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Testimony by Robert Miller

Assembly Health & Human Services Committee

April 9, 2003

Good afternoon, Chairman and members of the committee. My name is Robert Miller and I am here today to support Assembly Bill 502. Let me first take the opportunity to say thank you to all the military and their families serving our country at this time.

I am one of 6 siblings in my family, and I support this bill based on my family's history of disease and involvement in clinical trials. Over 40 years ago, my younger twin sisters who were born with Wilm's tumors (a type of kidney cancer) were treated at Sloan Kettering Hospital with what was at the time experimental treatments of radiation and chemo. They each lost one kidney, which were removed with the tumors, and then they were given early forms of radiation and chemo-type therapy. My parents were presented with a choice to allow doctors to use an experimental treatment which could possibly harm them further, or it could help give them a few years of life. Without that treatment, they would not have lived for more than a few months.

My parents made a tough decision to allow Sloan Kettering to use my sisters in their medical trials. At that time, Sloan Kettering shouldered the costs of the treatments. There were 48 children with the same type of cancer at the hospital then, and I'm sorry to say that my sisters were the only two children to survive. My sisters never led a normal life, but because of Sloan's dedication to medicine and my parents' willingness to participate,

they did have life. Debbie lived to be 30 years old, before succumbing to a life on dialysis, and Diane lived to be 40 years old, before dying from another type of kidney cancer.

More recently, my eldest brother has been getting experimental treatments for the last 6 years, to treat his terminal cancer in Florida. Not only has he benefited from radiation treatments that are now far more refined than when my sisters were young, but he has been given a combination of cutting edge chemotherapy drugs which have given him years more to live than his doctors predicted upon diagnosis. The cancer is still there, but my brother and his doctors continue to battle on, trying new treatments as technology and medicine move ahead. Some of the costs of his treatment are being absorbed by the hospital, and some by the state of Florida. He will never be out of medical debt, even though he is participating in experimental trials that will help future patients as well as himself.

Lastly, I am currently participating in a clinical trial. I have had Chronic Fatigue and Immune Dysfunction Syndrome since the 1980's. The illness had me bedridden and unable to work for most of the 90s. It weakens my immune system, and makes me even more susceptible to things like cancer on top of my family history. Before getting sick, I was a leader in my profession and an avid exerciser. There are no approved medications that treat this illness, and only one medication that is being tested in an FDA approved clinical trial. That drug is called Ampligen. Dr. Peterson, my doctor, enrolled me in a double-blinded, placebo controlled clinical trial of Ampligen, in which the company testing the drug paid the costs. The point of a placebo controlled trial is that half the patients get a sugar pill to truly

test effectiveness. So, at the end of the trial, the company gave all participants 6 months of Ampligen. In those last 6 months, I responded to the drug. I saw a glimpse of my old life and health. I was stronger, had more energy and began to dream again.

When that trial ended, I had a choice. I could stay on the medication, but I would have to pay for it myself, under the FDA's cost recovery program, which allows companies testing treatments to recover their costs. The cost of twice-weekly infusions, the medication, and the testing ranges from $20-30,000 a year. This is the only treatment available, so I really have no choice.

I have been on Ampligen for 3 years now, and am able to do some of the day to day activities that most people take for granted. I have twin boys that will soon be 3, and while I am very grateful that I am one of only 100 people who can access this treatment, I am torn that I have taken away from my boys' financial future. I have attached a copy of a petition that was submitted to Congress ← the FDA last year signed by all of the patients on Ampligen in Nevada. These participants are all paying for their treatments, and some have stopped due to the lack of funds.

In closing, I wish to say that without all those who participate in clinical trials, advances in medical treatments would come to a halt. We will all be touched by the benefit of medical advancements some time in our lives. For those that can participate, clinical trials are often a link to life that otherwise would not be there. But the financial costs are considerable, sometimes financially devastating, and that's why I think it is imperative

that you approve AB502 and set an important example for others to follow. Insurance companies are an important part of paying for medical treatments, and I believe that progress in treating illnesses ultimately benefits insurance companies as well, as we learn to treat illness more cost effectively. But I also think it is most important to tell everyone that the person or patient's life is more important than the money it takes to make him well.

Petition To Fast Track Ampligen for CFIDS Patients Now

We the undersigned, request that you as one of Nevada's state representatives examine why Ampligen, the only drug in advanced clinical trials for the treatment of Chronic Fatigue Immune Dysfunction Syndrome {CFIDS / CFS }has not been given Fast Track status. Only a handful of patients can be treated now under limited compassionate care status. There are thousands of the illest CFIDS patients who should have access to this drug without having to wait for full FDA approval.As participants in the drug trial, Ampligen has had a positive impact on each of our lives to varying degrees. Some of us have been able to leave our beds for the first time in years while others can do some normal things again, such as walking outside, cooking a meal, holding our children or just being able to focus and read a book and recall the story. After learning that the CDC misdirected millions in research funds away from CFIDS, we want to be reassured that the FDA is treating CFIDS as a serious medical condition for which there is only one treatment in advanced trials. That is the purpose of Fast Track status, and we urge you to determine why Ampligen has not been given Fast Track status.

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