

IDEA

.... A Pathway of Hope

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Still Dear to My Heart

The Restoration of Family Ties

"Some people who are trying to learn about their family history will come to find out they had relatives at Kalaupapa. If they feel at all the same way that we do, they will be proud that their family was part of the 'aina, part of the soul of this land."

Bernard Ka'owakaokalani Punikai'a, Kalaupapa, Hawaii



Photographs (clockwise from top left): Bill Malo with a relative at the *Quest for Dignity* Exhibit (IDEA photo); Jean Shimose places flowers at the grave of Kenso Seki, the uncle she didn't know about until the last few years of his life; Pauline Hess with her mother, Cathrine Puahala; Paul Harada (center) with his two brothers, Taka and Glen; Gloria Marks (second from left) with her grand-daughter Nicole (left) and daughters Rita and Elouise. *Photos by Wayne Levin.*

The Disease That Tears Families Apart

The greatest tragedy for people personally challenged by leprosy was, and still is, the separation of families. In Hawaii, one of the earliest names given to leprosy was "*Ma'i Ho'oka'awale 'ohana*" - "The Disease That Tears Families Apart".

"I strained my poor eyes to catch a glimpse of Sweet Home but I strained in vain . . . So I sung the Air 'The dearest spot on Earth to me' when a man passed on Horseback and he too struck up a native song . . . He too, probably, was endeavouring to avoid the anxieties that his poor aching heart was crying for, Home . . ."

Peter Kaeo, a member of the Hawaiian royal family, who was isolated on the remote Kalaupapa peninsula in Hawaii because he had leprosy, in a letter to his cousin, Queen Emma, in 1873. From: News From Molokai, edited by Alfons L. Korn



Unidentified resident of Kalaupapa, early 1900's. IDEA photo



Mamoru Kunimoto at "Homecoming Hill", which was built by the residents of Tama Zenshoen National Hansen's Disease Sanatorium in Japan so that they could look over the fence that surrounded the sanatorium in the direction of their hometowns. Photo by Nobuyuki Yaegashi

*Away for years, mountain in my hometown so green,
still dear to my heart*

*A person standing frozen for ever and a day
I too visit the hill to look towards my hometown again*

*The sun setting like warm blood trickling down the walls,
sets me to wondering about my life.*

Mamoru Kunimoto, poet, author, Japan



"Peace Hill" at Palo Seco Leprosy Hospital, Panama, designed for contemplation as a place where the residents could look out at the countryside toward their homes. Photo by Mark Chestnut

To Go Back Home

"Society just does not recognize that there has been a cure for leprosy for more than 60 years. I have traveled around the world. Why is it that I cannot go back to my hometown? Between my wife and I, we have close to 50 relatives . . . the majority of them do not even know that I exist."

Yasuji Hirasawa, Japan



Yasuji Hirasawa with Sayuri Yoshinaga, a famous actress in Japan. *Photo courtesy Yasuji Hirasawa*



Feng Ke Teng speaks to the press on **IDEA's** Sixth International Day of Dignity & Respect, Guangzhou, China. *Photo courtesy Handa*

"My hometown is only 50 km away from where I live. Since 1968, I have only visited my hometown twice. My father died in May 2002 and my mother in 2003. I was told not to come to their funeral. That made me very sad. Leprosy stigmatized our family and relatives, so some people thought it best to just 'eliminate' the existence of their family members to protect the rest."

Feng Ke Teng, P. R. China

"I feel ashamed to go to my father's house. My father knows I have passed through this condition but my brothers do not know."

Elizabeth Imhanlenrio, Ossiomo, Nigeria, Age 23

"I am from Mali. I came here to Ghana for treatment. I have been here for 47 years now. When I was coming to Ghana for treatment, I left my wife with three boys and a six month old baby girl. I have been cured for a very long time but there is no money for me to go back home."

"Ah! Hooome -- I miss my family too much. Ah, God help me to see my children and my wife again. Please help me to go back home."

Paul Zongo, Ghana & Mali



Precious Etuokwu, Ossiomo, together with many other young people in Nigeria, live in dilapidated leprosy villages without hope, education, or a future because they are not accepted by their families or the community. *Photo by Pamela Parlapiano*

The Past Inspires and Dignifies the Present



Rep. Sol P. Kaho'ohalahala

"The past inspires and dignifies the present to malama, take care of, the future of Kalaupapa."

Ka 'Ohana O Kalaupapa

"The most important thing for us is to remember our 'ohana (family) who have passed on. We're the last of the legacy. We need to let people know we existed."

Kuulei Bell, Chairperson, Ka 'Ohana o Kalaupapa



Clarence Kahilihiwa

Ka 'Ohana O Kalaupapa was established in August, 2003, as a non-profit organization dedicated to promoting the value and dignity of every individual who was exiled to the Kalaupapa peninsula beginning in 1866. Its members include the permanent residents of Kalaupapa, most of whom have lived on the remote peninsula for more than half a century and have chosen to live out their lives there; family members; interested citizens; state legislators; and representatives of non-profit organizations that have had a long-standing interest in the future of Kalaupapa and her residents. As the population of Kalaupapa decreases and watches similar facilities around the world being closed, it was deemed of vital importance to bring together people who would support and help do what is necessary to ensure that the remaining residents of Kalaupapa will be able to live out their lives in this, their home, and have the assurance that their history will be preserved and interpreted for the education and inspiration of present and future generations.

"She deserves this. She deserves dignity and to remain with her family at Kalaupapa the rest of her life."

Pauline Hess, with regard to her mother Cathrine's choice to live out her life at Kalaupapa, where she was forcibly sent as a teenager in 1942



(Left) Founding Meeting of Ka 'Ohana O Kalaupapa, August, 2003, Kalaupapa, Hawaii



(Right) Gloria Marks with Meli Pili behind her and Winifred Harada to the left.

Photographs on Page 4 & 5 by Wayne Levin

A Place Where Hope is Shown in the Most Magnificent Way



John Arruda at the grave of his father, John Arruda, Sr.

*"Kalaupapa is a monument.
We are a living monument."*

Gloria Marks, Chairperson, Kalaupapa
Patients' Advisory Council.

*"The heart honors the past. We
carry the past in our hearts, and
through our hearts into the future."*

Ellen Rycraft

*"I'm here on behalf of my
grandfather."*

Wesley Hori, grandson of Henry Hori



Wesley Hori is maintaining the cross
that his grandfather was instrumental
in building at the top of the crater

"I'm here representing my great-grandmother who was here."

Bunnie Reeser, Great-granddaughter of Rosina Weber, who was sent to
Kalaupapa in 1911

*"Going forward means we have to look back too. Interpretation is
helping people learn to feel something."*

Representative Sol Kaho'ohalahala, relative of Ambrose Solomon Kaho'ohalahala and
Lilian Awai Kaho'ohalahala, both of whom lived at Kalaupapa in the early 1900's

*"Kalaupapa should never be forgotten Make sure that the
memories of the past can continue and that my children and
grandchildren will continue to know Uncle Paul and Aunt Winnie.
This is a place where hope is shown in the most magnificent way."*

Taka Harada, brother of Paul Harada



*"I'm Nellie McCarthy, I've been
here for 62 years."*



Paul Harada and Makia Malo



*"I'm Pali and this is my home." -- Edwin Lelepali,
Musician. Photo by Henry Law*

Torn Apart, But Still a Family



Photo of Rose Marks that she had taken to send to her daughter Winnie for Christmas



Rose Marks with her sons, Richard (left) and Eddie.
Photo by Pat Boland



Winifred Marks with her mother's plaque at the National Women's Hall of Fame

No book has ever been written about Rose Silva Marks, the gentle Maui woman who died with little fanfare in the summer of 1993, but her life of unimaginable loss has finally emerged to shine some light on a chapter in Kalaupapa's history too often forgotten: the families who were left behind.

Although Rose Marks never contracted leprosy, it's doubtful that anybody in Hawaii has experienced the pain of the disease more than her. "One by one, she lost almost everybody close to her," said her son, Richard Marks, Kalaupapa's outspoken sheriff without a gun, whose blunt statements about the injustices he suffered as a leprosy patient have been printed around the world. "As a little girl, her mother, brother and sister were sent to Kalaupapa. Then her husband got sent away. Then she lost every one of her kids in just a few years, thank God one of them got to come home."

For her courage, faith and never-failing devotion to family, Rose Marks was honored on May 9, 2003, 10 years after her death, in a moving Mother's Day tribute at the National Women's Hall of Fame in Seneca Falls, New York.

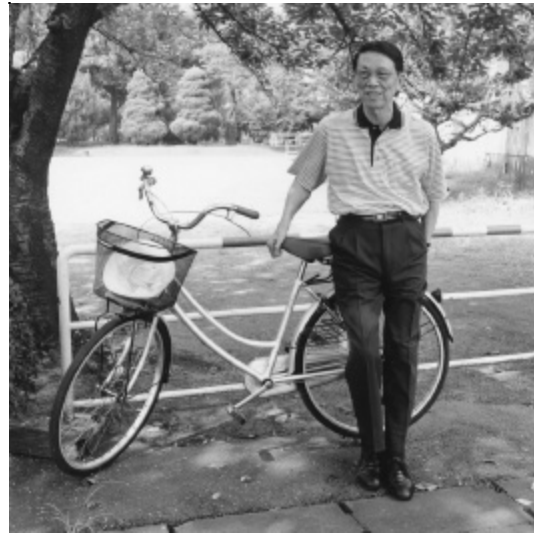
"What was so amazing about my mother is that even though we couldn't be with her, she still kept the family together," said Winifred "Winnie" Marks Harada, a daughter who attended the emotional ceremony that was bedecked, quite fittingly, with roses in every form. "Our family was torn apart, but because of my mother's love and sacrifice, we were still together. We were still a family." On behalf of her brother, Richard, and her sister, Mary Jane Ramelow of Colorado, who could not attend, Harada accepted a commemorative plaque as her mother's name was entered into the Hall of Fame's Book of Lives and Legacies. As a special surprise, Harada learned that she was also being honored for her part in helping her mother keep the family afloat during difficult times. Harada's plaque was placed on permanent display in the Hall of Fame, next to her mother's.

Valerie Monson, *The Maui News*, May 11, 2003

"We Have to Get Rid of the Wall"

"I went to my hometown to give a speech. All the classmates of my elementary school came. They thought I was dead. They said, 'You are no different from us. Why don't you come back more often?' There was a class reunion of the elementary school that I went to. I got back all that was lacking from my life. I felt like an elementary school student again. I was reunited with my friends after 50 years of separation. My heart has been dark for so many years. Finally I could see blue sky over my head."

-- Michihiro Koh, Japan



Michihiro Koh. Photo by Nobuyuki Yaegashi

Their telephone conversations sometimes lasted more than an hour. "If I, a person with leprosy, cannot even convince my own family, then there is no way that prejudice in the world will disappear." "I completely understand what you are saying, but it is not always logic that moves society, especially in suburbia. What if, thanks to your leprosy, our children cannot get married, or cannot find jobs?"

Born the second son of a Shinto priest, Michihiro Koh was diagnosed with Hansen's Disease when he was 17 and has spent 53 years living in Hansen's Disease Sanatoria. General Secretary of Zen Ryo Kyo, the National Association of Residents of Hansen's Disease Sanatoria, Mr. Koh has made speeches throughout Japan. In 2002, he was scheduled to make a speech in Fukuoka Prefecture, where he was originally from, but, despite his attempts to persuade them, his family refused to lend their support for his speech. His brother was his sole supporter.

Mr. Koh did not stop calling his sister and brother. They finally agreed that he was right, yet their worries about the neighbors were clear enough. Two months passed following Mr. Koh's first telephone call to his family. Then, his younger brother suddenly called to announce that he had persuaded their relatives. He said, "We are all waiting for you."

In mid-March of 2002, Mr. Koh went back to his hometown for the first time in 50 long years. The sea of Sou lay in front of their home. His younger brother, remembering what Mr. Koh liked, had gone to the beach that morning to collect little clams. Several dishes of them were on the table. He sat at the table with his elder sister, elder brother and younger brother, crying as he ate.

In following months, Mr. Koh and his brother toured together, speaking about the importance of restoring family ties. "What we really want is to achieve a society where people say it doesn't matter what disease you have had . . . I cannot allow society to remain as it is. We have to change the direction. We have to get rid of the wall. It's not about logics and theories. We have to make a move now or it will be too late."

Adapted from an article in the *Mainichi Shimbun*, May 10, 2002, and other interviews with Mr. Koh

A CIRCLE OF WARMTH

"I pray for a circle of warmth to spread through society little by little."

Miyoji Morimoto, **IDEA** Japan

In 2003, **IDEA** Launched a Global Campaign to Eliminate the Stigma Associated with Leprosy. Whether it is to return home to live, or simply to be able to freely visit and be visited by family members, the restoration of family ties is a key step in eliminating the stigma associated with leprosy.

If you would like to help with this effort worldwide and **IDEA's** other activities aimed at eliminating the stigma, please send your tax deductible contributions (made payable to **IDEA**) to:

Will Kikuchi, Membership Coordinator, PO Box 2073, Marrero, Louisiana 70072 USA

Our Thanks

To New Members: IDEA Angola: Nátalia Isabel da Graca Marcal, Alexandre de Jesus, Justino Domingos, Teresa Evaristo Gunza, Rosa Fafa Toko, Avelino Simão N. Gunja, Maria Júlia, António Martins, Esperanca Raimundo, Isabel João Domingos, Maria António, Arsenia Domingos, João Fernandes, Madalena Backstrom, and Paulo Manuel.

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