

# Together we can end TB!



**Strategy for LHL International 2019-2025**

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## Introduction

Tuberculosis (TB) is the world's deadliest infectious disease and among the top 10 of all death causes worldwide. Every year about 1, 5 million people die from TB.

TB is a socially determined disease, both rooted in and exacerbating poverty. It is estimated that about 3 million people of the approximated 10 million people who fall ill with TB every year are not found, not tested and not provided treatment.

Considering that TB is a preventable and curable disease, this is a violation of human rights and it is a public health catastrophe.

## The fight against TB is a fight for basic human rights

The right to life and health is a central human right, and LHL International therefore consider the fight against TB as a fight for basic human rights. As the disease is entrenched in unequal access to resources and health services, and is aggravated by social exclusion of people affected by TB, medical treatment alone will not ensure the right to health for people with TB. Ending TB requires a rights-based response that includes reducing the psycho-social and economic burdens that TB exerts upon the individual and the society. From our own history and experience we know that involvement of people affected by TB is absolutely crucial if we are to end this epidemic.

The spread of TB must be stopped. With joint efforts by affected people and organisations representing them, and with political will, it is possible: Together we can end TB.

## LHL International - who are we?

LHL International is the most important civil society player in Norway working to fight tuberculosis (TB). The foundation originates from the TB Relief Society (THO), who worked for patients rights and fought and won the fight against TB in the Norwegian society in the 1940s and 1950s. This heritage, and our experience from the international expansion in the 1980s, give us a unique competence on fighting tuberculosis.



### History

Our predecessor; the Norwegian TB patients Relief Society was founded in 1943. The organisation later transformed into the National Association for Heart and Lung Disease (LHL), as TB became less of a problem in Norway, and many former TB patients developed heart diseases due to the TB treatment and/or complications. Today LHL is focusing on heart and lung diseases in Norway, while the purpose of LHL International is to strengthen and develop the dedicated focus on eradicating TB, nationally and internationally.

LHL International's vision is *A world free of tuberculosis!*

Our main goal is to *Reduce the burden of tuberculosis*. We work according to a people centred and holistic approach, including everyone affected by TB, particularly focusing on vulnerable groups. We leave no one behind.

Our vision and approach is in line with the leading global initiatives, most importantly the WHO's End TB strategy<sup>1</sup>, the sustainable development goal 3 (SDG) about health and well being<sup>2</sup>, the declaration from the United Nation high level meeting on TB in 2018, and UN Conventions on Human Rights. All these initiatives recognise that upholding rights for all – leaving no one behind – and addressing poverty as a determinant of health are vital to end the TB epidemic.

### About LHL International Tuberculosis Foundation

LHL International is an independent foundation founded in 2013, based in Oslo, Norway. The overall governing body of the foundation is the board. For an updated list of board members and staff, please visit our website [www.lhl-international.org](http://www.lhl-international.org).

Our interventions and projects are supported by partners and donors like the Norwegian Agency for Development Cooperation (Norad), the Norwegian Ministry of Health and Care Services, the EEA Grants, Oslo municipality and various public and non-governmental foundations. We also have important support through the local branches of LHL and private donors.

### Where and with whom do we work

We work with groups vulnerable to TB in Norway and in countries where the burden of TB is high. In Norway today, there are few TB patients, and most of those falling ill with TB are immigrants from countries where TB is still prevalent. The approaches of our predecessor with peer support, information, anti stigma work and advocating for patients' rights are even more important today when TB hits people who already are in a vulnerable situation. The strength of engagement of affected people is our added value.

LHL International develops, mainly long-term, partnerships with patients' organisation, and/or other relevant civil society actors, research institutions, often in combination with health authorities or other governmental actors at regional and district level. We network with national and international stakeholders and keep up to date on the latest research and work within the field of TB.

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<sup>1</sup> <https://who.int/tb/strategy/end-tb/en/>

<sup>2</sup> <https://sustainable.development.un.org/sdg3>

### **LHL International is a learning organization**

This means that we continuously strive to enhance our capabilities, and we support and make use of both experience based and evidence based methods. By modelling new approaches, we collect data and information, gaining new knowledge that provides recommendations to local and national health authorities and other stakeholders.

Knowledge management is a priority, and we share program related methods and results between all partner organizations, partner countries and in scientific journals and conferences.

## **What do we do?**

In simple words; we find, treat and cure. Together with our local partners we find the people who are sick with TB and get them diagnosed as early as possible. We ensure that those diagnosed are put on the correct treatment and prevent drop-out and lost to follow up. We support and care for patients both during and after treatment to ensure cure and to reduce health complications.

And we find, treat and cure through our four main approaches:

- Provide people-centred TB prevention and care
- Combat stigma and discrimination of people affected by TB
- Support community engagement and organisation(s) of TB patients
- Advocate for political commitment and funding of TB initiatives and TB research

### **By the end of 2025, LHL International will**

- Reach 500 000 people from vulnerable groups with TB information, prevention or care
- Screen 250 000 persons for TB
- Ensure that 60 000 people with TB will be followed up by a treatment supporter
- Collaborate with 30 000 volunteers providing community care
- Include post-TB disabilities in all our programming
- Increase the project portfolio in NOK by 15% (baseline 2018).
- Expand programming to at least one new country with high burden of TB

## **Provide people-centred TB prevention and care**

Provision of people-centred TB services is a comprehensive concept that, on the one hand, entails the governments' duty to provide quality assured diagnosis and uninterrupted treatment through qualified health care workers, while on the other hand also secures a friendly and supportive environment. Patient participation and



cooperation between civil society and the public health service is important to ensure provision and access to people-centred TB care.

LHL International focuses on patient rights and access to treatment, especially for vulnerable groups. Health communication, community sensitization, and peer support are key methods. By addressing each patient's medical as well as social rights and needs before, during and after treatment, the health staff's competence, and the community's ways of dealing with TB, LHL International contributes to successful treatment of TB patients and thereby reducing the burden of the epidemic.

### Health communication

Health communication is one of LHL International main methods to ensure accessible patient friendly quality services. We organize training in health communication for peers and health personnel who work with tuberculosis. Important elements of the training include motivating patients to complete the treatment and handling feelings such as fear, stress and anger.



**We have no difficult patients anymore!**

Members of Mukikute patient organisations are trained as trainers in health communication.

LHL International have also developed patient friendly booklets that are based on patients' need for information about TB. They are an important part of the support towards successful treatment.



A peer and member of Mukikute TB patient's organisation in Tanzania sharing the TB patient friendly booklet to an older woman on treatment for TB.

The booklet contains facts about the disease, the treatment and diagnosis, but also about family life, sexuality, food and work.

## Peer support

Social and psychological support is vital in enabling patients to complete the

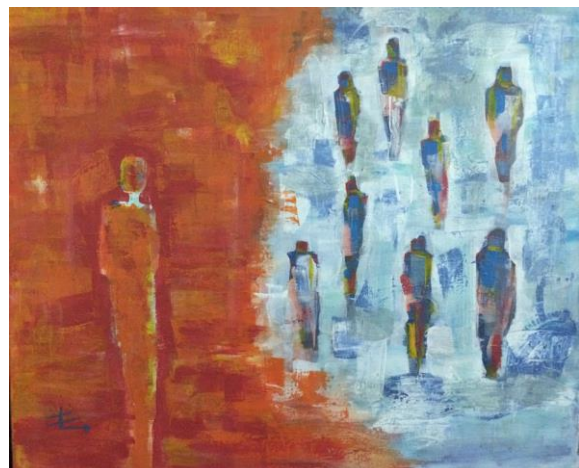
treatment period. Former TB patients play a vital role in supporting patients to adhere to the treatment. LHL International together with local partners organize peer services and train former TB patients as peers. The peers give psychosocial support and can also help supervise the daily intake of medicines. Peers work prevents self-stigma, isolation and creates a sense of belonging.

### LHL International will

- Have a strong focus on finding the missing cases/ active case finding
- Continue to empower local communities
- Advocate for health communication being part of the curricula for health workers in at least three countries
- Expand the number of qualified trainers in health communication
- Advocate for patient friendly booklets being provided for free for all patients
- Recruit and train more former TB patients as peers for patients
- Build competence in TB, HIV and Post-TB disability among health professionals and volunteers
- Document after-effects of TB on people's lives and health and develop interventions to meet the needs of this group.

## Combating stigma and discrimination of people affected by TB

LHL International place a great emphasis on combating stigma and discrimination of TB patients, as it causes suffering and impede the fighting of the TB epidemic. Stigma and discrimination are usually related to fear of TB transmission, and often based on misconceptions about transmission ways and lack of knowledge that TB is curable. Many people with TB are isolated in their communities or dismissed from their work. The fear of being stigmatised and discriminated against make sick people delay care seeking, something which aggravates the disease and creates risk of further infection. Moreover, social isolation and loss of work exacerbates poverty.



To counteract stigma people need correct information about how TB is transmitted and cured. Thus, information campaigns and community sensitization, as described below, are anti-stigma measures. But in addition, we must address the fear and mechanisms behind stigma specifically, something which cannot be done with rational information alone. We therefore make use of methods from health communication with interactive learning and reflection tasks, and use dramas to convey messages and change attitudes. In all these activities former patients, who are role models and proofs that TB is curable, take part.

### **Awareness raising**

It is important to empower people with knowledge about TB, so that they seek the right care when having symptoms. LHL International and partners develop and distribute information materials about TB and TB services to people in local communities, we organize public information sessions including drama and role plays and we do "door to door" campaigns screening people with symptoms.

#### **LHL International will**

- Fight misconceptions about TB
- Inform local communities about TB prevention, treatment and life after TB
- Sensitize local leaders, such as village heads, religious leaders and traditional healers about TB.
- Work to prevent stigma and discrimination in the work place
- Commemorate the World TB Day
- Promote and support former patients as role models

### **Supporting community engagement and organisation of TB patients**

LHL International believe that involvement of affected communities is key in the fight against TB. Our own history exemplifies that personal experience is the best basis for fighting TB and promoting the interests of people affected by TB disease. In our work we therefore support affected people and communities to organise themselves and engage in activities to fight TB and improve their own conditions. Most of our partners are patient organisations or other civil society organisations (CSOs). Involvement of civil society actors is especially important in countries where the health care system is not sufficiently developed to diagnose and treat all TB persons with TB. CSO's are well placed to provide support to patients in their communities, and their capacity to operate in hard-to-reach areas and with vulnerable and marginalized groups offers a unique opportunity for TB control. LHL International therefore facilitate collaboration between the health service system and the CSOs by involving volunteers and peers in the follow-up of patients.



### Income generating activities

People falling ill with TB are often amongst the poorest of the poor, and many face very high direct and indirect costs due to TB illness and care-seeking, putting them at risk of financial ruin or further impoverishment. While TB services may be free, the transportation to services and attaining good nutritional supports are not free. Many patients do not have work or have to quit their work because of the sickness, and are not part of any social security system.



Through our CSOs we provide various skills training or income generating activities to patients to help improve their chances of accessing health services, adhering to treatment and returning to their normal life upon completion of their treatment. Former TB patients, peers and/or the local TB clubs might also benefit from such support.

### LHL International will

- Provide a platform for former TB patients at national and international conferences, including submission of at least 3 abstracts to the union conference every other year, together with the partner organisations
- Continue to support partners in organizational development
- Continue strengthening partner's capacity in advocacy and resource mobilization
- Continue providing various skills training for patients and former patients who lack income
- Map current income generating activities to create a portfolio of ideas that can be shared between partners
- Evaluate the current skills trainings and income generating activities
- Develop holistic programs for care and support for people with activity limitations due to TB

### Advocating for political commitment and TB research

The slow progress in the global fight against TB shows that there is an urgent need to increase efforts to fight the epidemic. TB work is heavily underfinanced, and political commitment is required to alter this situation. Strengthening of health systems to find more people with TB and follow them satisfactorily up until cure is needed. Also, new diagnostic methods and medicines that can shorten the treatment period, and a new TB vaccine which is more effective than the BCG, must be developed.

LHL International advocate this urgency towards decision makers in Norway and partner countries to increase funding for TB work and research. We also dialogue

with relevant international bodies and lobby for inclusion of the patient perspective in TB strategies and plans at different levels. Furthermore, we support operational research aimed at strengthening patient rights and removing discriminatory barriers to health care for people with TB and persons suffering from post-TB complications.

### **LHL International will**

- Call on more Norwegian politicians to be member of the Global TB Caucus and contribute to the establishment of a Norwegian and/or Scandinavian TB Caucus
- Advocate that Norway increase funding to Global Fund in 2023
- Demand increased earmarked funding to development of new vaccine
- Continue close dialogue with LHL local branches
- Work purposefully to increase revenues and strengthen the foundation's work against TB
- Promote the SDG agenda in Norway and partner countries
- Hold policy makers accountable to the commitments made in the UN high level meeting on TB
- Advocate for more TB funding from the Norwegian Government
- Increase knowledge and creating more awareness about TB through campaigns, social media and other networks
- Work systematically to increase knowledge about life after TB, that is complications and implications TB has on people's lives, and to advocate for Post-TB issues to be included in TB control programs, plans and strategies
- Strengthen the relationship with relevant actors, both national and international
- Advocate progress towards universal health coverage to ensure “universal access to needed health services without financial hardship
- Advocate for social protection mechanisms for patients with TB
- Advocate that “no TB-affected family should face catastrophic costs due to TB”



LHL International contributes to a tuberculosis-free world for future generation

## Crosscutting issues

In addition to our four approaches there are some crosscutting issues that are essential in our work. These are:

- Vulnerable groups
- Gender
- Anti Corruption
- Digitalisation
- Climate and environment

### Vulnerable groups

To reach those with the greatest needs, and to make an impact on the TB epidemic, one must target vulnerable groups which are disproportionately affected by the disease. Groups such as migrants, slum dwellers, drug users, sex workers, prison inmates and others who live in poor and overcrowded conditions have increased risk of TB and often limited access to health services. Also children, people with multi-drug resistant TB (MDR-TB), people with disability, and people living with HIV are particularly vulnerable.



George works as a miner in Tanzania. He has 14 times higher risk of getting TB compared with the general population.

Down in the mines, it is cramped and many people share the limited air. In addition, large amounts of dust are breathed in, and many develop the lung disease silicosis, which significantly increases the risk of developing tuberculosis.

We assess the health needs of the various vulnerable groups and identify concrete measures which will give them access to quality health services. Examples are outreach information work, screening of certain groups, training health workers to ensure quality treatment, nutritional support, and opportunities for income generating activities.

### **LHL International will**

- Explore funding opportunities to reach more migrants
- Expand our work within mines and prisons
- Prioritize identifying peers and resource persons among the groups
- Do more outreach work
- Advocate for better diagnostics and treatment for MDR-TB, people living with HIV and children
- Liaise with and support stakeholders that work with harm reduction programs for drug users and sex workers
- Document the after effects of TB on people's health and its consequences and expand our work to support them

## **Gender**

Gender related barriers to TB services may take many forms, affecting both men and women. Overall, men face higher risk of developing TB than women and there are more TB deaths among men. Men are more likely to have a late diagnosis or not having their TB detected. Men are also more vulnerable to TB due to gender-specific occupations. Men are more likely to have jobs such as mining or blasting and may be more likely to migrate for work. Men may also be more likely to smoke or use drugs, both independent risk factors for TB.

On the other hand, women may have less access to TB treatment and prevention services than men. Women may have less financial and decision making power making it difficult to gain access to TB services. Women generally wait longer than men for diagnosis and treatment, maybe due to TB in women being more stigmatized than in men, they may be discouraged from seeking care by a lack of privacy or childcare facilities in health care settings.

LHL International work to promote gender equality in TB care and to adapt interventions and measures to reach both women and men.

### **LHL International will**

- Develop the capacity of the partner organisations to identify and mitigate gender related barriers to prevention and care
- Ensure that all programs are grounded in a gender analysis, and address the plight of TB for both men and women
- Develop a generic TB and gender training package that can be used by all partners

## **Anti-corruption**

LHL International have no tolerance for corruption, and work with partner organisations where transparency and honesty are core values. LHL International is committed and legally bound to set up contracts that enable us to follow up on book-

keeping in our partner organisations. Thus we can monitor that the funds are used as intended and uncover any non-conformance with agreed guidelines. LHL International work continuously to build competence on anti-corruption in our partner organisations.

**LHL International will:**

- Ensure that we and our partner organisations have sound financial management, good internal control systems and complies with the requirement of donors
- Prioritize capacity building of partners and other stakeholders about anti-corruption
- Participate in national anti- corruption networks in Norway

## **Digitalisation**

Digitalisation and new technological innovations can make it easier to reach the sustainable development goals, and increase health and development in a country. To combat the TB epidemic we also need innovative approaches, and opportunities created by new technologies are huge. Digital tools are increasingly being used in health interventions to facilitate prevention and care. As more and more people have access to Internet and smartphones, digital tools can play an especially important role in health interventions in low income countries. In addition, they make communication and workflow more efficient. On the other hand, there are certain risks and pitfalls that always have to be considered. Privacy rights and increased surveillance and control of the users are examples of such. There may also be a risk that the development of digitalisation will increase the divide between disadvantaged groups, with poor access to digital tools, and resourceful groups with full access. As in other areas of our work, LHL International will give priority to disadvantaged groups.

LHL International endeavours to keep up to date on the development of digital solutions and opportunities and to make active use of new tools in our work. One of the areas in which we use and benefit from digitalisation is our awareness raising work. We have developed online educational films that are easily accessible for people in target groups. We also assess and support implementation of video observed treatment (VOT) in different settings. In the coming period, digital methods to follow up and support patients will be considered.

**LHL International will**

- Develop, implement and assess digital tools and/or methods to follow-up and support TB patients and persons with post-TB disabilities
- Develop and adapt online training courses to new settings and target groups
- Technological solutions and innovations, such as digital training platforms and app development, are applied in the projects



## Climate and environment

Looking at TB and climate change on a macro level, it is likely that the TB epidemic will be affected negatively unless addressed properly. Rising temperatures and sea levels, drought, floods, and natural disasters, are all likely to cause famine and migrations, and conflicts due to migrations. Experts suggest there may be up to one billion climate change refugees within a few decades. This has far-reaching implications for infectious diseases. Mass migration impede health- and vaccination services, and overcrowded housing and camp conditions increase the risk of spreading of TB infection. Additionally, exposure to air pollution appears to increase risk of TB infection and illness. The consequences of climate change must be addressed, and LHL International will advocate with local and national health authorities to secure TB and other essential health services for the potentially increasing numbers of internally displaced people and refugees, as well as ensuring that they develop emergency preparedness plans for health.

The dangers of antibiotic resistance are a serious challenge within the TB epidemic. Wrongful diagnosis and excessive use of antibiotics is a threat for the environment. Not only is it polluting the eco-system, but it is causing multi resistant and extensively resistant TB in the population, making the TB epidemic even more threatening.

LHL International deliberately work to keep our carbon footprint at a low level. We consciously run our activities in such a way that it does not pollute the environment beyond the level that is considered acceptable in our sector. Air travels are, whenever possible, limited, and projects are followed up by telephone, emails and WhatsApp/Skype.

### **LHL International will:**

- Address TB in refugee camps
- Raise awareness among health workers and TB treatment supporters about the dangers of antibiotics resistance, both for human and environment.
- Early identification and diagnosis is thus key in reducing the threat of antibiotics resistance, as well as adherence to treatment.
- Prioritise finding / tracing patients who have dropped out of treatment / missing cases
- Strive to keep our carbon footprint as low as possible