

# Abstract Submission for ILC 2013

## Community Based Rehabilitation (CBR)

ILC2013-1284

### REAL INTEGRATION OF PEOPLE HAVING PAST HISTORY OF LEPROSY (ACTIVITIES IN A COMMUNITY-BASED CLINIC IN JAPAN)

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**Preferred Presentation Method:** Oral or Eposter

**Would you like to be considered for the Young Scientist Award?:** No

**Introduction:** For 89 years, Hansen's disease (HD) had been managed under segregation law in Japan until its legal abolition in 1996. Now we have almost no new case except for sporadic immigrant cases, but there are about 4500 people having past history of HD, and half of them are supposed to be living in the community. These people usually don't visit local clinic worrying about disclosure of their past history. In Japan, discrimination of HD has been decreasing, but they themselves cannot get out of their gloomy depressed memories. We started community-based clinic 8 years ago near Tokyo, aiming real integration of these people into the society.

**Methods:** Based on about 50 medical records of ex-patients of HD in our clinic, we review their medical and social situations. The diseases frequently occur in daily lives, vigilant follow-up study to find early sign of relapse are presented. The details of surgical cases are shown in another poster presentation by one of the coworkers. Communications between ex-patients and general citizens are reviewed; searching effective factors which leading to real integration of HD.

**Results:** 1) Their ages are in the range of 50ys and 80s, on the average 71.6 years old; 10 years younger than the people living in sanatoria. Most of them have no communication with their relatives.

2) HD-related disability rate is very high. 70%, 67.4%, 93% of their faces, anterior part of eyes, upper and/or lower limbs respectively have grade1 or 2 disabilities. They frequently need surgical, ophthalmological care, or management of chronic neuritis.

3) They have common adults' diseases and 3 developed cancer of their lung, prostate and colon. When they need treatment of other specialist, they usually hesitate worrying about their past history. In these occasions, the support of Medical Social Worker (MSW) is greatly helpful to persuade them to get most appropriate medical cares.

4) In Japan, many ex-patients haven't received WHO-MDT when their disease was active, so the observation is inevitable to find early sign of relapse. Now we have 4 cases having some active signs of HD. In one relapsed case, drug-resistance related mutations were found in 3 drugs; DDS, RFP, and OFX. In Japan, multi-drug resistance is not rare in relapsed cases.

5) Through frequent study, many volunteers, students, Buddhists' group etc. achieved good understanding about HD. They supported and encouraged ex-patients to step in the local community. Now friendly communication between ex-patients and local citizens has been emerging and growing.

**Conclusion:** We have 1.5 ex-patients each day together with many local citizens. In our community, although it's small, real integration of HD was achieved, getting good understanding of local citizens. We must also emphasize the great contribution of IDEA-Japan, many MSWs and ex-patients' association; they did a wonderful cooperation with us in the 3<sup>rd</sup> Workshop on Sentinel Surveillance for Drug-Resistance in Leprosy held in Tokyo (WHO Global Leprosy Program; Nov. 2010).

**Disclosure of Interest:** None Declared