“Today I am Fully Ready to Tell The Whole World My Story . . .”

The Oral History Project -- Regaining a Place in History

More than 200 individuals affected by leprosy and their family members from 33 countries, speaking in more than 20 languages, participated in The Oral History Project of the ILA Global Project on the History of Leprosy. IDEA coordinated project, in which members of the younger generation of people affected by leprosy, family members, university students, historians and other knowledgeable persons conducted hundreds of hours of interviews, often in remote and difficult to reach areas.

Countries represented include: Angola, Azerbaijan, Bolivia, Brazil, P.R. China, England, Estonia, Ethiopia, Ghana, Guam, India, Israel, Japan, Kenya, South Korea, Latvia, Malaysia, Mozambique, Nepal, Palau, Panama, Paraguay, Philippines, Portugal, Romania, Singapore, South Africa, Spain, Taiwan, Tinian, Ukraine, United Kingdom and the United States.

I was not yet thirteen when I started to feel a different sensation in my hands. It was suspected that I was cursed by the taotaomona, (ancient spirits who dwell in the jungles) so they kept trying to find medicine for me and my parents made many attempts to ask the taotaomona for dispensation on my behalf. It was later that they realized I was not suffering from Chetnot maipe (demonic possession/spell bound) but from what they called leprosy.

It was decided then that I would be deported, separated from the public. I was attending school, but I didn’t care about school because I was depressed . . . . It was the late part of 1948 to the late part of 1949 that my parents got a letter telling them that I was going to be placed at the Umatac Colony for treatment. At that time, we were getting shots of Chaulmoogra Oil. It was very painful, it made me ache, but it didn’t do any good. It was after we arrived at Tinian that they gave us Diasone pills. I am not sure that it helped me; I continued to feel the same and my energy level remained the same, but they told me that I was cured . . . I was the first to be released from there.

-- Excerpt from oral history with Jose Taijeron Champaco conducted by Rlene Santos Steffy in 2006. Photograph and Translation from Chamorro by Rlene Santos Steffy.
Lucy Achieng Odhiambo and Yudis Akoth Odego (Kenya)

“We left for Mfangano Island in a small timber boat. On the island we stopped at the Abasuba Community Peace Museum. We were to camp there for the three nights we were to say on the island. After three days in the narrow footpaths of the bushy island, climbing rocks and going down hills, we had interviewed a total of six people. Despite the numerous cases we encountered of people challenged by leprosy who were willing to give us their stories, we could only do a maximum of two interviews in a day because the island has no electricity and we could only recharge the camcorder back at the museum using a small diesel generator.

“During our trip we encountered several examples of human rights violations faced by people challenged by leprosy, including: 1) People are denied the right to a decent burial; 2) People are denied the right to property and land ownership; 3) People are denied the right to free movement and association; 4) People are denied the right to an honorable marriage.

“At the same time, we witnessed how some people challenged by leprosy live positively and are trying to overcome the challenges.” -- Jack Maurice Obonyo, Coordinator, IDEA Kenya

It was a shock to me when I learned that I had leprosy. What tore into my heart most was the haunting thought that I had leprosy because my parents were witches. It is what everyone including my husband believed. My husband was so ashamed of me that he would not accompany me to the health centers and hospitals when I went for treatment. To him I was a curse and he said that he wanted nothing to do with me.

-- Excerpt from oral history conducted by Jack Obonyo and Joshua Oraga with Lucy Achieng Odhiambo, a widow in her mid-30’s with six children.

When the dead body of my husband was brought from Alupe, the village elders said that it could not be buried inside the homestead. They buried him out in the bushes and left all his clothes and belongings at the gravesite. No one visits the gravesite. The village elders said that anybody who goes back there would get the disease. Even herders do not take their cattle to graze there.

Sometimes when I am asleep I have a dream that we are together -- my husband, my sons and their wives. When I wake up and realize that it is all a dream, I cry for days.

-- Excerpt from oral history conducted with Yudis Akoth Odego by Jack Obonyo and Joshua Oraga. Her husband and three sons had leprosy and died between 2000 and 2003. The wives of her three sons later died of other diseases, probably HIV/AIDS and her grandchildren are living away from her, not going to school. She lives alone, without visitors.
Eufemia Hima Dimitru and Ioana Miscov (Romania)

It was on the 16th of May, 1946 that I received the information that I had leprosy. My mother started to cry and gave me powder so I could cover my face. It was a tragedy for the family. For three years I was in bed, sick in both spirit and body. I was 18 years old when they sent me here. On the 6th of June, I’ll be 79 . . . .

Many have died, many came before me and many come after me . . . . Write the truth.

-- Eufemia Hima Dimitru, one of the last residents of Tichilesti, the last leprosy hospital in Romania. Excerpts from oral history conducted by Anwei Law. Translation from Romanian by Jon Brodal and Violeta Basa.

I was born here. I was born in 1945. My mother is from a family where there were four children. My mother was the oldest. They found out she had leprosy at 11. Her sister, the fourth child, was also ill. The two in the middle were healthy . . . . I stayed here for the first 13 years of my life . . . . They usually wanted to send children away to relatives. I didn’t have relatives . . . . I’ve been here for all of January. I come here and I stay a week with my mother and then I go for two weeks . . .

-- Domnica, the daughter of Ioana Miscov. Excerpt from oral history conducted by Anwei Law. Domnica spends part of each month in her mother’s home at Tichilesti. Translation from Romanian by Jon Brodal.
On July 21, 1950, I was brought to Suruga Sanatorium by the train which was separated from other cars. I remember that I arrived here at 3 o'clock. I was treated with Promin for six months and the disease was completely cured. I came here when I was 20 and now I am 76.

I was married but my wife passed away eight years ago. In 1954, my wife got pregnant but she was forced to get an abortion when in the third month. Many fetuses were sacrificed by the Leprosy Prevention Law. [More than 100 fetuses preserved in formalin were recently discovered. Ten of these were from Suruga, one of which was identified as Mr. Kaneda’s child.]

I took a picture of this child when it came back to me before it was cremated. I put the photo beside my wife’s photograph. I pray in front of them every day. I named my son “Takatsu”.

This monument is established to pray for those 10 fetuses in order for us not to forget about this sad fact, in order not to repeat the same thing in the future.

My child must be happy if I tell this story to the people. If there are people who want to come here to listen to me, I speak about everything.

-- Koji Kaneda, sharing his experience with representatives from IDEA and Ka’Ohana O Kalaupapa. Translation from Japanese by Hiroe Soyagimi.

“Takatsu”

You stand tall this day as I gaze upon you, Takatsu
You have finally become a boy and a person
You became a person for all to see
You became more than a fetus to me
For every moment your story is told
You grow, you stand tall, you mature
You inspire, your voice is heard again
Over and over and over again!

-- Excerpt from “Takatsu”, written by Takayuki Harada from Hawaii the day after he met Mr. Kaneda and learned about Takatsu.
Mahmud Nuray (Azerbaijan)

Mahmud Nuray was born May 5, 1939 in Derekend village of Lachin region of Azerbaijan. During World War II, Mahmud’s father went to the war and never came back. Mahmud was raised by his mother, Ziba Mursal, and they worked on a collective farm. Mahmud started to write poems at the age of 12 and they were often printed in various newspapers. In this poem, he is lamenting the conflict in Garabag -- Nagorno-Karabakh, his homeland.

Translation of poem from Azerbaijani by Aida Patterson and Nargiz Khalibekhova.

MY GARABAG

You’re like a Sun, Garabag,  
A crown of my Motherland,  
But now in the need of care.  
So colourful you are, my Garabag,  
Let me be your sacrifice, Garabag.

With beautiful pastures  
And wonderful springs,  
And embrace of a paradise,  
You are my homeland, Garabag,  
Let me be your sacrifice, Garabag.

One mournful Shikeste (traditional song)  
Is being heard over a spring  
Your eye is on the road,  
Your ear is longing for a sound,  
You’re so lonely now, Garabag,  
Let me be your sacrifice, Garabag.

Storms are blowing over lowlands,  
The mountains are all in storm too,  
How I want to be a balm  
On your bleeding wounds, my Garabag,  
Let me be your sacrifice, Garabag.

Ulo Kirs (Estonia and Latvia)

I was born in Estonia in 1926. My father had a farm of 70 hectares and I did farming work. I started as a shepherd . . . . In 1941, one of my two brothers was deported to Siberia and I had to work instead of my older brother on the farm. I found the disease when I was captured as a prisoner of war in the Russian Camp. In 1946, I was arrested and sent to an Estonian leprosy hospital [Kuuda]. I was involved in a saw mill, produced timber for 15 years. I consider that during this period I was forced to work in the forest, just taking down the trees. An extremely hard physical work . . . .

In 1963 I came to Talsi (Latvia) . . . . Under these conditions, I had planned many years ahead what I would do. Here I have my small car and I can drive to Talsi to buy what I want. In the new hospital, I’m afraid I won’t be able to cope and I am expecting death to release me . . .

-- Ulo Kirs, excerpts from oral history conducted by Anwei Law. Mr. Kirs had been told two weeks earlier that he and the other residents of Talsi, the last leprosy hospital in Latvia, would have to move within a month to a hospital in Riga. Translation from Latvian and Russian by Benito Groshus.
Today I am fully ready to tell the whole world my story beginning with when I found out I had leprosy. My father and mother were all cocoa farmers in a small town called Waja. I can’t remember my date of birth, but I can say I am about 67 years now. I contracted leprosy when I was about 9 years old. No, no! Don’t tell me to use the word Hansen’s disease. I do not feel shy to say leprosy, because it did not feel shy to attack me and destroy part of my life. I also will not feel shy to mention its name.

When my father saw that I had contracted a disease which he did not know of, he took me to the next town in our area. There he gave me to an old man called Nana Gyasi, who started treating me with some local herbs the following day. That man told my father that when you have the type of disease I had contracted you are not allowed to eat eggs, okras, salt, oranges, or apples, so I stopped.

The old man called my father one Sunday afternoon and told him that he had tried all his herbs on me, but there was no improvement so he wanted to try kerosene. He hoped that this would cure me, so I started taking it as my treatment. It is only God that helped me to live up to this time. I used kerosene for nine months and drank it every week as treatment for leprosy. There came a time that I couldn’t even sit, when I went to the toilet what came out was kerosene.

My father went and sold his cocoa farm and came for me three days later. The old man, my father and I spent thirteen days before we got to the Mankesimu hospital. There they told me that I had contracted leprosy so they had to take me to Kokofu Camp. My father said he would come back in a month. That was the last time I saw my father. Now I am 67 years and I have never seen my parents or brothers and sisters all these years. They all neglected me so long ago.

It was in this camp that I learned how to make baskets. I have been using basket weaving to feed myself and buy clothes. I sometimes use some of the money I make from basket weaving to help those who are very old in our camp. I have trained about 17 people on how to weave and I am very proud of myself. Though I have lost both my legs I am still a happy man. I do not think about my parents anymore, because I don’t think they are alive. For me I did not face much discrimination since I came here. I have spent almost all my life here in the camp. Now my dream is to get money to buy land outside this camp and build my own house and move from here.

-- Excerpts from oral history interview with Papa Mantey conducted by Kofi Nyarko, IDEA Ghana.
Parwati Oli (Nepal)

I am 32 years old, studying for a Masters Degree in Sociology. I was diagnosed with leprosy at the age of nine . . . . none of my friends touched me or treated me properly. I was segregated from the social circle. I was alone in my school. My mother was the only person who cared for me. She also had leprosy and was neglected by her husband and the village people. My father married another woman and went away. Life became even worse when my mother left home in search of him. There was no one to take care of me. I was given the responsibility to look after the cattle, collect firewood and fetch water. I had to stay in the referral center for a long time, missing school.

Even in those hard days, I did not lose courage and interest to continue my studies. I could complete my schooling with some support from my elder sister . . . . After 18 months of volunteer service, I was offered a nursing job at Green Pastures Hospital. I took in one girl who is affected by leprosy from Green Pastures Hospital. She wanted to study so I admitted her in class 7. She has been living with me for four years. Now she studies in class 9. IDEA Japan members have given her a scholarship.

I am happy that I am now leading an independent life. I support myself, although life is hard in our community for a person who has had leprosy. It is even more difficult for a woman in Nepal, as they have very little rights to make any kind of decision for themselves. Women are not as advanced because they are deprived an education, so my desire is to start a school for women.

-- Parwati Oli, participant in IDEA Nepal’s First Women’s Empowerment Workshop, which was videotaped for the Oral History Project.

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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: 91-424-226-7395  
FAX: 91-424-226-0729  
E-mail: 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

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

Parwati Oli with young friend. Photo by Pamela Parlapiano