

Interview with Rep. Diane Primavera, Sponsor of House Bill 09-1059, Clinical Trials Bill



Diane Primavera is a second-term Colorado state representative (District 33, Broomfield). She is a committed supporter of legislation that benefits cancer patients and increases access to health care and for that track record she will be honored on February 17th by the Colorado Community Health Network as Legislator Community Health Champion Award for 2009. Recently, she initiated bill 09-1059 — the clinical trials bill — which is described on the front

page of this issue of *Focus on the Search*. Judy Gordon, *Focus on the Search* editor, visited with Rep. Primavera.

How did this clinical trials bill come about?

Last summer (2008), I was approached by the Rocky Mountain MS Center. The Center was concerned that patients were reluctant to participate in clinical trials. The reason patients were reluctant was because insurance coverage was inconsistent for clinical trial participants—some participants had their basic coverage dropped. So the MS Society asked me to develop a bill that would make insurance coverage more consistent for clinical trial participants. I agreed and soon thereafter the American Cancer Society became involved as did the Chronic Care Collaborative (Alzheimer's Association, Colorado Chapter, American Cancer Society, American Heart Association, American Lung Association of Colorado, Arthritis Foundation Rocky Mountain Chapter, Brain Injury Association, Colorado AIDS Project, Colorado Gerontological Society, Crohn's and Colitis, Easter Seals Colorado, Epilepsy Foundation of Colorado, Hepatitis C Connection, Huega Center for MS, Huntington's Disease, Lupus Foundation of Colorado, March of Dimes, Colorado Chapter, Mental Health America of Colorado, Muscular Dystrophy Association, National Kidney Foundation, National MS Society, Colorado Chapter, Parkinson Association of the Rockies, The Persons Living with HIV/AIDS Initiative of Colorado, Rocky Mountain MS Center).

Colorado's advocacy groups have been great to work with.

What's exciting about this Colorado bill is that it will cover clinical trials not only for cancer but for other progressive life-threatening conditions such as AIDS and MS. About half of the states in the country have laws covering cancer clinical trials, but Colorado's bill will be one-of-a-kind in its expansion of coverage to trials besides those for cancer.

I am pleased that this is cutting edge. It will positively impact so many people in so many ways.

Do you think passage of this bill will increase participation in clinical trials?

I definitely think it will increase participation in clinical trials. There are a variety of criteria for participation in clinical trials, which creates a limited

pool of potential participants. If we can eliminate barriers to participating that don't have anything to do with criteria, then we will be able to get more people enrolled. One of those barriers has been fear of losing insurance coverage.

I had an experience with clinical trials 20 years ago. I was diagnosed with an aggressive form of breast cancer and was told that I had no longer than five years to live. I had previously been very healthy. At the time, my two children were ages 3 and 5, and I was devastated to imagine that I would not be there to raise them. I was a mess and desperate to find a way to stay alive. I had a mastectomy, chemotherapy, and radiation and then I tried a lot of other treatments including acupuncture, tea, healing touch, vitamins, and more. Finally, after lots of desperate searching I connected with Dr. Bill Robinson at the University of Colorado hospitals. He enrolled me in a clinical trial. It was one of the early trials with Tamoxifen, which is now a recommended protocol for certain breast cancer patients.

As a clinical trial participant, I felt so much better being in a controlled setting with a hope for a cure! But even if I might not be cured myself, it gave me hope that by participating in the clinical trial I would do good for others. And here I am 20 years later, alive and healthy, despite other cancer experiences, too (cervical and basal cell). (From an earlier interview, Rep. Primavera said, "I probably wouldn't be here if it weren't for a clinical trial.")

I understand that you were also responsible for initiating the Colorado Breast and Women's Reproductive Cancers Fund Income Tax Check Off. Can you tell us about that?

Again it was the advocacy community that brought this to my attention. I did some research and realized it would be an excellent way to generate dollars. Often these check offs generate \$200,000 in their first few years. I also initiated the adult stem cell income tax check off.

I will also be working on a revised breast cancer license plate bill. It is the most popular theme license plate with 26,000 plates sold. Unfortunately, the bill was not written to actually generate research dollars. The Denver Affiliate of Susan G. Komen for the Cure has asked me to sponsor a revision to the bill so that dollars generated can be designated for research.

How can *Focus on the Search* readers help move the clinical trials bill forward?

The bill passed the House Committee on Health and Human Services on February 2nd. It will be discussed in the full House of Representatives and then it will go to the Senate committee and then on to the full Senate, and finally to the Governor. Readers can contact their representatives and senators and the Governor to indicate their support, and they can encourage others to do the same. This URL will get readers to directories for all those elected officials www.leg.state.co.us.