

## *“Human Rights Begin Within Us”*

### IDEA’s Global Campaign to Eliminate the Stigma Associated With Leprosy



Mrs. Januka Baigai speaks at IDEA's First Women's Empowerment Workshop in Nepal. *Photo by Pamela Parlapiano*

***“We believe that a person who feels dignity will not allow anyone to negate their rights.”*** -- IDEA's First Latin American Women's Workshop, 2006

In July 2006, IDEA was granted special consultative status by the Economic and Social Council of the United Nations (ECOSOC), one of the six organs of the United Nations. The ECOSOC includes the UN Human Rights Council and is responsible for several areas including “establishing universal respect for human rights”, “status of women”, and “creating higher standards of living” that IDEA is actively involved with and can contribute significantly to on an international level.

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## Leprosy as a Human Rights Issue

*“This culture of discrimination has to end . . . ”*

-- Henrique Ramon Galeno, Paraguay

For over 3,000 years and continuing into the 21<sup>st</sup> century, the stigma associated with leprosy has been one of the most persistent and pervasive forms of social injustice 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 Despite the fact that there has been a cure for leprosy for more than 60 years, outdated images and stereotypes persist, resulting in widespread prejudice and discrimination.

In March, 2003, IDEA launched a Global Campaign to Eliminate the Stigma Associated with Leprosy. IDEA has identified nine strategies that have been shown to effectively get rid of this stigma. Through these activities, stigma is being replaced with images of honor, dignity, self-confidence, respect and creativity. Social injustice and discrimination are being replaced with a concerted Global Effort aimed at the Restoration of Human Rights.

1. Acknowledge that Stigma Can be Eliminated.
2. Continue to Expand IDEA’s National and International Network of Support.
3. Ensure Adequate Support and Counseling to Enable Individuals to Resolve the Deep Emotional Issues that Continue to Accompany a Diagnosis of Leprosy.
4. Promote Opportunities for Education and Economic Independence.
5. Transform the Social Image of Leprosy by Promoting a Positive Image and Emphasizing the Legacy of Creativity and Inspiration.
6. Build Bridges Towards Universal Human Rights and Peace through the IDEA Center for the Voices of Humanity.
7. Promote the Restoration of Family Ties.
8. Respect and Promote the Dignity of the Older General of Individuals Affected by Leprosy by Using Their Life Experiences to Effect Social Change.
9. Ensure that Individuals Affected by Leprosy are Accorded Their Rightful Place in Their Own History.

## IDEA's National and International Network of Support

*“When the health professional told me the diagnosis, I was crushed. I started taking the treatment but I was afraid of telling my family I had the disease. As time went by and as I got involved with ARPAL, I started feeling courage to speak about the disease and to tell my family about the diagnosis.”*

-- Jaimie Tomas Cabeto, ARPAL/IDEA Angola, who was diagnosed with leprosy in 1999



(Left to right): Mrs. Shree Pati Dalit, Mrs. Jhapasiya Devi Mandal and Mrs. Rama Devi Sing, participants in IDEA's Women's Empowerment Workshop in Nepal. *Photo by Pamela Parlapiano*



Alhaji Shehu S/Fada (right), Chairperson, IDEA Nigeria, with Abubakar Muhammed community leader and IDEA Sudan representative. *Photo courtesy IDEA Nigeria*

IDEA's international network reaches at least 35 countries on five continents, with official branches established in 19 countries -- Angola, Brazil, P.R. China, D.R. Congo, Ethiopia, Ghana, India, Japan, Kenya, South Korea, Mozambique, Nepal, Nigeria, Norway, Paraguay, Philippines, Sudan, Taiwan, and the United States. IDEA expands to an average of three new countries a year through its Expert Exchange Program. In this exchange, two individuals from a country where IDEA is well established visit a new country to promote an understanding of IDEA and how it works locally, nationally and internationally. Once IDEA is established in a country, national workshops are often held to provide people with an opportunity to participate in discussions about their lives and speak in public, often for the first time.

*“The workshop helped me to look again at extinguished potentialities, forgotten within me. It helped to raise my self-esteem -- to dream possible dreams.”*

-- Maria Terezinha, Brazil, participant, Women's Empowerment Workshop sponsored by the IDEA Latin American Network



Adenir Maria Soares de Paulo (left) and Alzira Rodriues dos Santos, participants in the Women's Empowerment Workshop. *Photo by Pamela Parlapiano*

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## Ensure Adequate Support and Counseling

Even in the era of a rapid cure, a diagnosis of leprosy often continues to be a traumatic and life-altering experience due to the ongoing fear of discrimination and rejection resulting from the stigma. As IDEA talks more and more in depth with individuals in different countries, we increasingly hear about many instances where people contemplate suicide when they learn of their diagnosis or as they try to cope with prejudice and social isolation by family members and the community.

IDEA has established a model for psychological counseling and support in Brazil, as well as a support group to reach out to individuals being treated as outpatients in the United States, most of whom have immigrated from other countries.

*“We need to be much more present in the lives of people -- to perceive their feelings and to be a support in an unconditional way. To be present there in life. Side by side. It is only possible to do this when we deal with the individuality of people.”*

-- Zilda Borges, Brazil, Coordinator, IDEA's International Women's Opportunities Program



Zilda Borges (left) with Ana Niemeiskhtz de Souza. Photos by Pamela Parlapiano

## In Honor of Rinku



Rinku Basnet struck everyone with her presence and personality when she participated in IDEA Nepal's First Empowerment Workshop for Women in March, 2006. Two months later, it was learned that Rinku had taken her life. IDEA will increase its efforts to promote support, counseling and the hope of always beginning again – in honor of Rinku.

*“We must never admit to failure because we never fail.”*

-- Rinku Basnet, IDEA Nepal

*“Rinku was a girl of dreams and positive thoughts to become a nurse . . . . She was working in the leather factory and she was also attending school. Her eyes were full of life. Something has made her to take this decision. This should not happen to any one else in the world. I am also planning to do counseling with women affected by leprosy . . . . Let us all combat stigma.”*

-- Nevis Mary, IDEA India, who met Rinku at the workshop in Nepal

## Promote Opportunities for Education and Economic Independence

*“I make handbags, purses, with paper. I embroider, crochet, and I knit. My house is full of people because I like to teach. I take pleasure in passing along what I know to others. I don’t charge anything. I want to see the person working. I tell the person, ‘You are learning. When you make something, give it to me as a present.’ For me, that is a form of payment. I will always remember that person and also remember that it was I who taught her. This is the best form of payment.”*

-- Luzia Silvério Martins, IDEA Latin American Network



Luzia Silvério Martins participates in the Women’s Empowerment Workshop sponsored by the IDEA Latin American Network. *Photo by Pamela Parlapiano*



Mary Amieleke, IDEA Nigeria, started a soap making business and now teaches this trade to other women. *Photo courtesy IDEA Nigeria*

*“I’m learning to be a lawyer so I can fight for the rights of people with leprosy, so that they cannot be discriminated against.”*

-- Phister Akoth, Age 17, participant in IDEA Kenya’s First Empowerment Workshop



Phister Akoth, IDEA Kenya. *IDEA Photo*



Recipients of IDEA scholarships in India. *Photo by Pamela Parlapiano*



Lu Yin Feng is part of Handa/IDEA China’s Quilt Workshop. *Photo by Henry Law*

## Transform the Social Image of Leprosy



William Malo, Hawaii, with portions of the Exhibit that were displayed on Robben Island, South Africa.  
*Photo by Henry Law*

Dignified images and inspiring quotations that reflect the wisdom and creativity of individuals whose lives have been personally challenged by leprosy work together to promote a positive image and transform the social image of leprosy.

*“My first time to enter the IDEA Center made me feel that all my people are on top of the world! We are really special. So many people cannot have experienced what we have experienced and continue to live. So to have this Center is very important for all IDEA members and all the people in the world, so that even if we die the young generations will come and see what we went through.”*

-- Kofi Nyarko, Chairperson, IDEA Ghana

The *Quest for Dignity* Exhibit, launched at the United Nations in 1997, is at the center of IDEA’s efforts to promote a positive image and further develop discussions of leprosy as a human rights issue. The Exhibit has been updated, expanded, translated into six languages, and adapted to new situations and different audiences.

The permanent venue for the Exhibit is the IDEA Center for the Voices of Humanity. Located in Seneca Falls, New York, an area with a 150-year tradition of advocating for equal rights, the IDEA Center for the Voices of Humanity serves as an international resource center on stigma, identity and human rights for students, teachers, non-profit organizations, and for the media. The Exhibit’s more portable form continues to play an important role in congresses and other international events. At the same time, IDEA branches work with the local media to replace outdated images and stereotypes with modern realities.



Portions of the *Quest for Dignity* Exhibit are viewed by a Rotarian at the Rotary International Convention in Osaka, Japan, 2004.  
*Photo by Pamela Parlapiano*



The *Quest for Dignity* Exhibit on display at the IDEA Center for the Voices of Humanity in Seneca Falls, New York. *Photo by Henry Law*

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## Use the Wisdom of the Older Generation to Effect Social Change

*“We are never ashamed to say that my father had leprosy. He taught us how to stand up, how to face problems and how to face the stigma . . . So, I see in my father a warrior and a saint.”*

-- Mrs. Bhawle, the second daughter of Anantrao Chaphekar, who was the first person to have the vision to organize people affected by leprosy from the different leprosy communities in Maharashtra State, India.



Mikhail Oreshkin (left), Ukraine, with Jose Ramirez, Jr., USA, who traveled to Kutschurgan to conduct oral history interviews with individuals whose lives had been impacted by leprosy. *Photo by J.R. Ramirez*



Nellie McCarthy, resident of Kalaupapa, Hawaii, for more than 60 years, participates in the ‘Ohana O Kalaupapa Annual Meeting. *Photo by Henry Law*

## Promote The Restoration of Family Ties

*“I am on my way to Victoria Amoako’s hometown to see how she is doing since she left the (leprosy) camp. She is 62 years old and she was in the camp for 35 years and with IDEA’s support she decided to go back home.”* -- Kofi Nyarko, IDEA Ghana

Millions of families throughout the world have been separated due to society’s response to leprosy. IDEA works to enable family members to return home and regain their rightful places in their families and communities. In Ghana, 48 people have returned home and 123 others have left leprosy camps to live in nearby communities. IDEA is also partnering with Ka ‘Ohana O Kalaupapa, based in Hawaii, made up of Kalaupapa residents, family members and other interested persons, to initiate discussions between countries on developing strategies to promote the restoration of family ties.



Taka Harada (left), member of Ka ‘Ohana O Kalaupapa, and Miyoji Morimoto, Chairperson, IDEA Japan, participate in a discussion in Japan on “The Restoration of Family Ties”. Taka’s brother, Paul was separated from his family and sent to Kalaupapa at the age of 15. Miyoji Morimoto was separated from his family at the age of 14 due to society’s reaction to leprosy. *IDEA Photo*

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## Now That The Stigma Has Gone Away From Us

*“I am Atsu Victoria and I was born in 1969. I was affected by leprosy when I was 17 years old. At first I was in public school in our village called Abase, and when this disease came into my way I was not allowed to join the other children, because they believed that it would affect them too. That is why I chose to stay in the [leprosy] camp, but now since the stigma has gone away from us I wish to move from the camp and go to my hometown, or elsewhere to get settled and continue my life there. Here I sell soap and every market day I go and sell in the market. At first if you told me to go to the public market and sell I would not go, but with the help of IDEA people have understood our problems and now I am free to go to anyplace and do my business.”*

-- Victoria Atsu, IDEA Ghana



Cai Ping, at the 10th anniversary of Handa/IDEA China in August, 2006.



Participants in IDEA's First International Women's Conference celebrate the Opening Ceremony at Women's Rights National Historical Park in Seneca Falls, New York, 2002. Photos by Henry Law

*“There's been a lot of change in my village. The biggest change is the happiness of the people. A few years ago there was a river that went by our village and we were not allowed to use that water. If we wanted to buy something, we could not buy from the nearby villages. One person used to have to go far away to buy things for us. Now we don't need to go far away to buy things anymore. In fact, the person who used to go to buy things for others lost his job. We can now buy things for ourselves. Now some people even come to our village to sell to us.”*

-- Cai Ping, HANDA/IDEA China

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### Addresses for Correspondence

**Dr. P.K. Gopal**  
President, International Relations  
58 Selvam Nagar, Collectorate P.O.  
Erode 638 -011 INDIA  
Phone: 91-424 -226-7 395  
FAX: 91-424 -226 -0729  
E-mail: [ideaind@sancharnet.in](mailto:ideaind@sancharnet.in)

**Ms. Mary O'Friel**  
Administrative Coordinator  
699 Main Street  
Ashby, MA 01431-2309 USA  
Phone: 1-978-386-0048  
FAX: 1-978-386-0065  
E-mail: [ideaofriel@verizon.net](mailto:ideaofriel@verizon.net)

**Ms. Anwei Skinsnes Law**  
International Coordinator  
32 Fall St., Suite A; P.O. Box 651  
Seneca Falls, NY 13148 USA  
Phone: 1-315-568-5838  
FAX: 1-315-568-5891  
E-mail: [alaw@idealeprosydignity.org](mailto:alaw@idealeprosydignity.org)

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