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Statement of Annette and Harvey Whittemore  
in Support of SB 105  
May 23, 2005

Good morning Chairman Raggio and distinguished members of the Finance committee. For the record, I am Harvey Whittemore and I am appearing on behalf of the Whittemore Family Foundation. Because of a family medical emergency, my wife, Annette, is in Seattle this morning with her sister, Connie. I am substituting for her.

By the way, after Annette successfully finished her most recent trip to Washington, D.C., I was advised by Senators Reid and Ensign that maybe she should be permanently substituting for me in the political arena.

Annette is also an expert in this very technical medical arena, and I know she would have done a better job explaining all of this to you.

First, Annette and I would like to sincerely thank each of you for your time and commitment to this legislative process. We truly appreciate the hard work and many hours of service that you give for the benefit of all Nevadans.

Second, Annette and I wholeheartedly support SB 105 and its appropriation for a new medical building and facility on the campus of the School of Medicine at the University of Nevada, Reno.

I would like to provide a little personal background to help you understand our reasons for this endorsement and the level of proposed financial support and involvement.

Our daughter Andrea suffers from a disease currently called Chronic Fatigue Syndrome or CFS. Since 2002 we have been extremely fortunate to witness vast improvements in Andrea's level of health. This is due in great part to her extraordinary doctor, Dr. Daniel Peterson of Incline Village, who understands immune dysfunction diseases and how to treat them with the use of appropriate immune modulators and anti-virals. This treatment protocol is based on the newest scientific knowledge of chronic viral illnesses of the central nervous system.

While Andrea's immune system is still very fragile, she is no longer bedridden or in need of constant care. To date, this type of care is the only long term treatment available to patients with her kind of immune dysfunction.

Andrea's medical treatment includes the use of an experimental intravenous drug called Ampligen two times a week. It is like chemotherapy which never ends. That is the bad news. The good news is that the medication has allowed her enough stamina and good health to complete a two-year program of study, thus giving her a chance to help others with chronic illnesses, while also helping her to create a self-sufficient lifestyle.

Although Andrea is doing better, thousands of Nevadans and hundreds of thousands of Americans like her are not.

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Patients with similar symptoms such as neuro-cognitive problems, sleep disorders, chronic low grade fevers, gastrointestinal disorders, chronic sore throats, severe exercise intolerance and drug hyper-sensitivities, continue to suffer through the experience of twenty to fifty different doctor's visits, only to be told that the doctors have no idea as to appropriate treatment.

Incredibly, some patients are told to get more rest while others are told to try counseling or practice pain management skills. When one has a disease with such serious and life altering symptoms it is devastating to be told "there is no treatment."

Many experts believe that is no longer the case, and we agree with them. Today there are treatments from immune modulators to anti-virals that offer real relief *if* the patient is appropriately diagnosed. Our daughter is proof. But many of these treatments are experimental and require patients to travel long distances, and many are required to pay huge sums of money from their own pockets for the special care that only a few doctors in the United States are capable of delivering.

This leaves those without the ability to pay, sick and without hope.

The idea of a medical center, where patients can go to be accurately diagnosed and treated has been taking shape for years. After seeing thousands of patients and hearing their stories of mistreatment and mismanagement, Dr. Peterson and Dr. Dedra Buchwald of the University of Washington, invited us to help them begin this process several years ago. Just last year, Dr. David Bell of the national CFS advisory committee also made a request of the

Secretary of Health to help create these centers of excellence. To this date that call has gone unheeded by many.

Due to many recent positive events that have occurred in our lives and a continued recognition of the urgent sense of need, Annette and I now feel we can contribute substantial dollars to a project of this magnitude. This project will involve so many favorable components, including treatment from doctors such as Drs. Peterson and Buchwald, that we could not say no when we were asked to help.

Now with your help and the help of the University, we can make a real change for thousands of Nevadans. We discussed this public/ private partnership with Governor Guinn and first lady Dema Guinn, Chancellor Rogers, the regents, University of Nevada, Reno President, Dr. John Lilly, the dean of the medical school, Dr. John McDonald, and many legislators. All have listened with hopeful enthusiasm, while encouraging us to continue this quest.

One of the users of the new proposed Center will be research laboratories. Annette and I have financially supported a new relationship with a research laboratory from Belgium which is now located and operational on the University of Nevada's Stead Campus. This entity would move to the new facility when construction of the Center is finished. This laboratory, known as RED Labs has developed proprietary tests that help to diagnose CFS as well as other diseases. Its founder is Dr. Kenny DeMeirleir, a world-renowned physician and researcher who has agreed to spend whatever time it takes to create the research

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facilities at the University to further a cure for these chronic human illnesses. He knows that the best research will be multi disciplinary, involving experts from multiple areas of experience to derive the most complete picture of causative agents and methods of detection. Thus RED Labs, has already begun the work of studying viruses of the central nervous system such as HHV-6A, a virus with high clinical association to both CFS and Multiple Sclerosis.

The HHV-6 Foundation, a Nevada-based organization, started and co-chaired by Annette and her friend Kristin Loomis from Santa Barbara, and its board of scientists from all over the world, have begun the difficult task of developing a new and more sensitive blood test to detect active HHV-6 viremia.

Their efforts have already taken them to Japan where the results of the Foundation's studies were delivered to an international community of uncommonly gifted and committed researchers at the International Conference on Fatigue Science this past February. After meeting in Washington, D.C. this past month, the HHV-6 Scientific Advisory Board ("SAB") will hold its next international conference in Barcelona in April 2006 under the direction of Dharam Ablashi, the Foundation's scientific director and a co-discoverer of the virus. Dr. Ablashi was coaxed by Kristin and Annette into a more active role with the Foundation after serving as a coordinator of DNA Virus Studies at the National Cancer Institute and as the Director of Herpesvirus Programs at Advanced Biotechnologies.

Each of the members of the SAB hopes that they will be able to

determine the true rate of this virus in various disease states of the brain such as CFS, MS, autism, epilepsy, and even Alzheimers.

As this important and extraordinary work continues, the Foundation is simultaneously supporting a series of in vitro or test tube tests with antiviral compounds to help uncover novel treatments.

The Foundation as a private, charitable nonprofit enterprise, is committed to find ways to stop the devastating effects of HHV-6A and B. It too will have an office in the Center to help organize and support clinical research on the University's campus from its own grants as well as grants from the federal government, individuals, and other private foundations. This research will speed the process of delivery of new treatments to the patients of the Center while continuing to support and encourage other researchers to do the same at other affiliated locations.

I hope that you can see, as we do, that so many pieces of the puzzle are falling into place at this particular time and in this wonderful state. It only seems natural that we would want to lead these efforts and to share this knowledge with the rest of the world. We will, therefore, encourage the Medical School to allow students attending the University's Medical School who would be experiencing rotations in the many different medical specialties, to include a rotation at the Center, thus giving them new training and an opportunity to meet, discuss, and learn from the many internationally recognized scientists who will be sharing their science and life skills at the Center. I have included a brochure from the HHV-6 Foundation with a list of the scientists and their

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office locations for your review.

Annette and I have many people to thank, including the people with me at the table today. They include the people who day in and day out support us and their loved ones suffering from diseases with no cures.

We also commend the vision of Governor Guinn and his staff for recommending such an important new medical building and facility, Jim and Heather Murren and the rest of the leadership of the Nevada Cancer Institute, and all of the others in support of SB 105 here today. A comprehensive research and clinical medical facility at the University is needed, and it is needed now to extend the hopes, dreams, and lives of your friends and constituents. A partnership between the University of Nevada, Reno, the Nevada Cancer Institute, and the Center of Excellence can become an example for world leadership in clinical care and will foster significant cutting edge research similar to the Mayo Clinic and the Dana-Farber Cancer Institute.

In summary, we have a unique opportunity to provide excellent medical care to many more Nevadans and to impact citizens from around the world with new and innovative solutions to cancer, CFS and other serious chronic illnesses.

It takes financial commitment, it takes vision and of course it takes hard work. We are willing to do our part.

We have pledged two million dollars more to this effort, we will raise another two million dollars, and we will continue to provide

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ongoing operational support as needed. We encourage the state of Nevada to adopt and advance this plan and give renewed hope to thousands of Nevadans by supporting Governor Guinn's request for this new facility at the medical school.

Thank you.

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