Open letter to Italian Foreign Minister Luigi Di Maio, organized by an informal, global network of people affected by leprosy.

Dear Minister,

As persons who have experienced Hansen’s disease, more commonly known as leprosy, we were disheartened to read international media reports today that quote you as calling on other nations not to "treat Italy as a leper colony due to coronavirus". Other national and international leaders have used similar language in high profile speeches over the past.

While it might be good at grabbing headlines, the use of ‘leprosy’ as a negative metaphor has consequences far beyond the political realm, because it perpetuates old and outdated stereotypes and reinforces stigma and discrimination against us, individuals affected by leprosy.

Leprosy is not a disease of the past. More than 200,000 persons are diagnosed each year with leprosy, and there are believed to be more than two million individuals affected by leprosy who are undiagnosed and untreated. Negative social attitudes towards persons with leprosy create a barrier to treatment, and hinder efforts to stop the transmission of the disease globally.

Leprosy is a curable disease. However, individuals affected by this disease are still marginalized and excluded in many places around the globe. We ourselves have experienced being isolated by family and friends, fired from jobs, discriminated against and insulted by people, and many other violations of our human rights. That’s why we work hard every day to change this reality in every community.

Persons affected by leprosy are people with hopes and dreams like everyone else. Most individuals affected just dream of a normal life: A place to live and work peacefully, surrounded by their family and friends. They do not want to be defined by their disease.

The COVID-19 pandemic has been devastating to many, but has particularly impacted individuals affected by leprosy. This has been detailed in a letter by the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, a human rights leader who has also denounced the misuse of leprosy as a metaphor.

It is fundamental to ensure that the word leprosy is always used without the burden of stigma. Some countries have taken the initiative to change the name of the disease. However, while such change has not taken place all over the world, public figures and authorities have the duty to be careful with the thousands of persons affected and the millions that have had their lives impacted by this disease worldwide.

We therefore respectfully ask you to not use leprosy as a negative metaphor, and to instead support people in Italy, Europe and around the globe fighting to stop discrimination against individuals affected by leprosy.

We believe that this form of discrimination against us was not the objective of your statement, yet that’s the effect it has had on us. Confident in your good will, a few of us would be happy and honored to meet with you and discuss this issue further.
In the name of persons affected by leprosy around the globe,

Organizations and groups of persons affected by leprosy:

HANDA (China)
IDEA Nepal
PERMATA (Indonesia)
Sam Utthan Apal Bihar (India)
FELEHANSEN (Colombia)
HEAL Disability Initiative (Nigeria)
IDEA Ghana
Morhan (Brasil)
Purple Hope initiative (Nigeria)
IDEA Nigeria
ENAPAL (Ethiopia)
APAL (India)
Comunidad de Apoyo (Paraguay)
Community of people affected by leprosy in Rajasthan (India)
IDEA Refaco (Kenya)
ILEP Panel of Women and Men affected by Leprosy
Global Leprosy Champions
IDEA INTERNATIONAL

Persons affected by leprosy:

Evelyne Leandro
Lilibeth Nwakaego Evarestus
Rachna Kumari
Jayashree P Kunju
L H Subodha Galahitiyawa
Amar Timalsina
José Ramírez
Mathias Duck
Mohan Arikonda
Ganesh Muthusamy
Sathya Arikonda
Linda Lehman
Braj Kishor Prasad
Sanjay Kumar
Anand Raj
Lucrecia Vazquez
Mainas Ayuba
Kofi Nyarko
Paula Brandao
Suresh Dhongde
Yurani Granada Lopez
Sofia Castañeda
Isaias Dussan
Felícita Bogado
Jimoh Hammed
Joshua T. Oraga
Dan and Babs Izzet