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Marcia de Braga Testimony

Thank you, Mr. Chairman and members of the committee. For the record, my name is Marcia de Braga. I'm here to speak in support of AB315.

This bill came about because of concerns about the purpose and focus of the state's Cancer Registry.

As you know, legislative hearings were held last session regarding the Acute Lymphocitic Leukemia cluster in Fallon. The purpose of those hearings was to try to bring together available resources and information to look for any possible environmental causes and to help families whose children were suffering from this horrible disease.

During the course of those hearings, we learned that the state law requires the State Health Officer, pursuant to regulations of the State Board of Health, to establish and maintain a system for the reporting of information on cancer.

By law, the system must include a record of the cases of cancer that occur in this state along with such information concerning the cases as may be appropriate to form the basis for conducting comprehensive epidemiologic surveys of cancer and cancer related diseases in the state and the evaluation of appropriateness of measures for the prevention and control of cancer. That's a very tall order, but I think it is imperative that every effort is made to carry it out.

What made Fallon's cluster stand apart from other cancer clusters was the fact that so many cases—16—occurred in such a short period of time—about a year and a half in a small population. Compare that to 15 or so cases over a 10 year period in Welborn, Mass that led to the events that were written about and made into the movie *A Civil Action*.

Fallon's problem received a great deal of media attention partly because it was discovered at about the same time as the nation was sympathizing with the families depicted in that *A Civil Action* and in *Erin Brokovich*. In addition to that stories of a showdown between the EPA and Fallon over the high arsenic content of its water were in the news all over the world.

Perhaps a more important cause for the attention it received was the high number of cases and time involved. Scientists viewed Fallon's crisis as a real opportunity to advance their knowledge about possible contributors to the disease.

One of the things we learned during those hearings was Nevada's cancer registry was being used as a research tool and that the data in it was two years behind. It was not analyzed in a manner that would have ever led the Health Division to discover Fallon's cancer cluster. Nor was it designed to promote a clearly defined manner in which it could lead to either prevention or control.

This is not a criticism of Nevada alone. I was asked to be a presenter and panelist at a national health conference in North Carolina last year. There were also speakers from other states and from the Center for Disease Control and Prevention, who stated that cancer data reported in other states and on the federal level was used in pretty much the same manner. At that time there was Congressional interest, which continues, in a national registry and the creation of a cancer SWAT team that could respond quickly and in an effective manner to a cancer cluster.

AB315 is a first attempt in that direction on a state level. And, whether or not the State Health Division is already moving toward those goals, it is imperative that the requirement to analyze cancer data be put into the law and that the current law be carried out.

Both the activities assigned to the CDC and Nevada's cancer reporting laws have a component that speaks of prevention. I think that if prevention is ever to be achieved—and more importantly, if causes are ever going to be found, our state health division has to know as early as possible that a statistical abnormality appears to be occurring and where it is happening.

A requirement that those elements be reported is already in state law.

If health officials are alerted early and if they already have a plan in place that includes investigative teams and protocols to be used, they can strike while the iron is hot. That might help them find any clearly obvious contaminants—before they have dissipated—that might be present in the particular area where the cancer exists.

We're told that the tests conducted in Fallon didn't find a cause of the cancer cluster. I don't believe that to be accurate. I think health authorities and scientists learned a great deal and that someday what they learned in Fallon will help lead to the discovery of both causes and cures.

We've also been told that for two years, the cancer registry was used to look for spikes of other types of cancers and there weren't any. It has since been verified that Fallon has experienced spikes in other types of cancers as well as spikes during other periods in childhood leukemia.

And, Fallon has an interesting statistical rate of extremely rare cancers and diseases which have gone relatively unnoticed. (Merkle cell, rhabdomyosarcoma, and several cases including an entire family including animals with auto immune deficiency hepatitis.)

Thankfully, the research done in Fallon is causing federal officials, scientists and members of the medical community to take a closer look at things like arsenic's effect on the immune system and tungsten's effect on cancer cell growth. Both are present in the Fallon environment.

Scientists will also benefit from mistakes that may have been made in Fallon. Should previous clusters have been included? Should other bone marrow diseases have been included? Should efforts have been made to look at adult cancer clusters and other disease statistics? I think ultimately, further study will answer those questions.

In the long run, proper analysis of health statistics could be the key.

You may hear from Health Division officials about all their hard work and the difficult things they had to deal with during the cancer investigations. I agree it was a rough time and I agree that they worked hard. You may hear that the division is overworked and under-funded. That may also be true. In 2001, I know the Department put a moratorium on grants that had a different focus than anything currently being focused on because of staffing problems even though 17 new positions had just been approved by IFC.

But we're not here to talk about what happened in the past or what has already been done. We're here to talk about what needs to be done—what must be done in order to prevent suffering and save lives.

State law already requires the reporting of the name, address, pathological findings, stage of the disease, environmental and occupational factors, methods of treatment, incidents of disease in the family, and the places patients lived for all cases of cancer.

It requires that reports will be published—keeping individual patient's identity confidential—and that appropriate uses will be made of the information to advance research and education and to improve the treatment of the disease.

The intent and purpose of the law can't be carried out if the data isn't analyzed and tracked. The intent and purpose of the law can't be carried out if the scope of the investigation isn't properly plotted. The goal must be to be able to hit the ground running—without delays—whenever and wherever there is a significant problem.

That doesn't mean unnecessarily alarming or exciting people. It does mean creating the ability to go into action quickly using data extracted from the cancer registry that shows that an unusual disease outbreak may be in progress.

In Sept. 2001, the Interim Finance Committee authorized \$525,104 for six new positions, whose duties would include the management, analysis, reporting, comparisons and the instigation of cancer in this state. And those positions were recommended in the governor's budget for the next biennium.

AB315 puts the duties of those positions into law and requires that Nevada's cancer registry data be analyzed and that unusual occurrences and statistics be investigated for the purpose of finding causes and of disease prevention.

This bill says there is a fiscal note. However, if the positions are still in the budget, that fiscal note should be removed. The requirement to pay a researcher, if needed, was already in the law and the duties of that person may have been assumed by one of the new positions.

The next goal will be a working national cancer registry. Many patients are diagnosed in places outside their home town or state. Matthew Warneke, whose daughter Anastasia had ALL, lived in Sierra Vista, AZ before moving to Fallon. Little Ana was diagnosed a very short time after moving to Fallon. Ana's father pleaded with authorities in both areas in the hope of helping advance knowledge. He was very frustrated by responses

Arizona would not include her in Sierra Vista statistics because that would have brought their total number to 6, which would have officially made them a cluster. Nevada officials didn't want to include her in the Fallon cluster because they thought she hadn't lived there long enough. Shortly thereafter, Sierra Vista had three more cases so their problem became a cluster, anyway.

Next to testify is Jeff Braccini, father of the most recently diagnosed Fallon case. Others who could not get off work have sent letters that they would like to have included in the record.

Thank you.