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Norwegian Association
of Heart and Lung Patients



PROGRAMME OF PRINCIPLES

Solidarity beyond frontiers

Global fight against tuberculosis
Aid and Cooperation



Norwegian Association
of Heart and Lung Patients

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Introduction



LHL' s Programme of Principles entitled «Solidarity beyond Frontiers» is the basis of LHL's fight against tuberculosis. LHL is involved in this area as an interest organisation for people contracting tuberculosis. To LHL the fight against tuberculosis is a global fight which includes work in Norway, in our immediate surroundings and in the poorest parts of the world.

LHL's Programme of Principles is derived from LHL's basic document on the fight against tuberculosis. This document provides professional and political guidelines for LHL's tuberculosis control. These guidelines are based on fact, knowledge, personal experience of the disease, different framework conditions for the activity and international experience of combatting tuberculosis. LHL's basic document was examined by LHL's association committee in March 2001, and the Programme of Principles was adopted by the association committee in May 2001. The framework agreement with the Directorate for Development Cooperation (NORAD), LHL's social policy programme in the national assembly periods and annual plans of action are also central steering documents for our aid work. In addition, policy documents of the registered charity Atlas Alliance, and practical involvement within this organisation, have provided new and clear guidelines for LHL's aid work. LHL's Programme of Principles has a time horizon of up to ten years. If important framework conditions were to be changed during this period, LHL may revise parts of its Programme of Principles.

1. LHL – an interest organisation of people with heart and lung disease

Norway's largest patient organisation

The Norwegian Association of Heart and Lung Patients (LHL) is an interest organisation for people suffering from heart and lung disease. LHL carries out active social policy efforts to take care of the rights of patients and handicapped people in the Norwegian society. In addition, LHL owns and runs hospitals and institutions aimed at covering the needs of patients and handicapped people in the areas of medical treatment, rehabilitation and vocational occupational rehabilitation. Furthermore, LHL has developed a number of measures and courses aimed at improving the quality of life of those suffering from heart and lung disease.

LHL was originally founded in 1943 as an interest organisation for people affected with tuberculosis, known as the Support Organisation for TB Patients (THO). The organisation led a fight against the fear of infection and prejudice and for the right to social security and jobs for people affected with tuberculosis. In 1961 the organisation changed its name to the Norwegian Association of Heart and Lung Patients. LHL today is the largest patient organisation in Norway and in 2001 has around 60 000 members organised in 301 local organisations and 19 county organisations.



2. LHL's global tuberculosis control activities



Basic view

Members of LHL who survived tuberculosis in Norway took the initiative in starting LHL's aid work at the beginning of the 1980s. This initiative was taken on the basis of a solidary way of thinking. LHL's contribution to the fight against tuberculosis in other countries constitutes a smaller part of LHL's total activity. The aid work passes on the historic tradition in LHL and keeps up the knowledge of tuberculosis. To the organisation the work has a symbolic value as the aid signals that LHL has a feeling of solidarity with patients and sick people beyond the Norwegian frontiers.

Vision – solidarity beyond frontiers

The vision of LHL's activity is a society for everybody, a united society which takes sufficient account of those affected with disease, by meeting basic human rights such as the right to treatment, rehabilitation and other measures capable of improving the life of the sick and handicapped. LHL's vision of a united society does not stop at the Norwegian frontiers, we have a vision of a united world society. For that reason solidarity beyond frontiers is a supporting principle in LHL's tuberculosis control activities. LHL wishes to convey an outlook on values resulting in a practical attitude of solidarity towards those affected with tuberculosis in other countries.

Basis of values in aid policy

LHL considers the fight against tuberculosis as a fight for basic human rights. The right to health help is central in these efforts. Basic human rights are universal in LHL's aid work, as these are formulated in the World Declaration of Human Rights. In LHL's aid work the target group's social and political rights are mutually dependent on each other, and they amplify each other.

Measures beyond treatment facilities are necessary in order to secure equality in the community for those affected with tuberculosis. LHL believes that those who have personal experience of the disease, are those most suitable for furthering the interests of those affected with tuberculosis. For that reason political rights – such as the right to organise and joint influence in the society – are also central to LHL's aid work.

Defender of the poor

LHL looks upon tuberculosis as a political disease, in so far as it is a disease that springs from poverty and poor living conditions. From an aid policy point of view, therefore, the fight against tuberculosis is a central area of concentration to combat poverty in the world. The extent of the spread of tuberculosis is a sensitive indication of a population's living conditions, and of whether the community is changing for the better or worse.

Tuberculosis is also a political disease as the continuous spread of the disease is a sign of violation of basic social human rights. An effective strategy of prevention to eradicate tuberculosis is to combat poverty and improve human living conditions. This turns LHL into a

political organisation whose aim is to defend the rights of the poor. Seeking and disseminating knowledge of social distribution policy, structural conditions causing poverty and other political issues of value is an integrated part of LHL's aid policy.



As a patient organisation LHL has little direct influence on bringing about improvements in living conditions, as poverty is caused by various social conditions largely beyond LHL's control. By encouraging tuberculosis sufferers themselves to involve themselves in the fight to improve their social conditions, LHL may nonetheless play a part in influencing the living conditions of a socially vulnerable group.

Principal aims of LHL's aid work

LHL's primary aim is to take care of the interests of health and lung patients. A superior aim for LHL's activity is equality in the community for sick and handicapped persons. In the international aid work LHL's policy is governed by the same interest policy aims as the rest of the organisation's work.

The principal aims of LHL's aid work are:

- **To secure the right to life and health for those affected with tuberculosis.**
- **To secure for tuberculosis sufferers the right to participate in the community, and prevent them being discriminated against.**
- **To combat tuberculosis and reduce the spread of infection in the society.**

3. Tuberculosis – a global problem

The World Health Organisation in 1993 declared that the spread of tuberculosis was a global catastrophe. Tuberculosis is a big challenge to the world community, and the disease is on the increase as we have failed to put in sufficient counter-measures. At the same time treatment of those developing tuberculosis is the best measure to prevent the disease spreading. As a significant number of those contracting tuberculosis are not secured adequate treatment, a multiresistant form of tuberculosis occurs which may be incurable. A frightening feature of the global threat picture is the danger of this incurable form of tuberculosis spreading.

The HIV-AIDS epidemic is another global epidemic which to an increasing degree interacts with the tuberculosis epidemic, a situation which calls for a common strategy in the fight against HIV-AIDS and the fight against tuberculosis. The spread of tuberculosis has shown a significant increase due to the HIV epidemic. Tuberculosis is curable in most HIV-positive individuals. By securing their right to treatment the spread of infection may be prevented.

Facts and challenges

- **1,7billion of the world's population are infected with tuberculosis.** Africa and Asia are the continents hardest hit.
- **A person who is a carrier of tuberculosis infection may infect between 10 and 15 persons annually.** Tuberculosis spreads through droplet infection via the respiratory tracts on social contact.

- **Eight million people develop the disease every year.** On average five to ten per cent of those infected develop the disease during their lifetime. 95 per cent of those who develop tuberculosis live in the poor parts of the world.
- **Between 1.5 and 2 million people die of the disease every year.** 98 per cent of deaths from tuberculosis occur in the poor parts of the world.
- **Tuberculosis is the infectious disease responsible for the most deaths among the world's population over a period of five years.** Tuberculosis affects specially the age group of 15–54 years, i.e. the reproductive age.
- **Tuberculosis is the disease that kills the most women (over the age of 5 years) in the poor world.** The disease takes the life of more women than all maternal diseases combined.
- **Tuberculosis is the most frequent cause of death of HIV-positive individuals.** HIV-positive individuals are 30 times more likely to develop tuberculosis than those who are HIV negative.

4. How to combat tuberculosis?

The DOTS Strategy

The internationally recommended strategy for tuberculosis control has been given the name of DOTS (Directly Observed Treatment – Short Course). The strategy combines several organisational elements with medicinal principles for treatment. In order to succeed in a national effective tuberculosis control, the strategy must contain five elements, elements that are mutually dependent on each other:

- Political and economic will on the part of the country's authorities to combat tuberculosis.
- The establishment of a national laboratory network where diagnosing is based on direct microscopy.
- A standardised reporting and registration system for diagnosis, treatment and control.
- A stable, continual supply of all recommended tuberculosis medicaments.
- Standardised treatment programmes for different patient categories with directly observed medicine intake (DOT) for all patients receiving a treatment containing the medicament rifampicin.



Vaccination – BCG

BCG vaccination is a part of an extended vaccination programme for children. The BCG vaccine protects young children against serious forms of tuberculosis and it is therefore instrumental in reducing illness and death among young children. Young children are more vulnerable to primary tuberculosis as their immune system is incapable of combatting the primary infection in the way an adult's immune system can. The BCG vaccine protects against primary tuberculosis but it does not protect against reactivation, or against the infection causing illness later in life. Primary tuberculosis in children is infectious only exceptionally. For that reason BCG has no impact on the spread of infection in the community.



5. What does LHL want?



Secure the right to necessary health help and equality in the community

As long as basic social rights for people affected with tuberculosis are not secured, LHL's main efforts in international tuberculosis control will be aimed at securing those rights. To many who are affected with tuberculosis this is a question of life or death.

User participation

The right to life is superior but the life of people affected with tuberculosis will not be automatically improved through a guarantee of health help. Measures beyond treatment facilities are necessary to secure those affected with tuberculosis equality in the community. For that reason political rights – such as the right to organise and the right to joint influence in the community – are also central to LHL's aid work. In order to achieve such rights the obstacles that exist to participation and joint influence must be removed. Prejudice and misconceptions about tuberculosis are such obstacles. It is often associated with shame to have tuberculosis, and stigmatisation of those affected with the disease prevents many from seeking treatment in time.

Strengthen the public health service – develop the primary health service

LHL considers tuberculosis control as a public responsibility. LHL therefore enters into contracts with governments to ensure that they commit themselves to the task. Primarily the building of institutions in the public sector is a state-to-state task in the aid work. LHL,

however, has long experience when it comes to developing public health services through a cooperation with public health authorities in Norway. In the Nordic model for a welfare society it has been a long tradition for voluntary organisations to be the legitimate cooperation partners of the state when it comes to developing the public sector. At the same time it is a tradition for voluntary organisations to be a critical corrective to the same authorities.

LHL builds on this tradition in its cooperation with governmental authorities in its cooperation countries. We maintain that LHL, from both knowledge and organisational perspectives, has a considerable advantage over governmental aid channels.

Tuberculosis programmes have functioned as a motor for the development of the primary health service, since it is the organisational elements which are those most important to an effective tuberculosis control. These elements are not specific to any one disease and they are necessary in all regional health services regardless of what kind of disease the patient is being treated for. In low-income countries LHL supports only tuberculosis programmes which are integrated into the primary health service. To integrate tuberculosis treatment into the primary health service is important in order to demystify the disease, by giving the patients access to general health services on a par with other sick people.

6. On what principles is the activity based?

Long-term commitment

Support for national TB programmes is conditional upon a stable and increasing investment in resources over time. In order to ensure that the conditions and objective of the partner cooperation are satisfied, the support of national TB programmes must be long term. The time perspective must be a minimum of ten to fifteen years. LHL's support must be adapted to the long-term plans for the health sector generally and to tuberculosis control specially. A clear objective in any contract period is to give the authorities more responsibility regarding the financing of medicines and other areas of concentration.

Aid policy principles: Recipient responsibility – sustainability

LHL's aid activity is based on its co-operation partner being responsible for planning, setting in motion and following up the activity. LHL on the whole supports a public health service and the cooperation therefore is based on a real recipient responsibility. LHL's principal task is to provide professional advice and supply concentration goods (mainly medicines and laboratory equipment), which makes it possible for the country's authorities to reach their health policy goals.

International solidarity

In all LHL's cooperation countries the authorities themselves carry the largest financial burden of these programmes. Most low-income countries are dependent on some external support for the most expensive medicaments in the DOTS Strategy, and this is also the conclusion of the World Health

Organisation. Hopefully, in the long term the international community will ensure that all countries have access to tuberculosis medicaments. According to LHL's view on values concerning a solidary world community a sustainable development does not mean that the poorest countries themselves must bear all costs relating to the large health policy challenges. This is a responsibility that the international community must share with those countries that carry the largest tuberculosis burden.

Partnership criteria

All LHL's aid projects are based on contract cooperation, whereby the roles, responsibility and tasks of the parties concerned are clearly defined.

National tuberculosis programmes

- The programme must follow the DOTS Strategy.
- The programme must be integrated into the primary health service.
- The programme must be developed into a nationwide and permanent programme.
- The programme must not be discriminating, i.e., it must include the entire population regardless of gender, socio-economic status, religion and ethnic attachment.
- Tuberculosis treatment must be free of charge to all patients.
- The cooperation partner must satisfy the administrative requirements contained in the contract between the parties.

User participation and joint influence
A decisive factor for LHL's support to organisations are the possibilities they

LHL cooperates with:

The Atlas Alliance, International Union Against Tuberculosis and Lung Disease (IUATLD), World Health Organisation (WHO) and The global partnership «Stop TB Initiative»



have for furthering the interests of people affected with tuberculosis. LHL in cooperation with the health service and the local community will stimulate to user influence and peer work for people affected with tuberculosis.

The building of alliances and cooperation – nationally and internationally

National professional network

LHL has developed a professional network in Norway by involving persons from different institutions as advisors in its aid work. In this way LHL wishes to provide the Norwegian professional community with knowledge and experience of tuberculosis control.

The Atlas Alliance

The Atlas Alliance is the most important cooperation body in LHL's aid work, as the Alliance is incorporated into the framework agreement with the Directorate for Development Cooperation. The Alliance unites most of the organisations of handicapped people that carry out aid work. Through its cooperation with the Atlas Alliance LHL wishes to show its solidarity with handicapped people internationally. In addition, LHL wishes to use the Alliance to further develop its aid competence and intensify its efforts in the fight against tuberculosis.

International Union Against Tuberculosis and Lung Disease (IUATLD)

LHL is a member of IUATLD. Through active participation in IUATLD's aid programme LHL was a party to trying out what the World Health

Organisation later called the DOTS Strategy. The cooperation with IUATLD has been and is vital in making LHL undertake to support the public health sector in low-income countries professionally and financially. As a patient organisation LHL is dependent on using professional medical expertise in tuberculosis control. Professional counselling is a significant part of the aid.

World Health Organisation (WHO)

LHL has a close cooperation with the World Health Organisation. This cooperation covers both the formulation of policy and a practical cooperation in relation to individual countries. External evaluations of LHL's tuberculosis programme are carried out in cooperation with WHO. LHL's cooperation with WHO is maintained through the global partnership of «STOP TB», where both WHO and IUATLD play an active role.

The «Stop TB Initiative»

– a global partnership

Through the global tuberculosis programme in WHO a partnership had already been formed between the most important participants in international tuberculosis control. This partnership was carried further and strengthened through the STOP TB Initiative, which was given a separate secretariat in WHO. The Initiative concentrates its work on four main areas:

- The implementation of a global plan of action.
- The development of a global mechanism to ensure universal access to tuberculosis medicaments.

- A global research agenda for tuberculosis.
- The preparation and political support of a global charter for the fight against tuberculosis.

Information and influence

LHL makes use of different channels to inform its own members and the Norwegian general public of the importance of the fight against tuberculosis. The media are the most important channels for reaching out beyond our own members and for creating an understanding of the fight against tuberculosis. LHL will influence the different media in putting tuberculosis on the agenda, and the organisation must also build up a constant preparedness so as to make it react to news in the media which is relevant to LHL's tuberculosis control activity.

Through its direct involvement in several countries LHL makes a specific contribution to the international fight against tuberculosis. LHL takes the view that since the tuberculosis problem is so large and widespread, the Norwegian state should commit itself to a stable, long-term and far stronger effort in the fight against the disease. LHL has an important task in continuously informing and influencing our politicians. People affected with tuberculosis have few spokesmen in Norway and internationally. Political work of influence, therefore, is an important part of LHL's aid policy.

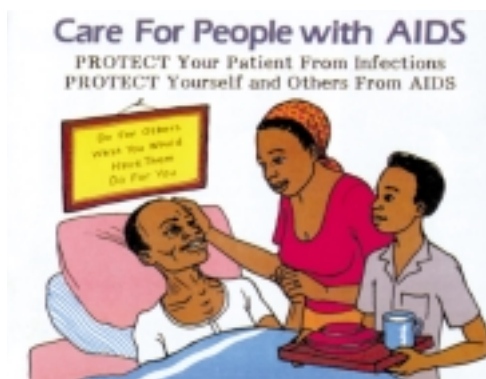


7. Future perspectives in LHL's tuberculosis control activities

Quality assurance – consolidation

LHL has extended its aid to several new countries and has sufficient human resources to follow up the commitments that follow from its aid work. LHL, however, is under constant pressure to assist new countries through direct approaches from the countries themselves or through WHO and other international organisations.

LHL is in a consolidation phase in relation to the commitments and plans made for this present national congress period, and in relation to the aim of its various aid projects. Several of the national tuberculosis programmes are not as yet nationwide and many different challenges and problems remain to be solved in each individual country. In the longer term we are considering a possible cooperation regarding the development of national tuberculosis programmes in new countries in relation to the discontinuation of cooperation in present cooperation countries. Instead of being operational ourselves, it is an important task for LHL to stimulate other organisations to involve themselves in the fight against tuberculosis, and to undertake to be advisors to these.



Fresh approaches

With our present capacity and resources LHL is involved in fresh approaches to aid work which we believe will strengthen LHL's total tuberculosis control. Through ongoing preprojects, pilot projects and research projects in several countries in southern Africa, LHL now has the opportunity to achieve a valuable professional development. These projects are specially important when it comes to adopting alternative ways of strengthening user influence and the general living conditions of TB patients. We also have the opportunity to try out models from LHL's activity in Norway in our involvement in Arkhangelsk and when we develop a future cooperation in Lithuania.

Intensification of the fight against HIV-AIDS

In LHL's tuberculosis control activity the HIV-AIDS epidemic will constitute an increasing challenge in the years ahead, and it will be necessary to bring about a constructive cooperation between the diverse groups involved in the fight against tuberculosis and HIV-AIDS. Persons who contract both these diseases have special needs in relation to the health service, and they are a vulnerable group as regards prejudice and discrimination. In all the countries where the organisation is involved, LHL must be a driving force in order to coordinate measures against TB and HIV-AIDS. In addition, LHL must make an active effort to gain more experience in this area by following up the preproject in southern Africa.

Geographical concentration – giving priority to Africa

The main emphasis of LHL's aid work is directed at the fight against tuberculosis in Africa, the continent hardest hit both by tuberculosis and HIV-AIDS. Today there is a good balance between LHL's aid to countries with the highest burden of tuberculosis and with the strongest need for financial aid, countries in our immediate surroundings and our work in Norway. This balance is maintained by LHL. Our activity in Norway is strengthened through the increased resources allocated to this area. It will be impossible to eradicate tuberculosis in Norway in the future unless we are willing to provide aid to the countries hardest hit by tuberculosis today. In addition to LHL's specialist skills as regards the treatment of tuberculosis, experiences from other cultures and countries make a valuable ballast in our efforts at home. Many of those who are in the increasing high-risk group for tuberculosis in Norway have a background from poor countries.

The fight against tuberculosis – an aid area of continued high priority

For historic and aid policy reasons LHL has concentrated its aid work on the fight against tuberculosis. To all poor countries the fight against tuberculosis specially and infectious diseases generally is of vital importance to improving public health. The fight against tuberculosis also has a clear poverty profile. With its aid to combat tuberculosis LHL reaches out to the very poorest in a population and enables them to receive health help. If integrated lung health programmes become a reality in

some of LHL's cooperation countries, this may become a future area of concentration for LHL. The fight against tuberculosis will then become a significant part of such a programme.

Dissemination of information and commitment

LHL's aid work is the carrier of the organisation's historic role as an interest organisation of and for people affected with tuberculosis. LHL, therefore, has a moral responsibility to pass on the history and to disseminate knowledge to new members in order to place the fight against tuberculosis in its right context; as an historic inheritance, and as one of the biggest health challenges of our time.

In the years ahead we will concentrate in a more determined way on dissemination of information to LHL members. The legitimacy and support of the aid work within the organisation are dependent on information reaching out to our representatives and members. Different methods will be used in order to stimulate and maintain a grass-root commitment to our aid work. We will try out different forms of direct member commitment, such as sponsorship schemes, cooperation with villages and separate health institutions, support for special measures for people affected with tuberculosis (peer work etc).



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