



## **AUTHOR'S NOTE**

As someone born and raised in Hawai'i, I was thirty-seven before I learned I had a relative with Hansen's Disease, known to the world as Leprosy. My mother, Lydia Marie Silva (1922-1996), was born on the island of Kaua'i to Portuguese immigrant parents from the Azores. Like her cousin, Olivia Robello (1916-2006), she grew up in a tight-knit, hardworking community where family pride and the magnetic pull of assimilation often clashed. People kept anything potentially embarrassing locked tightly in the closet. If word got out that someone in the family had contracted such a dreaded disease it would have negative effects on their social standing, the way they were treated at work, at school, even in church.

By the time I met Olivia in December of 1989, on the remote peninsula of Kalaupapa, the historic landing place for generations of leprosy patients on the island of Moloka'i, the antiquated rules surrounding "the separation sickness" had largely vanished. In the seventeen years that we were able to share together, this tough, razor-witted lady taught me more about humanity than I could have ever gotten from any university degree in the subject. She was a woman for whom truth was an emotion and candor an essential card in her deck. She doled out both in measured degrees. This was not out of mere orneriness, though that would often come into it, but more as a protection from what she saw as the distractions of a public life she never asked for.

Olivia was a living witness to the wrenching public policy decisions that forever altered people's lives and brought them to a place from which few ever expected to emerge. It was through her 1988 memoir, "*Olivia-My Life of Exile in Kalaupapa*", that I, along with thousands of others, began to finally appreciate the reality of people used to being disdained, avoided and scorned as "lepers".

Olivia realized that this hurtful word, like many others, may never completely disappear from use. She also knew that it was extremely important to accurately comprehend the historical attitudes that have caused labels like this to be accepted in common parlance for far too long. Like so many other tags whose purpose is to exclude people by invoking their color, religion, sexual orientation or, in this case, their medical condition, the word perpetuates harmful stereotypes and robs people of their rights as individuals. Each time I hear it, and I've heard it quite a lot since being sensitized to it by Olivia, I can feel the pain she felt when she heard it used on TV.

*"From time to time on the soap operas I've heard the actors say, 'Oh, you look like a leper.' 'I feel like a leper.' I said, 'Oh, yeah? You feel like a leper? Well, I'm going to let you know what it feels like to be this 'leper'".*

She was especially shocked to hear the word used on her favorite show, M\*A\*S\*H. When her protest letter to Alan Alda, the show's star, initially went unanswered, (he did eventually write her two years later) she decided to put her own story down on paper.

Olivia's slim but highly influential book, which has remained in print for nearly twenty-five years, chronicles her personal and medical history as well as her nearly 70 years of life in Kalaupapa. Her devotion to the legacies of the Catholic priest, Father Damien de Veuster (1840-1889), and the Franciscan nun, Mother Marianne Cope (1838-1918), who both selflessly ministered to people during the early days of the settlement, helped form Olivia's own streak of righteous determination. She writes with passion of her struggle and, by extension, the struggles of thousands of others against centuries of stigma and fear. Olivia exhorts us, through the hardships of brave people living and dead, to see them not as societal outcasts but as individuals, as flawed as the rest of us, who tried their best to rise above their adversities with quiet dignity. Anwei Skinsnes Law, international coordinator of IDEA, an advocacy and support organization for people with Hansen's disease, knew Olivia well and has herself worked diligently to help dispel historical inaccuracies related to the condition. *"She was very opposed to the word 'leper,'" Ms. Skinsnes Law wrote. "She wanted people to know her as Olivia, for people to see her for who she was and not the disease she had."*

Now that she is gone from here, Olivia's lifelong struggle with authority is over. But her mission to restore the rights of people suffering from this long-misunderstood condition continues. Knowing her was as close to a blessing as I have ever felt. She was not merely a found relative. Olivia was a complex woman who lived the life that she was dealt, ninety years of it, and was transformed by that experience into the unlikely but powerfully eloquent and respected social activist she eventually became.

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