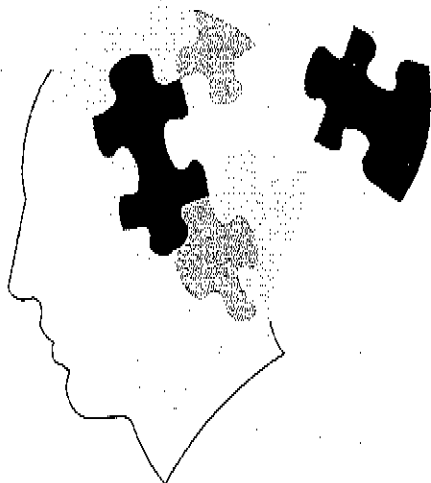
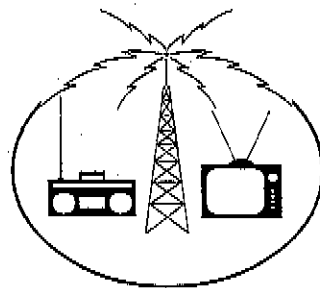


EXTRA!!! The Times EXTRA!!!

**Advocacy for the
control of disabling
tropical diseases**



**Report
of a
brainstorming
meeting**

(Annecy, France - January 1998)

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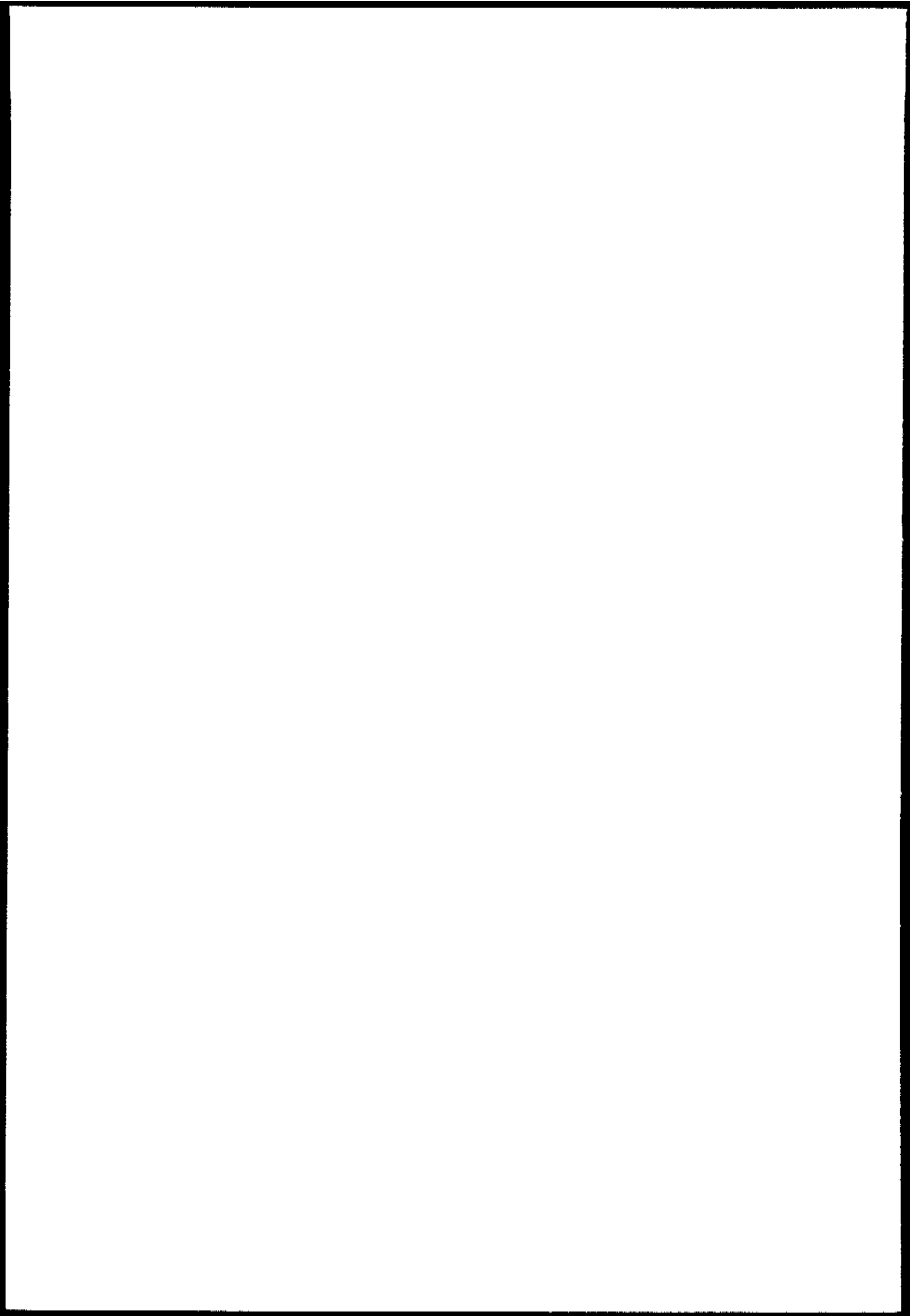
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Introduction

More than a billion people are disabled by tropical diseases. Blindness, disfigurement, and impaired physical and mental capacity can be severe; and may begin in childhood. The human suffering is enormous. But this does not need to be. Some of the most prevalent tropical diseases can be treated effectively today; and it would be possible to control them if only they were given sufficient priority and resources.

In disease control, priority usually goes to those diseases which kill. Burdens of disability are little known and disabling diseases are given only low priority. They are diseases of the poor, whose voice is seldom heard.

The present opportunities for controlling the disabling tropical diseases must not be lost, and there is a need to find more effective ways to advocate their control. But new ideas are needed on how to do this. For this reason, TDR held a brainstorming meeting with participants from a wide variety of backgrounds and experience - from governments, industry, donors, the arts, banks, communications, NGOs and marketing. The ideas generated during the meeting are reported here. The TDR Task Force on Community-Directed Treatment of Filariasis will follow these up by research to develop more effective advocacy methods for the control of disabling tropical diseases.

For the purpose of the meeting, advocacy was defined as:
the process of generating sustained commitment to the control of disabling tropical diseases.

Advocacy and marketing

Advocacy and marketing have much in common, and the meeting reviewed some of the relevant marketing principles. These included the following:

- Clear definition of the objective being pursued
- Availability of the product for marketing
- Development of an image for the product
- Clear definition of the target audiences
- Clear definition/identification of key factors characteristic to the audience
- Strategic Planning:
 - Medium + measures for reaching the audience at each level
 - Available resources
 - Follow-through

In advocacy for tropical disease control, the principles would be basically the same as for marketing, though details of application may differ. The meeting agreed that the above provided an appropriate framework for the discussions on advocacy, and that the discussions should be structured by focussing on the issues of target audiences and ways to generate commitment.

An important research objective is to develop and test a standard methodology for advocacy of disabling tropical diseases

A major problem in advocacy for tropical disease control is the lack of a clear methodological framework. An important research objective, therefore, would be to develop and test a standard methodology or 'protocol' for advocacy which can be applied widely and be adapted easily to different situations.

Examples of WHO approaches to advocacy

Some examples of WHO approaches to advocacy for the control of onchocerciasis and lymphatic filariasis were presented to the meeting. They included selected parts of a presentation on onchocerciasis control which was targeted at Ministers of Health and potential donors for the new African Programme for Onchocerciasis Control (APOC), a presentation on lymphatic filariasis control also mainly targeted at donors, and an overview of country-level advocacy workshops to generate support for Community-Directed Treatment among APOC partners. An advocacy video on the burden of onchocercal skin disease and short video clips on onchocerciasis control for the Nigerian television were also shown.

During the discussion of these examples, the following points emerged:

WHO's advocacy on disabling tropical diseases focusses on the health sector, especially Ministries of Health and its major international donors. But the message on the importance of the disabling tropical diseases and the feasibility of their control, has not reached beyond the health sector. For instance, WHO considers Uganda to have one of

The message on the importance of disabling tropical diseases and the feasibility of their control has not reached beyond the health sector

the best onchocerciasis control programmes which receives considerable priority from the Ministry of Health. During the meeting it was learnt, however, that according to medical advisors of the Ministry of Planning and Economic Affairs, onchocerciasis is not a problem in the country. A participant from Nigeria had grown up in a hyper-endemic onchocerciasis area but only realized during the meeting that the skin disease and severe itching, which were so common in her village, were due to onchocerciasis. The message that there was now a simple and free treatment for this disease had not yet reached her, even though she is a well-informed journalist. The meeting concluded that the current focus of advocacy is too narrow and that there is a need to get the main messages across to a much broader audience, including the general population and other government ministries in endemic countries

Because of the focus on Ministries of Health and donors, WHO's advocacy materials are rather technical and detailed. Other audiences beyond the health sector would require much simpler advocacy materials with simple messages highlighting the positive aspects of control.

Advocacy should also take into account that there exists a social hierarchy of diseases in which disabling diseases rank very low. The disabling tropical diseases are not understood by people and there is a need to clarify what these diseases are and what can be done. The challenge is too keep the information as simple as possible while avoiding that it gets misinterpreted. A second challenge is to combine information for different diseases. Disease specific advocacy would appear to be inefficient and brings the risk of information overload. The third challenge is the language barrier: advocacy is best done in the language of the audience.

There exists a social hierarchy of diseases in which disabling diseases rank very low

WHO increasingly uses economic arguments in its advocacy. The meeting agreed that economic considerations could be useful in advocacy aimed at major donors and governments, but beyond these specific uses the value of the economic argument was considered limited. Instead there appears to be a need for more social and psychological information relating to tropical diseases. Such information should be presented carefully, because from a marketing point of view the focus on disease problems, with its disturbing images, is risky. Negative messages do not sell and advocacy should always show ways to do something about the problem. Advocacy should highlight the human angle of the disease and the positive impact of treatment on individual people. In this connection, the use of images is important.

Advocacy should highlight the human angle of the disease and the positive impact of treatment on individual people

Finally, if advocacy is to be done seriously, it should have adequate funds. Planning for tropical disease control needs to take this into account.

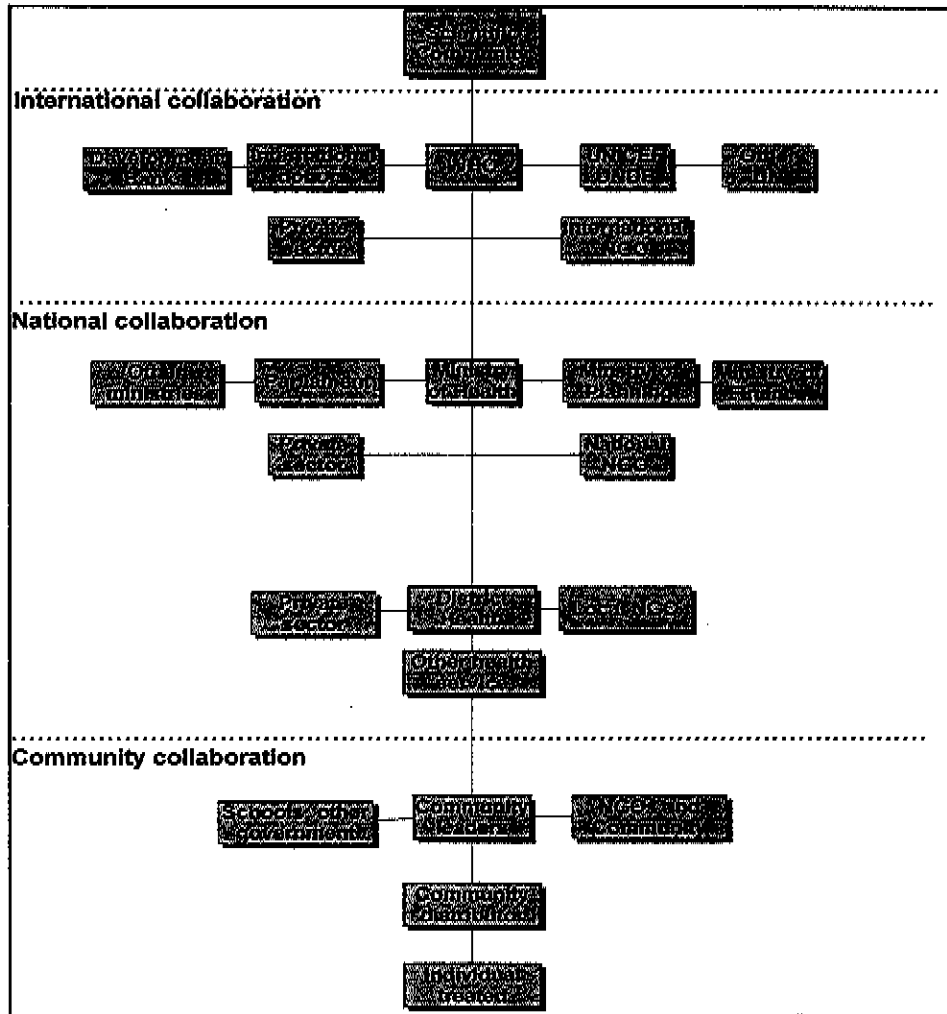
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Target audiences

The meeting identified the main target audiences at the international, national and local level. They are shown in the diagram below. It then discussed how the different actors and potential collaborators from outside the health sector at the different levels could contribute to the control of disabling tropical diseases, and what advocacy would be required. Each of these discussions started with a presentation by one of the participants who represented the specific group of potential collaborators being discussed.

Figure 1: Target audiences for advocacy on disabling tropical diseases



International level

International development banks

Advocacy has been very effective in influencing funding by international development banks, particularly on environment, agriculture and education issues. Gradually, it has been accepted that tropical diseases are an important impediment to development in tropical countries, but funding in health remains very small compared to the agricultural and other sectors. This is somewhat paradoxical given the excellent performance in economic terms of several large scale health projects which have achieved some of the highest economic rates of return of international development projects. These successes need to be used more effectively in advocacy for increased funding on health. Such advocacy should aim at international funding agencies as well as at governments of endemic countries who often do not identify with disease control and do not give priority to financial assistance for health projects.

In the assessment of proposals for development funding in health, international development banks and international donors focus these days on the feasibility of the intervention and the likelihood of successful implementation. The proposal should have a sound scientific basis, the tools for intervention should be available, there should be a well-defined and feasible control strategy, and there should be a clear and practical plan of implementation including an 'institution' with experience and expertise that can carry out the project. Predictions of the economic rate of return may be useful, but the economic rationale is ancillary - it's not the primary justification and a good social justification may be just as important. Advocacy should aim at demonstrating that a health project makes sense and that it is actionable.

Several large scale health projects have shown excellent economic performance. This fact needs to be used more effectively in advocacy

Multinationals operating in DEC's

The private industry operating in endemic countries is a potential partner for tropical disease control which has been greatly overlooked in the past. There are important opportunities for collaboration with private industry as was illustrated by the example of a multi-national mining company which got recently involved in tropical disease control in Papua New Guinea. It is urgent to further explore opportunities for collaboration on tropical disease control with multinational companies operating in disease endemic countries.

There are several reasons why such collaboration might be effective. Private industry is operating in many endemic areas, including some of the most remote areas where it is often more effective than government agencies. It has a vested interest and tends not to commit itself unless it can deliver. Private industry may want to be involved in order to fulfill its social obligations, make its staff feel good, and boost its corporate image, thus gaining a commercial advantage. It will require some financial return - direct or indirect - and appropriate information and recognition of its contributions.

The time seems right for greater collaboration with private industry

The collaboration with private industry may be opportune at this moment as large corporations are changing. Ethics and transparency are becoming important and the concept of sustainable development is also penetrating into industry. The time seems right for greater collaboration with industry, and that will require advocacy directed at decision makers in private

industry and to national governments to explain the opportunities which may become available through this new collaboration.

Drug industry

The Research-based Pharmaceutical Industry (RBPI) is an obvious partner for new initiatives on disabling tropical diseases because of the research and development capabilities concentrated in RBPI, the wide range of experience in manufacturing and distribution, and its capability to supply superior products. However, there are several disincentives for the RBPI such as the costs

of resources taken from other research projects, the fact that adverse experiences could hurt other already marketed product, that intellectual property rights may not be honoured and that there is probably little or no return on investment, especially when drugs are donated for tropical disease control.

To ensure an effective partnership with the industry, each partner should do what it does best, carry only a fair share of the load and expense, stay within its area of competence, treat others with respect, respect the rules and intellectual property rights.

To involve the RBPI, there is a clear need for advocacy, starting where and if possible with the CEOs of the industry. Secondly, there is a need for a realistic assessment of drug requirements, something which is particularly urgent for lymphatic filariasis. There should be an assurance of fair practices and a measure of return which goes beyond "Thank You". WHO is not particularly popular with the industry and that should be taken into account.

Advocacy should target CEOs of the pharmaceutical and other private industry

National level

Governments of Disease-endemic Countries

Governments of disease-endemic countries are both important targets for advocacy by the health community, as well as advocates themselves for disease control. Governments need to be convinced that a specific disease is a public health problem and that intervention is warranted, feasible and cost-effective. They need to be provided with the relevant information in an appropriate format. This advocacy should aim at different actors in government including those outside the Ministry of Health. Ministries of Planning and Economic Development play a particularly important role but health advocacy is rarely targeted at these key actors in the government.

Advocacy is particularly lacking at the government and political level

Advocacy for disabling tropical diseases appears particularly lacking at the government and political level. For instance, in India there are regularly questions asked in parliament about malaria but never about lymphatic filariasis even though the burden of filariasis in India is greater than the burden of malaria.

To improve the effectiveness of advocacy targeted at the governments of endemic countries, it might be necessary to identify those in the government who can influence decisions and health program planning as well as those who can forestall a health program. If the decision process is properly understood, advocacy can be targeted accordingly.

The major prerequisites for the effectiveness of Government's own advocacy work are appropriate policies and public investments which promote the control of disease. Government departments responsible for planning and finance have a special role in advocacy for the control

of tropical diseases, given the heavy demand and costs of mitigating the impact and consequences imposed by these diseases on individuals, society and the economy generally.

NGOs

NGOs can play a major role in tropical disease control, especially at the national and local level. They are a very heterogeneous group with each NGO having different competencies e.g. in communication, health education, health care delivery etc. NGOs should be involved in the control of disabling tropical diseases when a component activity falls within their area of expertise.

There is often a tension between the formal health sector and the NGO world. NGOs tend to be given only contractor status for health projects while policy making and planning remain the exclusive domain of the government and international agencies. NGOs resent this and insist on equal partnership from the planning stage onward and not just in implementation, and of appropriate recognition of their contributions. Advocacy aimed at NGOs needs to clearly address the role and status of the NGOs in the control programme.

Advocacy aimed at NGOs should address their role and status in the disease control programme.

Endemic communities

Though not represented at the meeting, the endemic communities themselves are clearly key to effective control. In onchocerciasis control, the actual drug distribution is already undertaken by the communities themselves and this approach appears promising for other disabling tropical diseases.

The main question is how to do community-level advocacy in a cost-effective manner at the required scale

It is important to create better awareness on the disabling tropical diseases in the target communities. It should ensure more effective control and enable the communities to exert pressure from below in priority setting and delivery of the interventions, thus contributing to the empowerment of endemic communities themselves.

Better advocacy aimed at the endemic communities is clearly needed, the main question is how to do it in a cost-effective manner at the required scale.

Communicating the message

Media

The key in using the media for advocacy is creativity in production and creativity in distribution. The first step in a media campaign is to analyse the media setup in a target country. A problem in many countries is that there are too many radio stations and that their main interest lies with DJ music. A solution to this problem is to produce nicely packaged CD's with short, simple

messages (Public Service Announcements or PSAs). PSAs can be used for a large and mixed audience, they are not expensive and because they take very little of airtime, they can be used as fillers by Radio and TV stations. The second step is to assess the medical infrastructure and whether the product is actually available. Finally, the local power structure should be analysed in order to identify key partners who can assure local ownership, and thus greater sustainability of the advocacy campaign. Sustainability is critical as it happens too often that good campaigns dry out over time. Media campaigns tend to be country-specific, and it is usually not possible to translate a media package from one country to another without modification.

Messages should be short, simple and focus on emotions

The messages should be short, simple and focus on emotions. The image of princess Diane shaking hands with leprosy patients has much more impact than a thousand words. People don't need to know all the causes, symptomatology etc. before they accept the main message and change attitude and behaviour in relation to a disease.

Messages need to be repeated often. This is why documentaries are not very effective as they are shown only once. More effective are soap operas around a health theme. Feedback is important and interactive live talk shows can also have a significant impact. Messages also get stale and need constant updating.

The impact of media campaigns on health related behaviour is rarely evaluated scientifically. No scientific evaluations have been done of media campaigns on disabling tropical diseases and this would be an important priority for research.

Arts

The meeting viewed two short video clips with songs on health education themes by two well-known Nigerian musicians. It was obvious from the clips that music can be a very effective tool in advocacy for disabling tropical diseases at the country and local level. The message to be conveyed through music should also be simple and clear. Music has the advantage that a message can be effectively repeated within the same song and by replaying the song. Before a musician will commit him/herself, there needs to be a guarantee that the intervention is feasible and that there exists an operational programme.

Music can be a very effective tool in advocacy for disabling tropical diseases

With respect to the use of famous persons, it was noted that Pele has agreed to be a goodwill ambassador for leprosy and the Martina Hingis for the EPI programme. Thus, it is perfectly feasible to get famous persons interested in collaborating in a health advocacy campaign. Many artists would also be keen to collaborate in advocacy for health issues as they like to be relevant and be seen to be committed.

Main conclusions and research issues

The main conclusions of the meeting, and some related research questions which could be targeted by TDR, are listed below:

Limitations of current advocacy:

The current focus of WHO's advocacy is on the health sector and its donors. But beyond the health sector, the disabling tropical diseases and the opportunities for control are hardly known. There is an urgent need to expand advocacy to other concerned target audiences in order to ensure greater effectiveness, better coverage and sustainability of control. Other problems with the current advocacy activities are a piece-meal approach, inadequate funding and lack of follow up.

Knowledge:

There is a need to better understand what people in endemic countries know about the disabling tropical diseases (especially lymphatic filariasis), what their perceptions are and how these vary between communities. If it is confirmed that the general public in endemic countries knows little about tropical diseases, it should be investigated why this is so: whether the information is not provided or whether it is provided but in an ineffective manner. It should also be investigated whether it is true that public perceptions of the safety of drugs have improved in recent years. If so, this must be taken into account in strategic planning.

Interventions:

Advocacy directed at international donors requires a detailed strategic plan with a sound scientific basis, a well-defined and feasible control strategy and a realistic plan of implementation. The development of such a strategic plan is a priority for lymphatic filariasis. Interventions should be actionable and attempts should be made to combine the control strategy for a cluster of disease, especially if the intervention is similar, such as single-dose treatment for endemic parasitic diseases. Whilst drug discovery and donation have been important achievements, the development of efficient drug delivery systems and associated advocacy strategies is an issue deserving more attention.

Actors:

There is a need to identify the key actors in the governments of endemic countries and the relevant power structure at the national level, and to take this into account in advocacy strategies. The availability and potential value of resources at the local level should be better explored.

Partnerships:

Serious efforts should be made to build real partnerships. It is important to involve all partners in the planning, execution and monitoring of projects, and to ensure that the contributions of the different partners are acknowledged and rewarded appropriately. This is especially important in partnerships with private industry and NGOs. It is important to examine periodically problems confronting the different partners and to make corrections where required. Advocacy should clearly address the concerns of the potential partners with respect to their role and status in the collaboration.

Industry:

The ongoing changes in private industry provide a good opportunity for attracting private companies as partners in tropical disease control. There is a need to develop an inventory of companies working in endemic areas, and to stratify them with respect to their potential contribution. There is also a need for advocacy materials specifically designed for reaching industry.

Communication:

Communities and governments do not define the disabling diseases as major problems; thus receptivity in endemic countries is low. This needs to be addressed using an approach different from that for diseases which kill such as AIDS and TB. There is a need for simple re-positioning of the disabling tropical diseases in the minds of the public. People do not necessarily need to know the exact cause of the disease but they need to know that disabling tropical diseases are serious and that they can be controlled. Better use should be made of well-known artists who are likely to be interested in collaboration. There is also a need to clarify the gender perspective: do men and women have different perceptions about advocacy messages or different ways of perceiving these messages?

Messages:

There is an urgent need to develop simple messages on the importance of the disabling tropical diseases and the feasibility of their control. These messages should have a strong human angle and highlight the individual benefits of treatment and control. Where possible, these messages should cover several diseases for which the interventions are similar.

Evaluation:

Any new approaches to advocacy should be scientifically evaluated with respect to their effectiveness in changing relevant behaviour and their impact on disease control. Evaluation is also needed of the sustainability and follow-through of advocacy campaigns.

Standard advocacy protocol:

There is a need to develop and test a standard methodology and protocol for advocacy which can be widely applied and easily adapted to different situations. The type of evidence which will generate sustainable commitment by governments, private industries, external partners, affected individuals and endemic communities needs to be identified. The appropriate advocacy message needs to be developed and tested for each level. For onchocerciasis this is a priority for the national and local level, and for lymphatic filariasis for all levels.

List of participants

Dr Uche Amazigo, African Programme for Onchocerciasis Control, Ouagadougou, Burkina Faso,
Tel: (226) 30 23 12/13, Fax: 30 21 47

Dr Ken Brown, World Wide Regulatory Liaison Biologics/Vaccines, Merck, Sharp & Dohme
Research Laboratories, Blue Bell, PA, 19486, USA, Tel: (1 610) 397 2552, Fax: 397 2962

Mrs Indu Capoor, Director, Centre for Health Education, Training and Nutrition Awareness
(CHETNA), Lilavatiben Lalbhai's Bungalow, Civil Camp Road, Shahibaug, Ahmedabad
380 004, Gujarat, India, Tel: (91 79) 786 6695/8856, Fax: 786 6513/642 0242,

Professor Jean-Emile Denis, Faculty of Marketing, University of Geneva, Geneva, Switzerland,
Tel: (41 22) 705 71 11, Fax: 705 8104

Mr Roy Head, Editor, BBC Marshall Plan of the Mind Trust, British Broadcasting Corporation,
Bush House, P.O. Box 76 Strand, GB London WC2B 4PH, Tel (44 171) 257 2462, Fax:
379 1622

Mr Arthur Hood, Mine Manager, Misima Mines Pty Ltd, PO Box 38, Bwagaioia, Misima Island,
Milne Bay Province, Papua New Guinea, Tel: (675) 643 7470, Fax 643 74 78

Professor Oladele Kale, Department of Preventive & Social Medicine, College of Medicine,
University of Ibadan, Ibadan, Nigeria, Tel/Fax: 234 2 810 356 (office), 810 0397 (home)

Dr Bernhard Liese, Director, Health Services Department, The World Bank, 1818 H. St. N.W.
Washington, D.C. 20433, USA, Fax: (1 202) 522 1616 (Chairperson)

Mrs Mary Muduuli, Commission for Economic Planning, Ministry of Planning and Economic
Development, P.O. Box 7086, Kampala, Uganda, Tel: (256 41) 235 051/3, Fax: 232015

Ms Onyeka Onwenu, Ayollo Productions Ltd, 28 Issac John Street, GRA, IKEJA, Lagos,
Nigeria, Tel: (234 1) 497 4086 or 824 064, Fax: (C/O WR) 234 1 269 4903

Dr Paul Turner, Department of Public Health & Tropical Medicine, James Cook University of
North Queensland, Townsville, Queensland 4811, Australia, Tel: (61 77) 225 772, Fax:
216 597

WHO SECRETARIAT

Dr Rafe Henderson, Assistant Director-General, World Health Organization

Dr Tore Godal, Director, Special Programme for Research and Training in Tropical Diseases

Dr Pamela Hartigan, Programme Manager, Special Programme for Research and Training in
Tropical Diseases

Dr Eric Ottesen, Chief, Filariasis control, Division of Control of Tropical Diseases

Dr Hans Remme, Coordinator Applied Field Research, Special Programme for Research and Training in Tropical Diseases

Ms Geraldine Farrell, Secretary, Applied Field Research, Special Programme for Research and Training in Tropical Diseases