**A Journey of 100 Lifetimes**

**By José Ramirez, Jr., LCSW**

**August 12, 2015**

**United Nations Human Rights Committee**

**Geneva, Switzerland**

Good morning. Thank you for allowing me the opportunity to represent the millions of persons throughout the world affected by Hansen’s disease, more commonly known as leprosy, as well as all of their family members impacted by a tiny bacillus, and form of enmity for 100 lifetimes. Your invitation is a perfect example of empowerment as described in the principles and guidelines of the resolution adopted by the Human Rights Council on July 2nd.  Your action to honor the rule of empowerment has helped to open doors for persons affected by leprosy to participate in the creation of policy… and not simply serve as the recipients of someone else’s policy.

My presence in this magnificent building reminds me of your colleagues from another era almost seven decades ago who voted to adopt Article I, Declaration of Human Rights, which reads, “All human beings are born free and equal in dignity and human rights.”

Today I would like to share four short stories with you. The first one has to do with the time when archaeologists in Egypt and India discovered that 40 centuries ago, the death of persons with leprosy resulted in being buried in segregated cemeteries. The practice of segregated cemeteries has occurred routinely throughout the ages, but the most painful practice has been our separation from human rights, whether breathing or no longer breathing. While alive, millions of my brothers and sisters have been subjected to isolation, arrest, denial of services, pejorative labeling and much more.

The second story relates to differences in language, culture, geography, politics and religious beliefs throughout the world. The irony of those differences is that all contain a common thread in labeling us a “leper” or the “L” word. Even when spelled backwards, it is still a negative term – repel. I have learned that there is actually a word to describe this phenomenon… it is semordnilap.

The leprosy bacillus is microscopic, but when multiplied into millions it has the power to destroy one physically, mentally, emotionally, and spiritually. This builds barriers that severely isolate the person affected by leprosy to islands. These are islands of lost identity, lost love, lost souls, lost families, lost homes, lost employment, lost rights. Some of the more famous islands where these losses have occurred include Spinalonga in Greece, Molokai in Hawaii, Robben Island in South Africa, Sorok Island in Korea, and Carville, in the United States. Carville is not an island, but this 300 acre facility is encircled by a river and encroached by swamps with snakes and alligators, so it is an island of isolation.

The leprosy bacillus allows the general populace to create special islands, as well as powerful stigma. My definition of stigma is “an act of labeling, rejection or unexplained fear of a person.”

The third story is about three realities. One reality is that medically speaking, leprosy is curable and the nine banded armadillo, found in the U.S., Central and South America, is the only form of zoonosis. How others throughout the world are affected is not scientifically known. Two, statistically speaking, leprosy may be deemed a non-issue in some countries. Regrettably, even in those countries where the number of new cases is low, the disease affects twice as many men as it does women, but it is the women who experience the greatest level of discrimination and stigma. Three, legally speaking, discrimination is outlawed in many parts of the world, as was the recent repeal of the “Leper’s Act” in India that was first enacted in 1898. Unfortunately, while leprosy can cause blindness as the bacilli attacks the nerves of the eyelids, society is also blinded as the infection of myths and ugly labels have multiplied throughout the ages, so discrimination laws that have been repealed become a secondary tier replaced by a higher tier… fear of the unknown.

The blindness by society has occurred because there is a belief that leprosy is a disease from biblical times. It has occurred because mass hysteria has led to massacres, burning of personal items, or arrest of those with the disease. It has flourished because policy makers have been forced to spend financial resources on brick and mortar to separate those affected by leprosy. It has occurred because society has been unwilling to see, and accept, the skills and talents possessed by those affected. It has occurred because incorrect information is routinely shared as fact.

This societal blindness has resulted in what I call “The Law of Silence”. This “law” refers to the lack of action by society to speak against the violations of rights directed at persons affected by leprosy. By remaining silent when injustices are witnessed, then it becomes OK, or a practice and assured “law” for continuing the denial of rights. It is a tsunami of bullying and gives life to “The Eye of Exclusion” that I have expanded on for 15 years.

The “Eye of Exclusion” refers to the consequences that occur when there is a lack of action by society against the violations of rights directed at persons affected by leprosy, and impacting the way we live, our formal education, our health and employment, our political base, and how the media generally portrays us with ugly and offensive labels.

The fourth and final story has to do with how persons affected by leprosy, and others supportive of our efforts to reverse discrimination, have created “The Eye of Inclusion”.

“The Eye of Inclusion” is a collective effort to reverse the painful practices of discrimination, stigma and violations of human rights. An example of this reversal occurred on June 17, 2015 on the steps of St. Peter’s Basilica in Rome, Italy. On that day, 4’10” Valdenora Rodrigues of Brazil, a person affected by leprosy, met 5’9” Pope Francis. She gently squeezed his hands while staring up at his face and pleaded, “Please stop using the word ‘leprosy’ to refer to all things that are bad or to refer to us as ‘lepers’. Pope Francis raised his hands up to the heavens and said, “No more. No more. No more.”

Similar to millions of others throughout the world affected by leprosy, we were deeply hurt and insulted by comments made during his first year as leader of the Catholic Church. Pope Francis said that the bureaucracy at the Vatican was “a leprosy.” He described those focusing more on their careers than their faith as “a leprosy.” With disgust he called the crimes of child abuse by priests as “a leprosy.”

With the simple response of “No more”, Pope Francis acknowledged that leprosy is NOT a punishment from God. Others who have also said “No more” include His Holiness the 14th Dalai Lama of Tibet, members of the International Congress on Leprosy, Secretariat General of the United Nations Ben Ki-moon, WHO Director-General Dr. Margaret Chan, the International Working Group on Human Rights and Leprosy, The WHO Goodwill Ambassador Against Discrimination and Leprosy Yohei Sasakawa… and millions affected by leprosy, both deceased and living.

Finally, I would like to leave you with the following information and challenges that I pose to those with incorrect information about Hansen’s disease, more commonly known as leprosy.

1. We are all human beings and having this knowledge is powerful.
2. Spreading ignorance and myths about leprosy is more powerful.
3. If left untreated, leprosy can cause blindness.
4. Society is oftentimes blinded by the offensive and inaccurate images of leprosy, giving rise to exclusion.
5. Persons affected by leprosy have formed a bond to demand inclusion, and positively impact our image, families, communities, and society.
6. Stigma and the pyramids of Egypt have lasted 100 lifetimes. We must demolish the former and preserve the latter.
7. We will no longer accept the label of the “living dead”, nor will we acknowledge the last rites from a priest as I was forced to receive when diagnosed with leprosy. The last rites resulted in my mother believing that God was punishing her through me. She stopped believing this only after Pope John Paul II referred to those of us affected by leprosy as his “brothers and sisters.”

In closing, I would like to reiterate the significance of self-empowerment, which I plan to continue practicing, and the type of empowerment offered via opportunities such as the one today.

Muchas Gracias… thank you very much members of the UN Human Rights Committee.