoms must be protected; due process and appeal mechanisms must be available and accessible; and the State must meet, at least, the person's basic needs, including, but not limited to, adequate food and water, as well any further needs as required to ensure the restriction of their rights effectively serves its purpose.

#### Article 8. **Freedom of movement**

Every person affected by tuberculosis lawfully within a territory of a State has the right to liberty of movement and freedom to choose their residence.

Every person affected by tuberculosis is free to leave any country, including their own.

The above-mentioned rights cannot be subject to any restrictions, except those which are provided by law, are necessary to protect national security, public order, public health or morals or the rights and freedoms of others, and are consistent with the rights recognized in international human rights treaties, including the right to liberty and security of person in Article 7 of this Declaration.

This means tuberculosis cannot be used as a ground for denying entry or re-entry into the territory of a State, nor as a ground for deportation or removal from the territory of a State. It also means tuberculosis cannot be used as a ground for restricting movement or travel within the territory of a State, except in accordance with the narrowly defined circumstances established in Article 7 of this Declaration, in line with Chapter 15 of the World Health Organization's *Ethics Guidance for the Implementation of the End TB Strategy*.

#### Article 9. **Right to privacy and family life**

Every person affected by tuberculosis has the right not to be subjected to arbitrary or unlawful interference with their privacy, family, home or correspondence, nor to unlawful attacks on their honor and reputation. Every person affected by tuberculosis has the right to protection of the law against such interference or attacks.



This includes the right of people with tuberculosis to keep their health status and personal health information and data private. It also includes the right to marry, found a family, and to have and care for children.

#### Article 10. **Right to confidentiality**

Every person affected by tuberculosis has the right to confidentiality in their personal health information and data.

This means that revealing, sharing or transferring, electronically or otherwise, the personal health information or data of a person affected by tuberculosis, including in employment settings, is only permissible with their informed consent and when done for purposes of their health care or protection of public health. For purposes of protecting public health, including in association with public health surveillance or health services delivery programs, such information may be shared or transferred without the person's informed consent only if it is done in an anonymous manner without the person's name or any personally identifiable information.

The right to confidentiality must also be respected and accounted for in the design and implementation of contact tracing and other related public health interventions. This includes, but is not limited to, providing access to disclosure counseling for people affected by tuberculosis, conducting joint decision-making about how and when to tell contacts about possible exposure, and ensuring access to trained health care and social workers to provide support and answer questions that may arise during the process.

#### Article 11. **Right to information**

Every person affected by tuberculosis has the right to seek, receive and impart information.

This means information about tuberculosis infection and disease, including disease symptoms, tuberculosis medical research and health technology development, and prevention, testing and treatment services, including possible adverse events during treatment, must be fully available, accessible and acceptable, of good quality, age and gender appropriate, culturally-sensitive, and imparted in a non-technical, comprehensible manner in a language understood by the person receiving the information.

It also means that every person affected by tuberculosis, at a minimum, has the right to:

- Request and receive official copies of their medical records;
- Receive a timely, accurate and understandable explanation of their health status and diagnosis for tuberculosis disease or infection, especially for tuberculosis key and vulnerable populations;
- Access voluntary counseling at any time from diagnosis to completion of their treatment; and
- Receive an explanation of the benefits, risks and financial cost, if any, of their proposed treatment, including preventive therapy, as well as possible treatment alternatives, with complete information about the specific drugs prescribed, such as their names, dosages, potential side effects and ways to prevent or reduce their likelihood, as well as possible effects from interactions with other drugs, such as antiretrovirals taken for HIV, when comorbidities or coinfections are present.

## Article 12. **Right to informed consent**

Every person affected by tuberculosis has the right to informed consent.

This means respecting a person's autonomy, self-determination and dignity through voluntary health services delivery. It includes the right to informed consent—verbal or written, depending on the situation—to all forms of testing, treatment and medical research associated with tuberculosis, with information provided in an age and gender appropriate, culturally sensitive manner, imparted in a non-technical, comprehensible manner in a language understood by the person receiving the information. For children affected by tuberculosis who lack capacity to give informed consent, all decisions made by their parents or legal guardians with respect to testing, treatment or medical research associated with tuberculosis must be made in the best interests of the child, based on accurate medical evidence.

The right to informed consent includes the right to refuse health care for tuberculosis, in accordance with Chapter 15 of the World Health Organization's *Ethics Guidance for the Implementation of the End TB Strategy*. The *Ethics Guidance* establishes that it is never appropriate to force treatment of people with tuberculosis because,

among other things, it amounts to an invasion of bodily integrity and may put health care workers at risk.

### Article 13. **Right to education**

Every person affected by tuberculosis has the right to education.

This includes the right to free and compulsory primary education and the right to access secondary and higher education, including technical and vocational education, on non-discriminatory basis, including for the disabled and the hearing or vision impaired. Children with tuberculosis have the right to be accommodated while they are infectious and while they are receiving treatment, with excused absences and other measures to allow them to continue their education without interruption, such as remote classroom participation and online learning. In the rare circumstance that children affected by tuberculosis require long-term hospitalization, they have the right to receive long-distance learning during the course of their treatment.

### Article 14. **Right to work**

Every person affected by tuberculosis has the right to work, and no person with tuberculosis shall be held in slavery or servitude, or be subjected to forced or compulsory labor.

This includes the right to safe and healthy working conditions, including for health care workers and all other people working in health care facilities, miners, labor migrants and all other workers at increased risk of tuberculosis infection and disease. It also includes the right to decide freely to accept or choose work, and to fair wages and equal remuneration for work of equal value, without distinction of any kind and with equal conditions and pay for equal work by people of all genders.

Every person affected by tuberculosis has the right to accommodations at work, including leaves of absences and breaks, to allow them to maintain their employment at the same status after their diagnosis and to accommodate them while they are infectious and while they are receiving treatment. If long-term hospitalization or partial or permanent disability makes it impossible for a person with tuberculosis to maintain their employment, due to restrictions imposed by law or the terms of their employment contract, they

have the right to social security in accordance with Article 18 of this Declaration.

#### Article 15. **Right to adequate food**

Every person affected by tuberculosis has the right to adequate food and to be free from hunger and malnutrition.

This includes the right to have physical and economic access, at all times, to food that is sufficient, nutritionally adequate and safe, including and with particular importance during the course of health care for tuberculosis, including for people deprived of their liberty. It also includes nutrition support therapy as required during treatment.

#### Article 16. **Right to housing**

Every person affected by tuberculosis has the right to adequate housing.

This includes the right to affordable, accessible and habitable housing in an acceptable location, with security of tenure that guarantees legal protection against forced evictions, harassment and other threats. It also includes the availability of services, materials, facilities and infrastructure, including, among other things, adequate sanitation and ventilation, heating, lighting and refuse disposal.

#### Article 17. **Right to water and sanitation**

Every person affected by tuberculosis has the right to water and sanitation.

This includes the right to access safe drinking water and adequate sanitation services, without discrimination, particularly in rural, indigenous and underdeveloped urban areas, including informal settlements and homeless populations, taking into account the needs of women and children.

## Article 18. **Right to social security**

Every person affected by tuberculosis has the right to social security and social insurance, including in the event of unemployment, disability, old age or another circumstance of loss of means of subsistence for reasons beyond their control.

This means every person affected by tuberculosis has the right to access and receive social security of all kinds, without discrimination, even if they are not receiving health care for tuberculosis or if they are not adhering to their treatment for tuberculosis. This includes the right to access and maintain benefits, whether in cash or in kind, in order to secure protection from, among other things: lack of income from work caused by sickness, disability, maternity, employment injury, unemployment, old age or death of a family member; unaffordable access to health care; or insufficient family support for children and adult dependents.

In particular, every person who acquires tuberculosis infection or disease as a result of their employment has the right to ongoing compensation for their medical and other costs associated with their occupational disease.

## Article 19. **Right to freedom of expression**

Every person affected by tuberculosis has the right to freedom of expression.

This right includes the freedom to hold opinions and to seek, receive and impart information and ideas of all kind, including about tuberculosis and individuals' experience with tuberculosis, through any medium, such as social media, without interference or retribution from public authorities.

## Article 20. **Right to freedom of assembly and association**

Every person affected by tuberculosis has the right to freedom of peaceful assembly and association and with others.

This includes the right to create, join and participate in non-governmental organizations and community groups of and for people affected by tuberculosis aimed at promoting and protecting

the rights and legitimate interests of people affected by tuberculosis, including in detention settings. It also includes the right to organize, assemble and protest peacefully in public around issues associated with tuberculosis.

Exercise of this right requires a conducive legal and policy environment that allows and facilitates the creation and operation of non-governmental organizations and community groups of and for people affected by tuberculosis. No restrictions may be placed on the exercise of these rights other than those prescribed by law and necessary in a democratic society in the interests of national security and public order, for prevention of disorder and crime, for protection of health and morals, or for protection of the rights and freedoms of others. This article does not prevent the introduction of lawful restrictions on members of the armed forces or law enforcement authorities.

#### Article 21. **Right to participation**

Every person affected by tuberculosis has the right to take part in public affairs, directly or through their organizations and freely chosen representatives.

This includes the right to participate meaningfully in all processes and mechanisms for the development, implementation, monitoring and evaluation of laws, policies, regulations, guidelines, budgets, and programs related to tuberculosis, health care for tuberculosis, and medical research for tuberculosis at all levels of governance, with support from and, when necessary, reasonable accommodation provided by the State, international organizations, indigenous groups and civil society organizations to ensure meaningful and effective participation.

#### Article 22. **Right to justice and due process**

Every person affected by tuberculosis charged with an administrative or criminal offence has the right to a fair and public hearing, without undue delay, by a competent, independent and impartial tribunal established by law, and to an effective, timely remedy when their rights are violated.

This includes the right to file complaints in the manner prescribed by law or regulation, including to public health authorities, and to

have a fair and prompt hearing of these complaints. It also includes the right to appeal to a higher authority, if they are not satisfied with the results of the adjudication, and to receive the decision and reasoning of their matter in writing in a language they understand.

Article 23. **Right to enjoy the benefits of scientific progress (right to science)**

Every person affected by tuberculosis has the right to enjoy the benefits of scientific progress and its application.

This means every person affected by tuberculosis must be able to access scientific advancements, without discrimination, respecting and protecting indigenous peoples' natural resources and individual and collective intellectual properties, whether these advancements are intangible things like knowledge and information or tangible outputs like new technologies for preventing, diagnosing or treating tuberculosis. It also includes the right to participate in the scientific process, from shaping research agendas, to participating in clinical trials.

The right to science also requires States to conserve, develop and diffuse science and its benefits. This means governments must: invest in and create legal and policy environments that enable research; make science and its applications widely available by, among other things, publishing results, establishing regulatory systems to evaluate new interventions, and basing public health programs and policies in scientific evidence; and ensure scientific progress and its benefits are preserved and maintained for future generations.

## Chapter 3. Obligations and Responsibilities

### Article 24. **State obligations under international and regional human rights law**

States have legal obligations established by international and regional human rights law to respect, protect and fulfil the human rights of people affected by TB, including the rights enshrined in this Declaration.

- I. **Obligation to respect:** States must refrain from interfering with the enjoyment of the human rights of people affected by TB;
- II. **Obligation to protect:** States must take measures to prevent third parties, including non-State actors, such as private health care providers, private health insurance companies, pharmaceutical and diagnostic companies, and others, from interfering with the enjoyment of the rights of people affected by TB; and
- III. **Obligation to fulfill:** States must adopt legislative, administrative, budgetary, promotional and other measures, to the maximum of their available resources, towards the full realization of the rights of people affected by TB.

### Article 25. **Non-state actor responsibilities under international and regional human rights law**

Non-state actors, including all kinds of business enterprises, such as private health care providers, private health insurance companies, pharmaceutical and diagnostic companies, and others, have the responsibility to respect the human rights of people affected by TB, including the rights enshrined in this Declaration. These non-state actors should avoid infringing on the human rights of people affected by TB and should address any adverse human rights impacts affecting people affected by TB with which they are involved.



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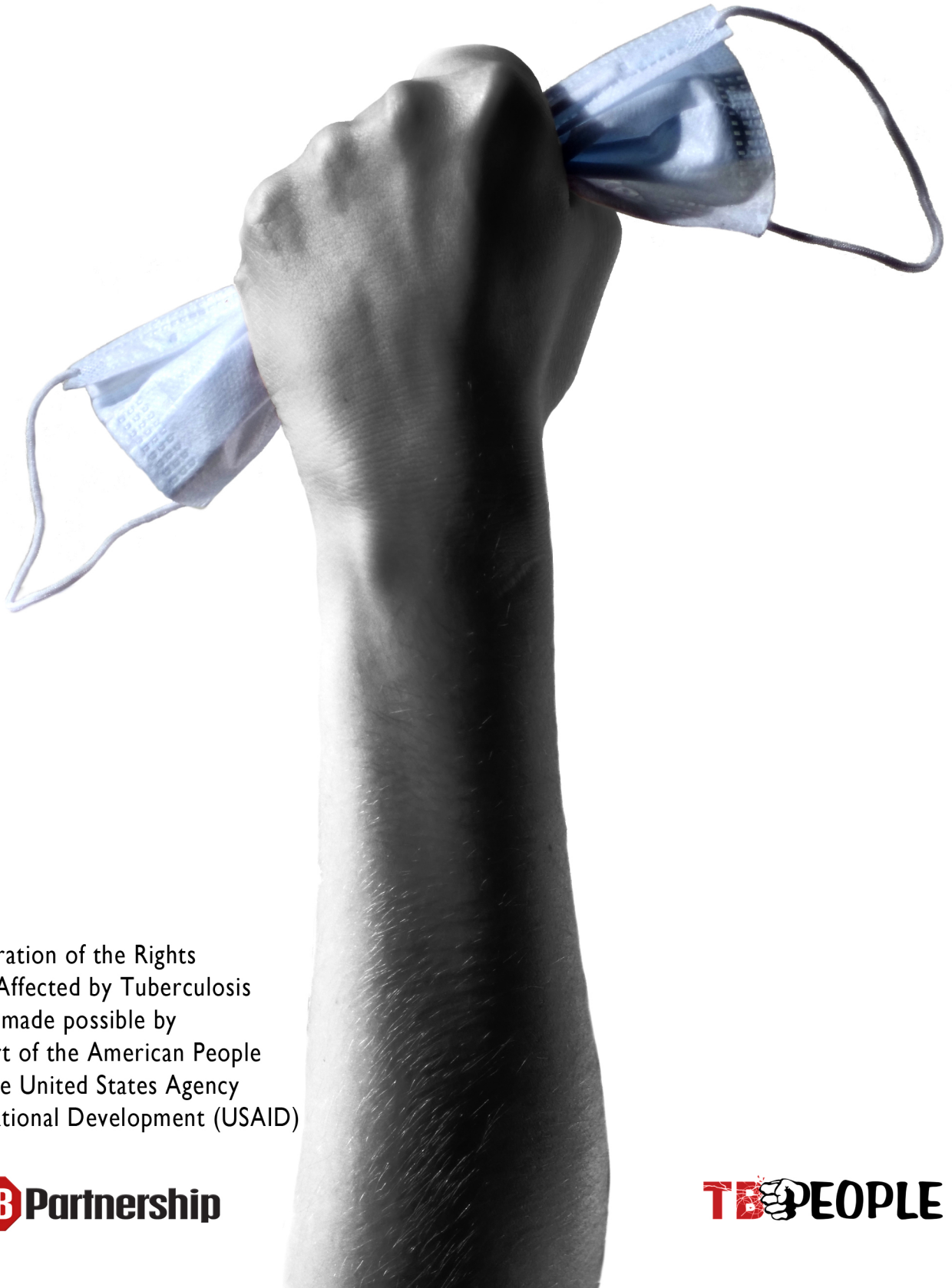
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info@tbpeople.org.uk

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instagram.com/stoptb, twitter @StopTB,  
www.stoptb.org, communications@stoptb.org

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