

## The Equal and Inalienable Rights of the Human Family

*"In the past we depended on charity, now our lives are based on human rights."*  
-- Humbert Willems, **IDEA**, Surinam



(Left to right): Dr. P. K. Gopal, President for International Relations, **IDEA**; Mr. Bertrand Ramcharan, then Acting High Commissioner for Human Rights; Ms. Zilda Borges, Coordinator, **IDEA**'s Women's Opportunities Program; and Mr. Yohei Sasakawa, President, The Nippon Foundation, meet at the United Nations Headquarters in Geneva, Switzerland, on the occasion of the 60th Session of the UN Human Rights Commission, March, 2004. *Photo by Natsuko Tominaga. Courtesy The Nippon Foundation*

On August 9, 2004, at UN Headquarters in Geneva, Switzerland, the 56th Sub-Commission on Human Rights reached a consensus to take up the question of human rights violations experienced by people affected by leprosy and their families. The Sub-Commission adopted a formal resolution to study the issue. Under the auspices of this resolution, members of the commission will conduct an investigation and produce a working paper on leprosy and human rights, which will be presented at the 57th meeting of the Sub-Commission in 2005.

# Human Rights Violations Faced by People Because of Leprosy

## Examples Compiled From Reports by IDEA Members

The Preamble to the Universal Declaration of Human Rights, adopted in 1948, recognizes "the inherent dignity" and "the equal and inalienable rights of the human family" as the foundation for freedom, justice and peace in the world. For over 3,000 years and continuing into the 21st century, the stigma associated with leprosy remains the most persistent and pervasive form of social injustice, prejudice and discrimination that society has forced upon its fellow human beings.

Men, women and children of all ages whose lives have been challenged by leprosy have had their most basic human rights denied by virtually every culture and major religion throughout time. Despite the fact that there has been a cure for leprosy for more than 60 years, the historical tradition of discrimination and social exclusion continues. Some of the basic rights denied include: The Right to Freedom of Movement; The Right to Family; The Right to Education; The Right to Work; The Right to Freedom from Degrading Treatment; and The Right to an Existence Worthy of Human Dignity.

*"Our exclusion has been taken for granted in the cultures, religions and languages of society for generations."*

Arega Kassa Zelelew, **IDEA**, Ethiopia



Unidentified young girl, Japan.  
*Courtesy HIH Prince Takamatsu  
Memorial Hansen's Disease Museum*



Blessed, Nigeria. *Photo by Pamela  
Parlapiano*



Noor, India. *Photo by Pamela Parlapiano*



Willie Wicke, who was isolated on the  
remote Kalaupapa peninsula in 1904.  
*IDEA photo*

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## **India:**

*Reported by Dr. P.K. Gopal, President for International Relations, IDEA:*

- \* Some hotels and temples carry a notice that persons affected by leprosy are not allowed inside.
- \* There are discriminatory provisions related to marriage and divorce with persons affected by leprosy in the following laws: Hindu Marriage Act of 1955; Muslim Marriage Act 1939 Sec. 2(vi); Indian Christians Marriage Act 1872 Sec. 13 (i)(iv).

In reality, most of the individuals are abandoned without even resorting to the court of law.

- \* The following Acts also discriminate against persons affected by leprosy: The Hindu Succession Act 1956; The Indian Railways Act 1890; The Motor Vehicle Act 1939; The Tenancy Act; The Industrial Disputes Act.

## **Ethiopia:**

*Reported by Birke Nigatu, Chairperson, Ethiopian National Association of People Affected by Leprosy (ENAELP):*

People have been denied their right to live at their birthplaces, the right to get an education, the right to get employment, etc. The denial of their rights has arisen mainly from the social segregation and psychological impact on those affected by leprosy. Society segregates persons affected by leprosy because of lack of knowledge about the cause of leprosy and an exaggerated fear of the disease. Baseline surveys of persons affected by leprosy conducted in different regions of Ethiopia reveal that individuals have been denied their rights. Some examples are as follows:

- \* In Jimma, the original settlers asked the people affected by leprosy not to share river water with them and reached a consensus that they must use water at the bank of the river (i.e. after those without leprosy had first used the water from the source).
- \* In Addis Tesfa Hiwot, those without leprosy stated that people affected by leprosy must not have religious services, including funeral ceremonies.
- \* In Shashemene, those affected by leprosy were forcibly displaced during the fall of the DURG regime, being forced to leave behind everything they had. The people in Shashemene did this because people affected by leprosy are not original settlers of Shashemene and they wanted them to leave the town.

These are only some examples. Although the degree of segregation has lessened, the problems persist and human rights continue to be denied. We, the Ethiopian Association of People Affected by Leprosy, continue to work hard to enable those affected by leprosy to have equal opportunities for normal lives as citizens.

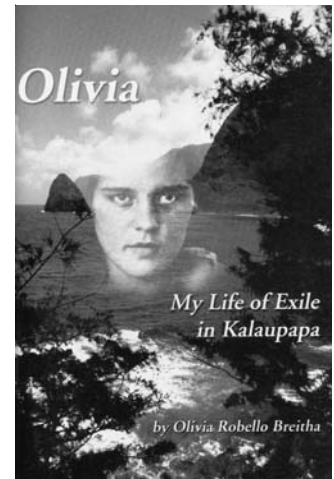
## I Want My Rights



Bernard K. Punikai'a and Jose Ramirez, Jr.  
*Photo by Pamela Parlapiano*



Betty Martin. *Photo by Tanya Thomassie*



Olivia Breitha's autobiography

I am a person  
 and should not face discrimination by others,  
 I have the rights that any other has.

Even though I have nothing.  
 The isolated village has become my hometown.  
 You may not care about my tears.  
 I may disappear without a name and soul  
 on the tombstone.  
 At least I am a person now.  
 I have my rights.

Even though I have been suffering a lot  
 physically and spiritually.  
 I feel the warmth and love in IDEA.

Mr. Feng Ke Teng, "*I Want My Rights*"



Arega Kassa Zelelew  
*Courtesy Arega Kassa Zelelew*



Left to right: Satono Hamamoto, Noriko Hirasawa, Yashoda Jirel, Bhim Kumari Gurung, Grace Akandoh, Beatrice Ntowah, Chen Jie, Yang Qian Mei, Elizabeth Shepherd, Zilda Borges and Didi Da Silva, participate in the First International Conference on Issues Facing Women Affected by Leprosy, held in Seneca Falls, NY, in 2002. The Conference was sponsored by **IDEA** in association with Women's Rights National Historical Park and the Eleanor Roosevelt National Historic Site. *Photo by Henry Law*

## **Nigeria:**

### ***Related at the IDEA Nigeria Workshop, 2003:***

There is discrimination in everyday life: Divorce, inability to get an education; the inability to work in society; being forced to live in settlements since there are no homes to return to.

Abubakar Musa: *"We have taken our treatment and have been declared cured, but there is still stigma."*

Alhaji Shehu Abdullahi Sarkin Fada: *"I was not allowed to eat with the rest of the students. I was always crying and praying for God to take my life because dying would be better for me. There was a time when I intended to kill myself. My father said I cannot leave education. I said I must go and beg . . . . I tried to get an education but they would not accept me because I had leprosy."*

Mohammed Mohammed: *"After the midwife delivered two of my children, it was discovered I had leprosy. The midwife wanted me to divorce my wife because she said they would all get leprosy. My wife's relatives asked me to divorce her. They even went to the court, but the court did not agree. The court said I should go for treatment and if I cannot be cured they will have to grant a divorce. I started taking treatment but my wife's family came and took her back home."*

Rabi Halidu: *"We are not allowed to pray with the healthy people, which has caused difficulties between the people with Hansen's Disease and the community."*

Nwoke Uche, age 30: *"I have been affected by leprosy since I was 24 years old. Since then I have been in Ossiomo waiting for manna to fall from heaven."*

## **Ghana:**

### ***Reported by Kofi Nyarko, Chairperson, IDEA Ghana:***

We have healthy minds and bodies, but the stigma has destroyed our whole lives for so many years in Ghana. So many people have died as a result of the stigma. Many also lose hope in life. The discrimination includes:

- \* It is difficult to get married in the community or society in Ghana.
- \* People do not consider those of us who are physically challenged when they are building churches, schools, markets, shops, public toilets and many other places necessary for life.
- \* We who are physically challenged are not accepted when it comes to employment. We are considered as "bad luck people" so people do not want us to come near them.
- \* Sometimes people stop their children from playing with our children, do not drink from our cups, do not eat with us, do not even greet us.

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## **Our Struggle and Efforts**

Zilda Borges, Brazil: *"In Brazil, when an employer discovers that a woman carries the Hansen's [leprosy] bacillus and is under treatment, she is fired without any rights. A man affected by Hansen's Disease may work as a bricklayer outside his employer's house, while a woman often works as a maid inside the house. She suffers in silence and continually tries to hide the disease. Denying it, she denies the possibility of an early cure."*

Arega Kassa Zelelew, Ethiopia: *"I was compelled to repeatedly produce medical certificates attesting the fact that I was not infectious. Then my 'work-colleagues' refused to touch what I had touched, and would not work alongside me. Everyone could guess how I felt deep inside, but I think no one imagined the shame and anger that came out of my unfortunate isolation. Because of my disability I was confined to the same position for over 20 years, and for 17 years with no salary increment . . . . I trust that you understand the sense of bitterness one would feel when his junior of 5 or 10 years, with the same qualifications, becomes his senior both in position and income."*

Nevis Mary, India: *"Women face many problems. There are problems in the family -- with the kith and kin, problems of getting married and in getting a good-earning husband. There are problems with friends -- being unable to tell them about the disease, the burden of secrecy. In many places people affected by leprosy who have visible disabilities are not allowed to use the glass tumblers which the others use. I have seen in many places how the affected person withdraws himself/herself from society, losing all human rights. Almost every second we struggle to live."*

Kazumi Sogano, Japan: *"The Leprosy Prevention Law neglected the human rights of those affected by leprosy. The law allowed society to treat us inhumanely. Once a person had leprosy, he/she became a non-human being. We have fought to change the law so that we would be treated as human beings just as anyone else for 45 years from 1951 to 1996. The law was finally abolished in 1996. Today is a result of our struggle and efforts."*

## **The Importance of Language in Promoting Dignity**

The strong negative associations with the term "leprosy" and thoughtless use of the derogatory word "leper" have resulted in many people advocating to change the name of the disease to "Hansen's Disease," after Dr. Gerhard Hansen who discovered the leprosy bacillus in 1873.

However, the issue of terminology goes beyond a preference for the term "Hansen's Disease" or "leprosy" and their equivalents in different languages. The images, language and labels used in association with "leprosy" or "Hansen's Disease" have the power to either destroy a person's life or reaffirm their humanity.

Every culture has language that is hurtful and language that promotes dignity. To promote self-confidence and change the traditional social image of leprosy, it is imperative to replace hurtful language with language that recognizes a person as an individual separate from the disease, and focuses on ability rather than disability.

## Our Message Will Be Carried



Stanley Stein. *Courtesy The STAR*



Yasuji Hirasawa being interviewed on television.

*Courtesy Yasuji Hirasawa*



Francisco A.V. Nunes "Bacurau"  
*Photo by Pamela Parlapiano*



Zilda Borges and Terezinha Prudencio da Silva prior to an interview with Vatican Radio, Rome. *Photo by Henry Law*

*"We are not illegal citizens on this planet. We need to have a voice."*

Francisco A.V. Nunes, "Bacurau"

*". . . as pebble thrown into a pond causes ripples in an everwidening circle, our message will be carried."*

Stanley Stein, in his first editorial for the new **STAR**, September, 1941



Founding members of IDEA.  
*Photo by Pamela Parlapiano*



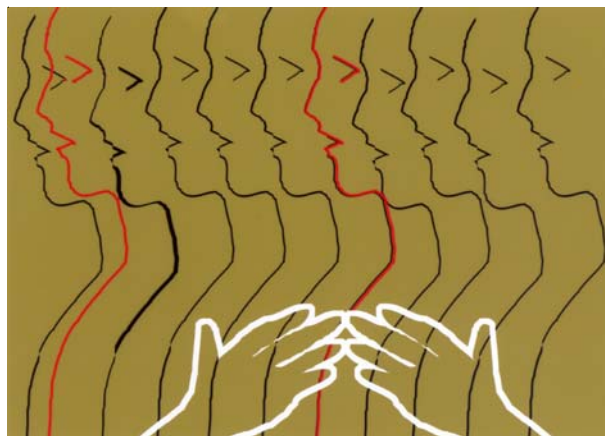
Press conference in Japan in association with the successful lawsuit filed against the government for severe human rights violations, including forced isolation, sterilization and late term abortions that resulted in the destruction of family ties and a generation without children. *Courtesy the Asahi-Shimbun*

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## IDEA's Global Campaign to Eliminate the Stigma Associated with Leprosy

*"It makes your spirit richer by being able to share and that, to me, is the essence of life."*

Bernard K. Punikai'a, Hawaii  
IDEA's President for Advocacy



"Chorus" by Kato, Japan; copyright 2004.

In July, 2004, **IDEA** launched its One Hour for Justice Campaign as part of our **Global Campaign to Eliminate the Stigma Associated with Leprosy**. We initiated this major fundraising effort amongst our members, people who themselves have personally faced the challenges of leprosy. We knew that the spirit of generosity so prevalent amongst those who often have so little themselves, yet who have historically reached out to help others, would lay a firm foundation for our efforts.

During the summer of 2004, 452 individuals who live in leprosy villages in India contributed the equivalent of one hour of their time to **IDEA's One Hour for Justice Campaign**. Their contributions totaled nearly \$400, even though many of those who contributed live at the extreme ends of poverty and, in some cases, find themselves having to beg for a living in order to have any sort of existence worthy of human dignity.

As we expand our **One Hour Justice Campaign** to the general public, our appeal is simple – we ask each person to contribute one hour's worth of their earnings a year as a **partner** in our activities to promote social justice by working together to eliminate stigma and discrimination. We feel that the steps developed to eliminate the stigma associated with leprosy will have broad-reaching implications for people with other diseases or conditions that are often accompanied by stigma and discrimination.

To become a **partner** in **IDEA's One Hour for Justice**, please send your tax-deductible contribution made payable to **IDEA** to: Will Kikuchi, IDEA Partnership Coordinator, PO Box 2073, Marrero, Louisiana 70072 USA

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