

*EDITORIAL*

## The leprosy mailing list

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### Introduction

The development of Information and Communication Technology (ICT) has given an opportunity for people from different countries who share a common interest to contact each other and exchange information. Over the past years, those in developing world, who were initially lagging behind in access to ICT infrastructure, are now able to join such common interest groups. Email-based mailing lists are one of the ways in which such groups can exchange information and work together.

There are many such mailing lists used by professionals. These lists have a special importance for health and social professionals engaged in areas that are highly specialised and about which expertise, knowledge and interest among majority of health professionals is limited. Leprosy is one such area.

This article briefly presents the experience of one decade of the Leprosy Mailing List.

### Background

The leprosy mailing list (LML) is an e-mail based list for sharing information among people working in the field of leprosy worldwide. It was started in February 2001 at the Centre for Training and Research in Public Health (Cefpas) in Caltanissetta, Italy and since June 2005 is hosted at the National Leprosy Referral Centre, Department of Dermatology, at San Martino University Hospital, in Genoa, Italy.

LML is independent and has no financial ties to any governmental or non-governmental organization or the World Health Organization (WHO). All information passes its editorial

board before being distributed. However, opinions expressed are those of the contributors and not necessarily shared by the editorial board. Clinical issues, like those related to diagnosis, treatment, reactions and nerve damage have received particular attention. LML accepts all contributions as long as they are relevant to leprosy. The rate published is near 90%. For a good understanding: LML contributions are not considered publications as a publication in a recognised scientific journal. They can (and are) however be cited because represent professional opinions.

A good example of the impartiality of LML is the discussion about 'elimination.' Although the feelings about 'elimination' on both sides of the battle ground run high, and this issue continues to absorb many people in the field, there does not exist a stated LML opinion. However, LML editors can on personal title contribute to the discussion as long as it is clear that they do not claim to express an "official" LML opinion.

### **Origins and consolidation**

In the beginning information was circulated among a few friends who had years of experience working in leprosy in Africa, but gradually it became popular among leprosy workers from all over the world. Presently, it reaches to 365 persons involved in different fields - e.g. leprosy control, research, public health, laboratory services, dermatology, tuberculosis control, ophthalmology, neurology, infectious disease programmes, communication, charities, journals, etc.

Since 2006, the archives of LML have been hosted by the website of 'Associazione Italiana Amici di Raoul Follereau' (AIFO), in Bologna, Italy. AIFO also manages the leprosy mailing list blog that publishes all messages circulated on LML. All the archives of LML, including attached documents, are freely consultable. Today four persons are involved in the running, on a voluntarily basis, of this initiative, namely Sunil Deepak, from Bologna - Italy, Bernard Naafs, from Munnekeburen - The Netherlands, Salvatore Noto from Genoa - Italy and Pieter Schreuder from Maastricht - the Netherlands. Salvatore Noto is the chief editor.

### **Objectives and Functioning**

The specific objectives of the LML are: 1) divulge information about leprosy, its causes, prevention and treatment; 2) share information about management of leprosy control activities and programmes; 3) share information about socio-cultural aspects of leprosy and rehabilitation of patients with disabilities; 4) offer a distance learning tool in leprosy for health professionals; and 5) create a forum to discuss the main issues on leprosy and its control activities and programmes.

Contributions like papers, clinical cases, letters, comments, reports etc. are sent to the moderator via e-mail, who edits them in a common format and are then circulated among the members. Often prior to circulation of the documents, there is an exchange of mails between the moderator and the contributor, to clarify or modify points that are not clear.

LML is not only a forum for those still active in the field of leprosy, but it also offers the opportunity to those not active in the field of leprosy anymore, but who have a wide and valuable experience to share, to continue to contribute to the education of their young successors (Table 1).

**Table 1.** Number of messages distributed through LML since 2005 (the LML archives are not complete for the period 2001–2004)

Year	Number of Messages
2005	159
2006	157
2007	202
2008	185
2009	137
2010	135
2011	179

### An analysis of messages distributed through LML in 2011

During 2011, LML was closed for almost four months (June to September 2011). In the remaining period a total of 179 messages were circulated. Contributors of these 179 messages were from 26 countries (9 countries from North and South America, 8 countries from Asia, 4 countries from Africa and Europe and, 1 country from the Middle East). It has been remarked that some people working in leprosy travel widely. When referring to countries we refer to the country of domicile/working address of the contributor. There are a few exceptions. For example, the medical secretary of one of the ILEP organisations does not live in the in the country where this organisation has its office. In his case we counted his contributions as coming from the USA.

Classifying the messages in clear cut categories is not easy, because some messages touched on more than one issue. Keeping in mind this limitation, the messages sent in 2011 can be grouped under the following main headings - around 38% of all messages were related to discussions and advice on clinical aspects of leprosy and its complications; around 27% were announcements and requests for information; about 20% were discussions about national programmes and strategies; and, about 10% were about laboratory diagnosis and research.

On LML different kind of issues can stimulate wide discussions such as issues related to clinical diagnosis, control strategy related and laboratory services. For example a popular thread of discussions during 2011 was about histoid leprosy that was initiated by circulation

**Table 2.** The monthly evolution of messages circulated on LML during 2011

Month	No. of messages	No. of contributors	No. of countries
January	14	9	5
February	14	14	8
March	27	20	14
April	18	17	11
May	15	10	9
June	6	6	6
September	3	3	3
October	34	23	10
November	25	18	11
December	23	19	8

of some case-studies from Ecuador. This led to 13 messages. Similarly a message questioning the usefulness of re-introducing elimination strategy in Brazil was followed by 11 messages. Finally a message about the possible role of Polymerase Chain Reaction (PCR) in diagnosis of leprosy resulted in seven messages.

The **monthly evolution of messages circulated on LML during 2011** is presented in Table 2: Note: the list was closed for four months June–September.

## **Conclusions**

LML is an e-mail based forum for exchange of information, mutual support, training and discussions on leprosy among persons based in different countries and continents. It runs at a volunteer level for more than ten years. With gradual decrease in incidence of leprosy and leprosy related expertise in many parts of the world, one of its most important role is for supporting persons actually working in leprosy control and rehabilitation in low endemic situations. Finally, any suggestions to improve LML, to make it more interesting for its readers and to solicit contributions are very much welcome.

## **How to subscribe to the Leprosy Mailing List**

Write to the editorlml@gmail.com, with information about your e-mail address, postal address, your professional qualifications and present position. In 2013 the editorial responsibilities will change. Dr. Salvatore Noto will stay the chief editor, but Dr. Pieter Schreuder will take over the daily responsibilities of the editors office.