

**HANDICAP
INTERNATIONAL**



Lymphatic Filariasis Disability Prevention for Field Managers

Noguchi Institute, Ghana. July 2007

Workshop proceedings



**Prevention of disability due to chronic illness
in resource limited settings**

Prepared by: Dr. Susan Girois,
Dr. Pierre Brantus
Dr. Charles Mackenzie
and all Workshop Participants

Table of Contents

Introduction	page 3
Workshop Proceedings.....	page 4
Day 1: Basic Science and Pathogenesis of disease.....	page 4
Day 2: Non-surgical treatment and care of symptomatic LF.....	page 6
Day 3: Public Health and Community approaches to disability prevention	page 7
Conclusions and Recommendations	page 9
ANNEX: Workshop Agenda	page 11

Introduction

Background of the Global Alliance

More than 1 billion people in approximately 80 countries live at risk of contracting lymphatic filariasis (LF). More commonly known as elephantiasis, LF is a devastating parasitic infection spread by mosquitoes. Currently over 120 million people are already infected, with more than 40 million incapacitated or disfigured by the disease.

In response to this monumental challenge, the Global Alliance to Eliminate Lymphatic Filariasis (the Global Alliance) was formed in 2000 with the sole purpose of supporting the Global Programme to Eliminate Lymphatic Filariasis (the Global Programme), which was at the time based in the Filariasis Unit of the World Health Organization (WHO). The Global Alliance provides fundraising, advocacy, communications and technical assistance in support of the Global Programme's two goals:

- The elimination of LF as a public health problem by 2020
- The alleviation of physical, social and economic hardship in individuals who have LF-induced disability

NGDO contributions

Non-governmental development organisations (NGDOs) have been a part of the Global Alliance since its beginnings. Present in a number of endemic countries, these organisations are committed to the goals and objectives of the Global Programme, using their respective strengths and networks to achieve effective mass drug administration, to implement best practices for morbidity management, to undertake much needed operational research and evaluation, and to advocate for mobilization of resources and funding. In 2003 at the third meeting of the Global Alliance (GAELF III) in Cairo, a nucleus of NGDOs committed to LF elimination and control joined to form an informal NGDO LF Network (the Network). The purpose of the Network to more effectively encourage NGDO participation in the policy and programming at all levels. The Network also aims to enhance communication and collaboration among NGDOs who may be funding, facilitating or implementing projects directly.

Today, NGDOs are among the few actors directly addressing morbidity management at the community level. Often in collaboration with district-level health staff, NGDOs have developed a number of approaches to enhance the quality of care for LF patients. Such approaches include training of peripheral health facility staff, involvement of community agents and education of LF patients themselves to engage in day-to-day practices.

NGDO LF project managers who spearhead community approaches are commonly from a variety of backgrounds, including public health, medical, or general management. A bulk of their time is spent facilitating coordination meetings, planning com-

munication strategies about MDA and morbidity management, facilitating training workshops for health personnel, monitoring activities, data collection, reporting and following budgets. Few have been given the opportunity to explore the reasoning behind the messages they communicate. Fewer still have ever seen a microfilaria worm under the microscope. Similarly, counterpart local health managers rarely have the opportunity to re-learn and understand the scientific basis or latest developments for symptom management of LF.

A unique opportunity

The LF Disability Prevention Workshop for Field Managers was a unique opportunity on a number of counts:

- It was the first of its kind in LF to provide an opportunity for learning and exchange among front-line management staff.
- It offered a rare opportunity for knowledge exchange among disability prevention workers in lymphoedema management from Africa, Asia and the United States.
- It provided opportunity for exploring a more integrated public health approach to prevention of disability due to LF and other chronic diseases affecting the lower limbs (i.e. diabetes, leprosy, Buruli ulcer).

Objectives of the workshop

The objectives of the workshop were

- to provide participants with knowledge about LF that can be used to improve local patient management practices
- to provide a forum for exchange among active (and potentially active) field projects

Ultimately, through this and future gatherings, there should emerge a network of resource persons who can be called upon to lend technical support to existing or future field project for LF disability prevention.

The workshop was organized by Handicap International in collaboration with the Noguchi Institute/LF Support Centre for Africa. The event was supported financially by GSK and by MDP.

The meeting agenda can be found in Appendix I. All PowerPoint presentations can be found on the CDrom accompanying this report or upon request to sgirois@handicap-international.org or CKanko@noguchi.mimcom.net.

Participants

Participants were identified and invited by members of the NGDO LF Network, including the Carter Center, Handicap International, Light for the World, Reggio Terzo Mondo, and Sight Savers International.

Field-level managers from 7 LF endemic countries participated (Bangladesh, Burkina Faso, Ethiopia, Ghana, India, Madagascar, Nigeria) (see Appendix II). Due to administrative problems, participants from Mali and Sierra Leone were unable to attend.

Participants were from a broad range of management positions, including NGDO project management staff, National LF Program staff, Regional and district level health authorities, and leaders of partner organizations working at the community level.

Resource persons who attended the workshop included the WHO Afro Focal Point for LF, Dr. Likezo Mubila, Ms. Mary Jo Geyer, physiotherapist from Chatham University (USA), Dr. Charles Mackenzie, pathologist and researcher from Michigan State University (USA), Dr. Daniel Boakye and Dr. Michael Wilson from the Noguchi Institute. Dr. Yao Sodahlon also attended on behalf of MDP. Mr. Mark Bradley of GSK was unable to attend due to a last minute emergency.

The meeting was chaired by Dr. Susan Girois, Medical Coordinator at Handicap International-France and facilitated by Dr. Pierre Brantus, consultant.

Overview of this Report

This Workshop report is organized in chronological order by Days 1, 2 and 3 of the proceedings. The descriptions here include not only the main points of each of the formal presentations, but also attempt to highlight items of particular interest that participants pursued through discussion.

The Conclusions and Recommendations were compiled through a participatory method:

- Participants met in small groups as “country delegations” to identify the 5 main conclusions and 5 specific recommendations that they had gleaned from the 3 days.

- Participants who were alone from their country of origin met together as one small group to do the same exercise: identify 5 main conclusions and 5 specific recommendations

- These items were read to the group and then compiled into a final listing, which is provided in this Report.

The Conclusions and Recommendations are, therefore, not necessarily consensus items. Rather, they are a compilation of the main areas of interest or concern retained by the participant delegations.

Workshop Proceedings

Day 1: Basic Science and Pathogenesis of disease

Welcome and introductions

After an official welcome by the Director of the Noguchi Institute, Professor Alexander Nyarko, Dr. Susan Girois extended a warm welcome on behalf of Handicap International. Participants then introduced themselves and the Workshop agenda was presented and approved.

Overview of the Global Programme for the Elimination of LF

Dr. Likezo Mubila, WHO Afro Focal Point for LF gave *an overview of the Global Programme* for the Elimination of Lymphatic Filariasis. Dr. Mubila also presented the basic principles underlying mass drug administration, including a look at the medications used, on behalf of Mark Bradley, GSK. Key points:

- Estimated 1.3 billion people at risk (this number may change when mapping is completed)

- Data available from up to six rounds of MDA with co administered drugs indicated that between 2 and 6 rounds of MDA were able to achieve the goal of < 1% microfilaremia in most areas. However, a minimum of 5 MDA rounds still need to be conducted based on the reproductive life span of the adult worms. In some areas more than 6 rounds may be necessary, since the effectiveness of the annual rounds of treatment was found to depend on level of endemicity; the treatment coverage rate and the type of mosquito vector responsible for transmis-

sion in the area.

- Mosquito control in collaboration with vector control activities in malaria control is a supporting strategy to MDA where possible and feasible.

- Integration both in the health system and with other disease control programmes offers good opportunity for cost-effective implementation of the lymphatic filariasis programme which, particularly in the Africa Region, faces serious resource constraints.

Epidemiology and burden of disease

Dr. Brantus presented an overview of the *epidemiology and socio-economic burden of disease* based on WHO data. Key points:

- The disease starts in childhood; health education for children is important to prevent occurrences of first chronic manifestations

- Disease of the poor

- Major loss of productivity (direct and indirect costs)

- 15 million women and men are living with lymphoedema

- 25 million men with hydrocele

- Lack of data on morbidity: how to implement a program without data?

- Morbidity divided into acute and chronic causes
 - Concept of disability: not just a question of 'impairments', rather disability has to do with body function, activity and participation
 - Data shows a sex difference in response to disability prevention interventions; "Why this difference?" was not addressed in the study.
- The presentation peaked some interest in gender issues as related to LF (further discussion Day 3).

Filarial and vector biology

Professors Wilson and Boakye then explored with participants (some for the first time) *the filarial parasite and mosquito biology*. Key points:

- Filarial worms (parasites) are tissue- and species-specific
 - Life cycle includes both human and vector (mosquito) phases
 - Microfilarial periodicity has implications for transmission (mosquitoes bite at night) and for microscopic diagnosis (night draw)
- Participants recognized that there are still many questions unanswered about the parasite and how it affects the patient. Further discussion raised issues about the sensitivities of the available tests, links with clinical disease, seasonal variation and mosquito species.

Participants also appreciated the natural system of parasite-vector checks and balances which facilitate and/or control transmission.

Pathogenesis of morbidity associated with LF

Dr. Charles Mackenzie and Dr. Brantus shared the session on the *pathogenesis of lymphoedema and hydrocele*. Key points: -The majority of persons infected with the parasite do not develop symptomatic disease.

- Symptoms are generally caused either by live worms (parasites) or by degenerating (dying) worms.
- These symptoms include acute filarial attacks as well as more chronic manifestations such as lymphoedema and hydrocele.
- Aggravating factors for lymphoedema: secondary infection
- Aggravating factors for hydrocele: acute filarial lymphangitis (dying worms)
- Research findings:
 - Treatment of the epidermis is central to improving the skin manifestations
 - Static lymph fluid can aggravate disease
 - Possible role of the parasite in reducing the host's immune responses against secondary infections
 - The parasite is central in maintaining clinical disability
 - WHO classification
 - Usefulness primarily for the health worker doing direct patient care and not for the informal caregiver

Overall, participants appreciated exposure to the research aspects regarding the underlying causes of lymphoedema.

They look forward to emerging research that will help dictate management strategies.

Basic LF morbidity management

The *basics of lymphoedema management*, based on evidence and as recommended by WHO, were reviewed by Dr. Brantus.

Key points:

- The basics of LF management:
 - Washing by the patients themselves using basic rules of hygiene (treatment and prevention of skin lesions). Basic hygiene of the swollen scrotum also reduced the number of acute attacks among men in Madagascar.
 - Exercises are most important
 - Elevation and appropriate footwear are likewise important
- Where basic hygiene is not enough to reduce the incidence of acute attacks, prophylactic antibiotics may be used.
- Indicators
 - # attacks/person/year
 - # persons with occurrences of attacks

- WHODAS II is a questionnaire developed by WHO to explore impairment, activity and participation. (See CDrom). It was adapted to the local context and tested via LF projects in Madagascar, Sri Lanka and Zanzibar.

- Data on the effects of MDA on acute manifestations of LF from Sri Lanka, Zanzibar and Madagascar revealed the same results regardless of whether care was given through doctors or community health workers. This has implications for the public health approach to LF (See Day 3)

- Regarding acute attacks:
 - Two causes: bacterial infection and filarial worms.Management depends on the cause

Participants recognized that these basic techniques are practiced widely around the world. There was general appreciation of their effectiveness from field experience, although there is admittedly limited data from non-research settings. Participants also agreed to try and promote *photographs* of patients washing themselves (not having leg washed by health worker) in order to communicate the notion of self-care. Participants were also reminded that images (e.g. photographs) showing gloves being worn for washing may communicate the possibility of infection via direct contact, and this false impression may frighten patients.

Regarding "pain" as a symptom, participants agreed that pain is universally present among patients with acute attacks and that there may be some need to identify a 'pain scale' for individual patient evaluation. Regarding pain management, NSAIDS (including generic non-steroidal anti-inflammatory agents) are widely used and generally felt by participants to be effective. Further discussion touched upon "scratching"—how to avoid it; evidence supporting the use of exercises and elevation for lymphoedema management is needed; and the unreliability of information that is self-reported by patients underscored the problem of bias in survey methods.

Day 2: Non-surgical treatment and care of symptomatic LF

PRACTICUM

Day 2 began at the Noguchi Institute grounds where participants divided into small groups to meet and interview LF patients. Mr. John Umaru of Nigeria, Mary Jo Geyer and Pierre Brantus were facilitators. Discussions with the patients focused on history of the disease as well as social impact on their lives.

Participants spent significant time on physical examination, assessing clinical signs to determine the stage of the disease. In one group, 3 women presented with WHO stages 1 to 3. One woman was recovering from an acute attack. This woman had presented for medical evaluation of “fever”, was told she had malaria and prescribed antimalarials. Apparently the clinician had not measured her temperature and had not considered her red, hot and painful right calf as possible source of her “feeling feverish”.

Discussion following the practicum was lively. Overall, participants appreciated the exercise. Some debate ensued about how to counsel a person with an acute attack: Is an acute attack a cellulitis and medical emergency or is the standing WHO recommendation to refer after 24 hours more appropriate? Further discussion surrounded the frequent complaint of “fever”. Participants agreed that “feeling feverish” was not diagnosis of “fever”. While all agreed that thermometer and measuring body temperature should be systematic in the clinical assessment, some felt that in resource-poor settings, even a thermometer is difficult to come by. Standard approaches to clinical examination should be used wherever possible.

There was a general call for a clear clinical assessment and management protocol for lymphoedema and acute attacks.

Advanced management techniques

As follow up to the PRACTICUM, Mary Jo Geyer presented an overview of *Multimodal Therapy* for lymphoedema. This experience is based on research primarily in Europe and North America. Key points:

- Components of multimodal therapy:
 - Skin care
 - Manual lymph drainage - Purpose is to “open lymphatic channels”. 7-15% effective in reducing lymphoedema.
 - Compression (the most important component) - 50-70% effective in reducing lymphoedema (greater reduction with early intervention)
 - Exercise
- Compression technique is complex
 - Contraindications are numerous, requiring medical differential diagnosis of the causes
 - Bandaging needs to be done correctly in order to achieve the optimal pressure grade
 - Need for bandage replacement and cleaning

- Other considerations: lifelong treatment, patient support system is critical, resources and supplies are important

Participants very much appreciated the overview of multimodal therapy, including practical demonstration of manual lymph drainage (MLD). They agreed that these advanced techniques should be included in general considerations of morbidity management, especially for early stages 1 and 2 (95% of patients). Cost and resource constraints, however, limit the use of some of appropriate compression techniques in many settings.

In the afternoon of Day 2, Dr. Mackenzie presented the topic of *wound care* based on a Tanzanian experience using a topical gel product called Chitosan. Key points:

- Wounds in LF can be classified as 1) initiating lesions, 2) wounds affecting a lymphoedema area, 3) secondary infections in altered skin.

- Goals of wound healing

- Stop bleeding
- Close wound
- Prevention entry of organisms
- Reduce scarring

- *Chitosan* is a natural product made from ground crab shells that has been found to meet the 4 goals of wound healing, although controlled trials have not been published.

- Chitosan is approved by the US FDA for haemostasis (stopping bleeding) and is used by the US military today.

Participants unanimously expressed interest in the possible use of the product Chitosan for the topical care of wounds in LF lymphoedema patients and were open to other products for use in morbidity management currently under development. They were careful to emphasize that the safety of such products for intended use in LF patients needs to be explored fully through clinical trials. There was interest among some to advocate for market access of Chitosan for resource-poor settings.

Ms Jeanne D’Arc Some, Burkina Faso, presented the “Opération Chaussures”, or *shoe initiative*, which is part of a larger LF morbidity management project piloted by Handicap International and the Burkina National LF Programme. Participants appreciated the hands-on perspective. Opportunities for exchange of techniques and technologies were identified, especially between participants from India, Burkina and the USA.

In order to launch general discussion on the *psycho-social and economic rehabilitation of LF patients*, Dr. Mackenzie presented 4 cases studies of individuals in Tanzania who were affected heavily by the disease. His key point was that patients who are improving are the best advocates for any LF programme. Participants shared experiences and anecdotes to illustrate the profound impact of LF on people’s lives but also the benefits of basic LF management techniques for reducing stigma. This happens primarily, it seems, through 1) sensitization of

local communities about the condition and 2) reduction of the odour through basic hygiene. The participants from India briefly reported on the similarities with leprosy in that country whereby more than 8000 people benefited from social and economic rehabilitation through links with the government welfare scheme.

Discussion also touched on the need to provide vocational training or micro-credit for income generating activities among LF patients. NGOs such as LEPRO and Handicap International both have extensive experience in such economic inclusion activities and reported that there is a large body of literature about approaches to excluded groups in resource-poor settings. Participants agreed that this could be an important contribution of these and other NGOs working with LF patients.

Finally, it was reiterated numerous times that the psychological needs of LF patients must be addressed and that psychological support at the clinical level must be explored in each of our programmes.

One challenge to the above issues is the need to quantify the problem (social, psychological, economic impact of clinical disease on the lives of people) as well as to quantify improvements after intervention.

There was a call for a “package of interventions” which combines both MDA as well as care and support initiatives. Participants felt that this forum can help bring this issue to the forefront of the international community’s agenda.

In summary, Participants appreciated that the comprehensive approach is appropriate for LF morbidity management. They emphasized the importance of a tailored approach to the individual patient regarding psychological, social and economic support. NGOs have particular experience in psychosocial and economic support (including vocational training) which could

be valuable to national programs.

Synergies between MDA and disability prevention

Day 2 ended with two very interesting presentations, the first addressing the synergies between MDA and disability prevention, the second a presentation of the Bangladesh National Programme for the Elimination of LF.

Regarding *synergies between MDA and disability prevention*, Charles Mackenzie reiterated the central role of patients in the LF programme. Practically speaking, this means giving visibility to patients, empowering patients with knowledge about their disease, and involving them in community mobilization for MDA. He also presented some early evidence supporting the notion that MDA chemotherapy does indeed help the clinical condition. In the areas of study, “no new cases of LF have been detected since the start of MDA”. This observation introduces “new cases” as a possible measurable endpoint for MDA effectiveness. It follows that a case definition for “new cases” needs to be developed and that this monitoring needs to be integrated into the routine monitoring of the peripheral health system.

Participants agreed that MDA and disability prevention are intertwined and need to be developed hand-in-hand. They recognized that the impact of MDA on their disability prevention activities could be significant.

Bangladesh experience: MDA links with disability prevention

Dr. Mamoon of *Bangladesh* presented the National LF programme in that country. Participants were impressed by the accomplishments made in Bangladesh toward disability prevention, including the number of patients already benefited from hydrocelectomy (>11 000). There was much interest in sharing experiences and pooling data among countries on hydrocelectomy.

Day 3: Public Health and Community approaches to disability prevention

Day 3 presentations and discussion focused on service delivery. The morning session was particularly rich with exchange among country delegations regarding both *public health and community-based approaches to LF disability prevention*.

Public health approaches to disability prevention

Dr. Brantus laid the groundwork for discussion emphasizing that in terms of disability prevention, the goal is increased social participation (and not simply improved clinical condition). Key points:

- WHO strategy for lymphoedema management
 - Chronic disease approach
 - Home-based care (patient is the first carer, strong links with the primary health care system)
 - Comprehensive approach
- Indicators must be few and they must be simple

- Estimated # patients
- Frequency of acute attacks
- (Impact evaluation of the programme) Evaluation of disability among patients using WHODASII questionnaire
- Integration
 - Using a clinical sign (the affected foot) as the common point for integration in morbidity management may be a useful strategy.
 - This approach would require common indicators, although today indicators for leprosy, diabetic foot, Buruli ulcer, and LF are all quite different
 - This integrated approach could be a useful means to convince communities to participate whereby they may not feel that one disease is worth community resources and attention

Participants appreciated the common sense approach proposed by WHO, which is already in use in many countries. There was a suggestion to include informal social groupings in the model which may have a role between “community” and “family” levels. There was also the suggestion to explore further the contributions of Community Approaches to Handicap in Development (CAHD) and Community Based Rehabilitation (CBR) in providing a comprehensive approach at the community level. Participants also agreed that using a common questionnaire (i.e. WHODAS II) to evaluate the impact of our respective programmes could have important advantages for comparison and advocacy. There was unanimous recognition that integration of disability prevention efforts a wide range of diseases, especially chronic conditions such as LF, diabetic foot, leprosy, Buruli ulcer is a pragmatic approach and certainly within the mandate of Health Ministries and a number of NGOs.

Community approaches to disability prevention

To complete the morning session, participants from Madagascar (RTM), India (LEPRA) and Burkina Faso (RBCAHO, Light for the World partner organization) presented specific aspects of their action to highlight alternative *community approaches to LF disability prevention*. Full PowerPoint presentations can be found on the CDrom.

Participants appreciated the presentation by Mr Caprotti, RTM Madagascar on community mobilisation based on traditional village and clan structures. Emphasis on the ‘empowerment of villages’ was an innovative concept that had not been encountered by other participants. Discussion focused largely on the challenge of community health worker ‘motivation’, which seems to be appropriately addressed through traditional mechanisms in this project. Further discussion considered the potential role of NGOs to pilot and communicate good practice in terms of community agent motivation.

Participants also applauded the action led by LEPRA Society in India (Dr. Poricha) whereby selfsupport groups (SSG) of LF patients lead to group and individual empowerment, including access to basic rights. In this setting SSG are seen as ‘change agents’ who promote targeted messages such as “If you don’t take care of your leg, who will?” Discussion explored the concept of self support groups in LF giving consideration to the fact that in some cultures such groups may be stigmatizing. Participants commented that reference to human rights is generally absent and that NGOs have a potential role in ensuring a rights-based approach at the community level.

Finally, as per previous discussion, participants were glad to see Community Based Rehabilitation involved in the community response to LF in Burkina Faso through the organization RBCAHO (Mr. Ramdé and Mr. Belemsigri).

Gender approach

Susan Girois gave an introductory overview to the concept of a gender approach. She led participants through an exercise to consider various aspects of a gender analysis, including identifying gender roles and gender differences (inequalities) with regard to access to and control of resources. She offered a list of suggested questions for LF programmes to highlight gender issues which may need special consideration in certain contexts. She emphasized that gender planning can contribute to equity, efficiency and sustainability of LF projects.

Participants agreed that gender considerations are generally absent from today’s LF programmes. They appreciated the exposure to the gender concept and committed to explore this issue further upon return home.

Monitoring and evaluation

Discussion about monitoring and indicators permeated the three days of the workshop. On Day 3, Dr. Brantus proposed a framework for monitoring and evaluation based on WHO’s guidelines and recommendations (see WHO Manual *Preventing and Managing Disability related to Lymphatic Filariasis at the Implementation Unit Level*, CDrom). Key points:

- There are three levels of indicators
 - Indicators for the follow-up of individual patients, for example,
 - . Presence of interdigital lesions
 - . Presence of wounds
 - . # lymphoedema patients
 - . Frequency of acute attacks
 - Programme indicators, for example
 - . # lymphoedema cases
 - . # visits per patient per quarter
 - . Other process indicators
 - Health impact indicators, for example
 - . Level of disability in people affected by LF (WHODAS II questionnaire)

Discussion touched upon the need for Baseline data and to harmonize/standardize monitoring methods and indicators. Some participants were concerned that resources are often limited for monitoring and evaluation activities and that this forum could call for more money to be allocated for this purpose.

Draft WHO Manuals

Dr. Mubila and Dr. Brantus presented to the group two draft publications recently produced by WHO (CDrom):

- *Preventing and Managing Disability related to Lymphatic Filariasis at the Implementation Unit Level*, which is a comprehensive guideline to management, including suggested indicators, standard forms, and so on. Participants were encouraged to review and use the manual for their projects/programmes and to give feedback to WHO if desired.
- *Manual on Approaches to Implementation of Integrated Control of Neglected Tropical Diseases using Common*

Strategies, which provides a guide on how to achieve integration and is more specifically targeted to the Africa Region.

Disability Prevention and the National Programs

Dr. Yao Sodablon of MDP provided some thoughts and insight from the perspective of his previous role as National LF Programme Director of Togo. He highlighted key historic disability prevention initiatives for LF, such as

- The Recife (Brazil) training in lymphoedema management (2000)
- The development of case management procedures and training tools by WHO
- Resource mobilization and allocation for case management from WHO, LF Support Centres and NGOs
- National-level training of health workers in case management
- National-level training in hydrocelectomies

He emphasized the need for improved reporting of case management (disability prevention) activities from NGOs and Districts to the National programs in order to capture this data in the overall statistics and progress reports at the global level. Dr. Sodablon also reminded participants of the familiar challenges to promoting disability prevention, including the fact that this is not prioritized by the LF programmes, and that little information is available for effective advocacy. In particular, the disability burden has not really been assessed, or rather, the data has not adequately been used for advocacy.

The presentation ended with very encouraging words to participants to continue the ground work, but to think strategically about how to use our collective experience to advocate not only the National Programmes but also the global community for more resources and attention to the plight of persons disabled by the disease.

Ms. Catherine Kabré, Disability focal point for the LF National Programme in *Burkina Faso*, presented an overview of the LF prevention and control strategy in that country. While MDA is becoming widespread, LF disability prevention is concentrated in four regions with local support from Handicap International, Helen Keller International and Rotary Club Ouaga Doyen. Since the beginning of the disability prevention program in 2002, over 20 000 hydrocelectomies have been performed and over 3836 lymphoedema patients are being followed clinically. The National Programme feels an ethical responsibility to patients who are identified during screening programs, but who benefit from no care whatsoever. The National Programme looks forward to scaling up the disability prevention activities to other regions and hopes to participate in operational research.

Dr RASOAZANAMIARANA LISY NIRINA, LF National Programme Coordinator of *Madagascar* presented an overview of the LF disability prevention experiences under the auspices of her programme. Dr Lisy emphasized the burden of LF disease on both the health system in Madagascar as well as

on communities at the village level. She highlighted the positive collaboration with partners, including WHO, Principality of Monaco and NGOs (Azafady, Handicap International, RTM) in order to facilitate coordination and provide effective services. Dr Lisy shared that she anticipated important follow-up from this Disability Prevention Workshop. In particular, she hopes to extend activities to other heavily endemic districts, to recruit local NGOs to participate in the community-level interventions, and to improve collaboration with NGOs. She also emphasized to participants the importance of common indicators, data collection and reporting in order to measure impact and progress.

Conclusions and Recommendations

The Conclusions and Recommendations were compiled through a *participatory method*:

- Participants met in small groups as “country delegations” to identify the 5 main conclusions and 5 specific recommendations that they had gleaned from the 3 days.
- Participants who were alone from their country of origin met together as one small group to do the same exercise: identify 5 main conclusions and 5 specific recommendations
- These items were read to the group and then compiled into a final listing, which is provided in this Report.

The Conclusions and Recommendations are, therefore, not necessarily consensus items. Rather, they are a compilation of the main areas of interest or concern retained by the participant delegations.

Participants recognized:

- The burden of disability related to LF
- Their improved knowledge about fundamentals of the disease and about new techniques regarding physiotherapy. Inclusion of manual lymph drainage can be helpful in management of lymphoedema and genital swelling
- The relevance of gathering participants from private and public fields
- The interest of sharing Information and experience among different conditions (practice in LF management)
- The inadequate coordination of the activities of NGOs and other organizations.
- Documentation and its sharing process are inadequate and doesn't fit advocacy; this should be published and shared among NGOs.
- The non-support of National programmes due to lack funds to support disability prevention
- The hope of results of researches and field experiences regarding efficient and sustainable solutions for preventing disability
- The availability of relevant strategies, technical tools and guidelines
- The non-existence of social support, there is a need to institutionalize it

- The inadequate integration of LF Case detection into the National Diseases Surveillance System
- The importance of shoes provision and the need for sharing among NGOs
- The need of discussion on vector control and personal protection issues
- The interest of use of traditional medicines in wound healing (solution/gel of chitin) cost effectively
- The importance of monitoring and evaluation of LF lymphoedema and hydrocele patients

Recommendations

- The National Programme Manager should conduct coordination of all the activities of stakeholders.
- An LF coordination/consortium/collaboration and communication bringing together NGOs should be established for effective consultation on un-addressed issues (Note: This is one of the objectives of the NGO LF Network).
- Opportunity for information sharing/review meeting should be regularly held (bi-annual) for updating the information. Work, findings, lessons learned, victories and progress report should be published widely. (Note: This, too, is one of the objectives of the NGO LF Network, which already meets bi-annually. Perhaps new ways of operating and communicating should be devised to meet the request for improved exchange among field staff of NGOs).
- A public repository of information on shoe materials and design including material properties and manufactures should be created.
- Skill and knowledge need to be incorporated from experience of other diseases such as leprosy morbidity management.
- Standardized technical tools/protocols on lymphoedema management should be developed by WHO and made available and used by all country programmes for implementing programmes, collecting data, monitoring and assessing activities. (Note: The WHO manual *Preventing and Managing Disability related to Lymphatic Filariasis at the Implementation Unit Level* was designed to address this need. The draft version is included on the CDrom and participants are encouraged to review and use as they feel appropriate.)
- Collection of data on lymphoedema and scrotum swelling during the MDA campaign could be relevant.
- Recording of functional outcomes and pain score using visual scale at individual level should be reinforced.
- Development of standardized training courses, training manuals across a number of diseases for integration is suitable. The training tools should be simplified for use at community level and tested. (Note: the WHO trainers' and learners' manuals were designed to address this need. Participants may request copies of the manual from WHO for use in their country programs.)
- Kits for lymphoedema should include chitosan and made available to patients.
- Funds should be sourced for disability prevention activities

- including rehabilitation. NGOs network and national programmes should become effective advocates for disability prevention and management, in providing data and information to rationalize the request for funds showing the return of investment, to ensure equal priorities in the programme direction.
- Advocacy should be coordinated by WHO.
- Attempts need to be made to use LF affected persons for strong advocacy with policy makers.
- Study/ operational research should be promoted among countries
- Gender issue in LF control needs to be looked into for more effective and sustainable outcomes.

Participants expressed thanks to the workshop organizers (Handicap International and Noguchi Institute/LFSC) as well as to the funding partners GSK and Mectizan Donation Program, for taking the initiative toward bringing prevention of disability due to LF back onto the international agenda.

Annex: Workshop Agenda

Lymphatic Filariasis Disability Prevention Workshop for Field Managers Noguchi Institute, Ghana 10-12 July, 2007

Day 1 - Basic Science and Pathogenesis		
9:00 -10:30	Welcome and Introduction Introduction of Participants Overview of Global Programme for the Elimination of LF	Pr A Nyarko, Girois Girois Mubila
	Coffee break	
11:00 -12:30	Epidemiology and burden of disease Filarial and vector biology Laboratory session	Brantus Wilson
	Lunch	
2:00 -3:00	Pathogenesis of morbidity associated with LF - Lymphoedema - Hydrocele	Brantus
3:30 - 5:30	Basic LF morbidity management - lymphoedema management - acute attacks	Brantus
Day 2 Non-surgical treatment and care of symptomatic LF		
8:30 -10:30	PRACTICUM Coffee break	
11:00 - 12:30	Advanced management techniques - Overview of Multimodal Therapy	Geyer
	Lunch	
2:00 - 3:30	Advanced management techniques (continued) - Wound care - Shoes - Psychosocial and economic rehabilitation	Mackenzie Some (Burkina Faso) Mackenzie
4:00 - 5:30	Synergies between MDA and disability prevention - Effects of MDA on disability - Effects of disability prevention on MDA Bangladesh experience: MDA links with disability prevention	Mackenzie Mamoon (Bangladesh)
Day 3 Public Health approach to disability prevention in LF patients		
8:30 -10:30	Public health approaches to disability prevention - Strategy: chronic illness, home based care, global approach - Integration with other chronic diseases Community approaches to disability prevention - Traditional community mechanisms - Self-support groups - Community-based rehabilitation	Brantus Caprotti (Madagascar) Poricha (India) Ramdé/Belemsigri (Burkina)
	Coffee break	
11:00 - 12:15	Gender approach Monitoring and evaluation	Girois Brantus
	Lunch	
2:00 - 3:30	WHO Manuals Preventing and Managing Disability related to Lymphatic Filariasis at the Implementation Unit Level Manual on Approaches to Implementation of Integrated Control of Neglected Tropical Diseases using Common Strategies Disability prevention and the National Programs - Burkina Faso experience - Madagascar experience WHO's strategic perspective and direction	Brantus/Mubila Sodahlon Kabré Rasoazanamiarana Mubila
4:00 - 5:00	Communication and next steps upon return home CLOSURE	Girois

HANDICAP INTERNATIONAL'S SECTIONS

France

14, avenue Berthelot – 69361 Lyon Cedex 07
Tel.: + 33 (0) 4 78 69 79 79
Fax: + 33 (0) 4 78 69 79 94
E-mail: contact@handicap-international.org
www.handicap-international.fr

Belgium

67, rue de Spa – 1000 Bruxelles
Tel.: + 32 (0) 2 280 16 01
Fax: + 32 (0) 2 230 60 30
E-mail: headoffice@handicap.be
www.handicap-international.be

Canada

1819, boulevard René-Lévesque Ouest
Bureau 401 – Montréal (Québec) H3H 2P5
Tel.: + 1 514 908 2813
Fax: + 1 514 937 6685
E-mail: info@handicap-international.ca
www.handicap-international.ca

Germany

Ganghofer Str. 19 – 80339 München
Tel.: + 49 (0) 89 54 76 06 00
Fax: + 49 (0) 89 54 76 06 20
E-mail: info@handicap-international.de
www.handicap-international.de

Luxembourg

140, rue Adolphe-Fischer
1521 Luxembourg
Tel.: + 352 42 80 60
Fax: + 352 26 43 10 60
E-mail: hilux@pt.lu
www.handicap-international.lu

Switzerland

Avenue de la Paix 11
1202 Genève
Tel.: + 41 (0) 22 788 70 33
Fax: + 41 (0) 22 788 70 35
E-mail: contact@handicap-international.ch
www.handicap-international.ch

United Kingdom

CAN Mezzanine
32-36 Loman Street
Southwark
London SE1 OEH
Tel.: + 44 (0) 870 774 37 37
Fax: + 44 (0) 870 774 37 38
E-mail: hi-uk@hi-uk.org
www.handicap-international.org.uk

United States

6930 Carroll Avenue - Suite 240
Takoma Park, MD 20912
Tel.: + 1 301 891 2138
Fax: + 1 301 891 9193
E-mail: info@handicap-international.us
www.handicap-international.us