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**To:** Nevada State Legislature Senate Human Resources and Facilities Committee

**From:** Lisa Black, BSN, RN; Executive Director, Nevada Nurses Association

**Date:** April 4, 2003

**Regarding:** Senate Bill 386

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Good morning Mr. Chairman and members of the committee. For the record, my name is Lisa Black. I am a Registered Nurse and the Executive Director of the Nevada Nurses Association. Today, however, I would like to talk to you as a Registered Nurse who has cared for many patients and families who have struggled with complex health care and end of life decisions. These sorts of circumstances, in the best of cases, are not easy. When we add to this hardship arbitrarily imposed definitions of family that may not fit every person's circumstance, the decisions are compounded dramatically. This is often thought of as a "gay rights" issue or one that is unique to the circumstances faced by same-sex partners. Sometimes this is the case, but most often, it is not. I'd like to share the stories of a couple of patients for whom I've cared that will illustrate the difficulties that are posed when the person a patient considers to be his or her family is not allowed to participate in the patient's medical care.

In one case, a 42-year-old female patient was admitted to the hospital when an emergent health care situation arose. This patient had been diagnosed with cancer several months prior and her condition has precipitously deteriorated to the point that her death was imminent. Because the patient became critically ill very quickly, decisions needed to be made about the level of care that would be rendered ... in other words, would this clearly terminal patient be allowed to die a peaceful, dignified death or would she be subjected to resuscitation and prolonged life support. The patient had been estranged from her father for twenty years, and had no other family. Her close friend, a male coworker, had been at her side throughout the course of her illness and he maintained that the patient had, on numerous occasions, expressed to him that she did not wish for her life to be maintained artificially. However, because this friend could not legally provide direction regarding the patient's care, hospital staff was forced to contact the estranged father for direction. The father, who had "disowned" his daughter 20 years prior, did not even know that his daughter had been diagnosed with cancer. Because he was the one living blood relative of this patient, however, he was tasked with determining her fate. In the end, this patient, who had made her wishes clearly known to those that she considered her "family" was made to endure repeated surgeries and multiple resuscitations before she finally succumbed a full week later to the overwhelming infection that had brought her to the hospital. Despite the friend's presence during the duration of the patient's illness, he was not allowed to visit when the patient had to be transferred to the intensive care unit for advanced treatment because visitation in that unit was reserved for "immediate family" only. The patient's father never did visit and the patient died in the intensive care unit without friends or family at her side. When the father was called and

informed of his daughter's death, he refused to claim her body and, of course, the friend was not permitted to do so. In the end, the patient's body was remanded to the custody of the county coroner and was cremated at the expense of the state. To my knowledge, her remains were never claimed.

In another case, a 34-year-old male patient was admitted to the intensive care unit after being involved in an automobile accident in which he sustained a serious head injury. The patient was comatose and was not expected to survive. This young man had a same-sex partner with whom he had lived for 8 years. This young man had not spoken to his family for 10 years since having "came out" about his sexuality. After the accident, the patient's parents came to the hospital, demanded that the patient's partner not be allowed to visit, and obtained a temporary restraining order against the partner. When the partner attempted to visit the patient against this order, he was arrested. The patient died while the partner was in jail being booked on this charge.

While the dynamics of these two cases are very different, the end result is the same. Each died without the person they considered to be their "family" at their side. While we traditionally have, as a society, imposed uniform societal rules that define a family member as one related by blood or marriage, it cannot truly be defined what constitutes a "family" for each person. What one considers to be family, is dismissed by another. Indeed, even the authoritative sources of such definitions cannot agree on the meaning of the word. In addition to the traditional definitions involving biologic lineage, Oxford English dictionary defines a family as "a group of individuals sharing a common purpose." Webster defines it as "a group of people united by certain convictions or a common affiliation" or "any group living together, as if they were related by blood." Certainly, the significant others in each of the aforementioned examples fit these definitions of family, and each were considered by those receiving care to be family, yet they were denied the ability to be with their family in their time of need.

Patients who are in need of medical care must be afforded the fundamental right to define for themselves who they wish to involve in their care and to determine who they wish to have recognized as family. I urge your support of SB 386 and would be happy to answer any questions of the committee.