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Testimony in Support of Clinical Trial Legislation

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My name is Jerry Crum. I have been a resident of Carson City since 1977. I am testifying in support of AB502.

I was diagnosed with Mantle Cell Lymphoma, a type of non-Hodgkin's lymphoma, in 1997. At that time I was given 3-6 months to live.

There is no known effective treatment for Mantle Cell Lymphoma. Chemotherapy can sometimes put it into remission. But statistically, whether you treat it or not, you live the same length of time. This is the situation that I faced when I was diagnosed. It still is. The only route that people with Mantle Cell Lymphoma have to try to treat their cancer, or help find an effective treatment for it, is through a clinical trial.

Let me put cancer into perspective: Referencing the American Cancer Society's publication, *Cancer Facts & Figures 2003*, approximately 40% of Americans will be diagnosed with an invasive form of cancer in their lifetime. 565,500 Americans are expected to die of cancer this year; this is more than 1,500 people per day. Put another way, every two days we lose as many

people to cancer as we lost in the terrorist attack on the World Trade Center: 9-11. Part of what I ask you to consider today is, given this situation are we and are you responding appropriately?

Cancer is an uncaring, unfeeling enemy. It has no intelligence, but it does have a set of instructions: Grow without control, invade nearby tissue, spread throughout the body of the host. These instructions continue until the cancer kills its host or the cancer itself is killed. Cancer can cause extreme pain, the level of pain that only the strongest pain medications we have can control. While some new cancer treatments are evolving, the big three remain the norm: 1) Surgery; 2) Radiation; 3) Chemotherapy. Or, as some of us cancer survivors refer to them as: 1) Slash; 2) Burn; 3) Poison. Because that is what we experience. Safer, more humane and effective treatments will only become available after research has been performed on human beings – the clinical trial.

Why would a person consider a clinical trial?

- 1) A clinical trial may be a person's only treatment option. Because there is no known effective treatment for their cancer. A trial may be offering the opportunity for a break-through and offer hope for the person with cancer. This is my situation.
- 2) Standard treatment that may have been working for a person at one time can become ineffective with use. That is, the cancer has developed immunity. Using the medical term, it has become refractory.
- 3) The cancer survivor wants to make a contribution.

Better cancer treatments come through *treatment trials*. Finding ways to prevent cancers in the first place, or keep them from returning after treatment, come through *prevention trials*.

Screening trials enable us to find ways to detect cancer early, when it is most vulnerable.

Cancer is perhaps the most feared medical diagnosis a person can receive. The question today is, can you as elected public office-holders at the state level do anything about it? You can. Pass AB502.

Opposition to this bill most probably involves concepts of finance and fairness. I have lived with cancer for over five years. I have counseled people with cancer. I can tell you that there is absolutely nothing fair about this disease. According to the National Cancer Institute, "Cancer clinical trials have brought enormous advances in the areas of cancer prevention, treatment and diagnosis. However, less than 5 percent of adults diagnosed with cancer each year will get treated through enrollment in a clinical trial."¹ The financial burden placed on the potential clinical trial participant is a significant disincentive. The only practical way that I can see to bring new, more effective and safer cancer treatments to our citizens more quickly is for all of us, including insurance companies and their policy-holders, to share the load.

I am now hoping to take part in a my second clinical trial. It is taking place at the University of California, San Francisco. It is designed for people with blood cancers who have undergone treatments that have failed. It involves a stem cell transplant from an unrelated adult donor. If the approach proves to be effective it will be a significant break-through for people with certain blood cancers that have not responded to other forms of treatment.

There is a financial gate-keeper that is increasingly cutting the middle class off from clinical trials. It is impeding cancer research. Many people think that clinical trials are done at no cost to the participant. This is not true. While the treatment or procedure being tested in most cases is paid for by the trial's sponsor, supportive and prophylactic medications, testing and procedures often are not. If the costs of these things are not covered by the trial protocol and an individual has no means of paying for them, effectively they are screened out from a clinical trial.

The justification or rationalization for clinical trials includes the idea that they benefit the whole of society. And in fact they do – the trials that fail as well as the ones that succeed. The trial that I hope to participate in has a foundation in the knowledge gained from previous clinical trials that have both failed and succeeded using human test participants. My odds of surviving a transplant procedure have been significantly increased because of knowledge gained from past transplant trials of various kinds. We should be doing everything that we can to encourage people to participate in clinical trials for cancer as they are the final step in bringing safer and more effective cancer treatments into the mainstream. Short-sighted financial gate-keeping is an impediment to this process.

I urge you to vote in support of AB502.

¹ <http://www.nci.nih.gov/clinicaltrials/digestpage/boosting-trial-participation>