



## Minutes

Attending	Klaus M. Leisinger N. Mistry (FMR) M. Birdi (FMR)	Th. von Stamm (Emmaus) L. Oskam (KIT) M. Weiss (STI) Y. Lunau
Copy To		
	Sept 17, 2008	Basel
Concerning	<b>Exploratory meeting on an envisaged follow-up study re leprosy prevalence</b>	

## Background

The meeting goes back to the 17th International Leprosy Congress in Hyderabad, India, earlier this year. The Foundation for Medical Research had presented preliminary results of a study in an urban and a rural district in the Mumbai area, suggesting prevalence rates about six and four times higher than the country's average of reported prevalence numbers. As it was not clear whether the study results allow for an extrapolation for India or even beyond, the Novartis Foundation committed to further research efforts, striving for a higher statistical relevance for the general situation in India and other leprosy affected countries.

Now, after FMR had submitted a more elaborated article on its study to Leprosy Review, the opportunity of Dr. Nerges Mistry, the director of FMR, traveling through Europe was seized to have an exploratory meeting to get more clarity on possible strategies, for the time being focusing on India.

## Next Steps

In the exploratory meeting it was a shared understanding that the present incertitude about the real prevalence cannot be accepted and that therefore resources will have to be invested to create more clarity in this respect. It was also consensus that both the focal nature of the disease and the need for data on the health seeking and (non-)treatment process make great demands on the envisaged research, not only in terms of methodology, but potentially also in terms of funding. The Novartis Foundation went on record that it will initiate the needed additional research to increase clarity and committed to at least having the overall study design (and on the open questions / problems to solve) by end of the year.

To get there, a pragmatic step-by-step approach will be followed: Dr. Linda Oskam (Royal Tropical Institute, Amsterdam) will sketch a first outline of a promising study design in the next few weeks, including an estimation of the minimum number and size of samples necessary.



The major principle of the envisaged research endeavor will be transparency (e.g. through an open webspace), to make sure that the project can benefit from the support by all kinds of organizations interested in leprosy control and also to assure that the credibility of the results is beyond doubt, thus securing ownership of all relevant partners in the fight against leprosy. The Novartis Foundation will finance the study project and intends to drive the activities forward in the role of a facilitator, aiming on a strong cooperation not only with the scientific community and the relevant NGOS but above all with the Indian government.

As a next step, Prof. Cairns Smith (University of Aberdeen) will be approached for a peer review and possibly additions to L. Oskam's draft: This cooperation will hopefully form the nucleus of a later formal steering group of some high caliber experts. C. Smith has been strongly recommended by Leprosy Relief Switzerland, not only because of his profound knowledge, but because he is well connected both with WHO players and NGOs on the ground and therefore could make sure particularly that ILEP and its members support the project and benefit from it in an optimal way.

Based on further input to the project outline by the participants of the exploratory meeting (provisionally by mid of October), the Novartis Foundation will gather the input of various players in the leprosy world, particularly with regard to enlarging the steering group to maybe three or four members and building up a scientific advisory board in 2009 with a strong representation of local experts. As soon as the study design is ready as a 95% draft the foundation will invite to a stakeholder meeting (government, NGOs, academics and WHO) in India, in order to give the opportunity to finalize the design and discuss implementation.

Dr. York Lunau