

Don C. Reed's Public Testimony for the Little Hoover Commission Hearing on the California Institute for Regenerative Medicine

November 13, 2008

Dear Executive Director Stuart Drown and Board Members.

As the father of a paralyzed young man, Roman Reed, I have been involved in the search for regenerative medicine and cure ever since my son's accident on a college football field, September 10<sup>th</sup>, 1994. His neck was broken, and he was paralyzed from the shoulders down. The doctors gave us no hope, saying our son would never walk again, never close his fingers, never father a child, and that he would live a shortened life.

But also at the hospital that terrible night, my son was given a steroid, methylprednisolone, developed by a scientist, Dr. Wise Young, later to be appointed one of the grant reviewers for the California Institute for Regenerative Medicine.

In the hospital we heard about a clinical trials going on at Santa Clara Valley Medical Center for a regenerative medicine called Sygen, a ganglioside, GM-1, made from dried-up cow brains. We tried for admission into the program, but were told we missed the cutoff time by one hour. I was able to locate the inventor of the medicine, Dr. Fred Geisler. Working with the FDA with the help of Senator Pete Stark, I found a loophole, compassionate use, and was able to legally obtain Sygen from Switzerland,.

Going deep in debt, we put Roman through seven months of therapy, with daily injections of Sygen. Whether the Sygen helped or not, I will never know, but Roman regained the use of his triceps, allowing him to transfer from bed to wheelchair, and to obtain a measure of independence by driving. He is the father of two sons, is the commissioner of health and recreation for the City of Fremont, and is going forward with his life. But he is still paralyzed.

Naturally, I support legislation for regenerative medicine. I worked with Senator Deborah Ortiz on her laws to legalize embryonic stem cell research in California.

California passed a law named after my son, the Roman Reed Spinal Cord Injury Research Act, which funded the first use of the Bush-approved embryonic stem cell lines. That experiment, Dr. Hans Keirstead's effort to remyelinate damaged oligodendrocytes in the newly-injured spine, is now under consideration by the FDA for human trials.

I served on the board of directors for the campaign to pass Proposition 71, the Stem Cells for Research and Cures Initiative, which led to the establishment of the California Institute for Regenerative Medicine (CIRM).

I am Vice President for Public Policy for the Americans for Cures Foundation, which sprang from that effort, and I receive a stipend for my work to support stem cell research.

I attend as many meetings of the Independent Citizens Oversight Committee as I can, about 90 percent of more than 100 meetings. I speak there as an individual, as I do now.

I opposed Senate Bill 1565 (Kuehl, Runner) which asked the Little Hoover Commission to consider modification of California's stem cell program.

SB 1565 is gone, vetoed by the Governor, but the Little Hoover Commission (LHC) is going ahead anyway. You are going to study the ICOC, and see if you can come up with ways to eliminate "conflicts of interest, real or perceived", as Senator Sheila Kuehl, sponsor of SB 1565, said at one of her hearings on the bill. (emphasis added) The LHC may suggest ways to "improve" the ICOC, and design a law to enforce those decisions.

Conflicts of interest, of course, everyone is against. It would be wrong for a board member to use his or her decision-making power to advance their organization.

The ICOC has careful laws to prevent that.

But "perceived" means a matter of opinion. If we try to eliminate every "conflict of interest, real or perceived", the cure may be worse than the imagined disease.

As you know, the California stem cell program is run by a 29-member Independent Citizens Oversight Committee (ICOC). Members of that board were chosen by the Governor, Lieutenant Governor, Senate President Pro Tem, and other elected officials.

Each board member was selected as an expert in his or her field: deans of colleges, a Nobel Prize Laureate, patient advocate champions, heads of biomedical companies, and more. Because they arrive on the job fully-informed, with a depth of knowledge, they can make decisions based on many years of experience.

But, and this is precisely because they are experts, it is easy to say, hey, there is a conflict of interest, or at least the appearance of one, in every decision they make.

If we disqualified every board member who might indirectly benefit—and therefore have a "perceived" conflict of interest—I doubt we could find anybody eligible.

Stem cell research potentially benefits everybody on earth. People who pay medical would be glad if cure research reduced their expenses. If they were board members, a case could be made that they have at least the perception of conflict of interest.

What would it take to remove even the perception of conflict of interest?

We could try getting rid of the patient advocates—people like Joan Samuelson, founder of the Parkinson’s Action Network-- and replacing them with ideologues, people who may know nothing about stem cell research, or even oppose it. This was the Bush Administration’s approach: because his Bioethics Commission was stacked with critics, it was an obstruction to stem cell research, instead of a help.

Or, the Commission could be run directly by politicians.

Would it be wise to give politicians direct control of our stem cell research money-- with the current financial crisis in Sacramento? Might they not be tempted to divert our funding to other useful purposes?

I have seen this happen. At least two state research programs were gutted of their funds. New York and Maryland had spinal cord injury research programs, one for eight million annually, the other for a million a year. Both programs had their research money sidetracked to the general fund. Today, both programs are back in action, but for years, their money was denied them, and to the best of my knowledge, it was never paid back. It was spent elsewhere, instead of on research trying to find cures for paralyzed people, like my son. That may have delayed the day when Roman “stands up from (his) wheelchair, and walks away from it forever,” in the words of the late Christopher Reeve.

We want no such delays. Under the present leadership structure the money is going exactly where it was intended (and legally required) to go: to advance stem cell research.

The California stem cell program is something shining, to be treasured and protected.

I’ve seen the ICOC in action, many times: they do an outstanding job. They are not a conflict of interest, but a conference of expertise.

Example: the budget for facilities (labs and building construction) was \$272 million. But the board figured how to increasing that money: by requiring matching funds. Any organization that wanted a grant had to come up with extra dollars on its own, and bring that to the table. This instance of expertise got California an extra \$800 million, leverage \$272 million into \$1.15 billion dollars in buying power.

How many government programs bring in extra money like that?

Like the California Institute for Regenerative Medicine, the Little Hoover Commission has a noble mission: the LHC exists to make sure California gets the best possible use of every taxpayer nickel.

Hopefully the Commission will approach its task with an open mind. If so, you may find you agree with the other four investigations and audits of our program, all of which found the California Institute for Regenerative Medicine to be an efficient and well-run institution, doing exactly what the people of California elected it to do.

But looking at the agenda of the November 20<sup>th</sup> meeting, I see that the only two speakers representing the “Consumer Perspective” are John Simpson of Consumer Watchdog, and Jesse Reynolds of the Center for Genetics and Society.

Jesse Reynolds and John Simpson are probably the two harshest critics of our stem cell program, speaking against it again and again. If there is anything negative to be said about our program, one or both of them will almost certainly be quoted.

It is their right to speak, and to be heard; their voices are part of the democratic process.

But I object to the choice of two critics as representing the entire consumer population of California. It is my understanding both men are paid lobbyists. (There is nothing wrong with that; they could make a similar comment about me. As mentioned earlier, I work for a group called Americans for Cures Foundation, which supports stem cell research, and receive a stipend from that organization.) But to choose such vocal critics without a balance is to ignore the 59.2% of California which voted in favor of Proposition 71.

Not one patient advocate is scheduled to be heard. Does this reflect an imbalance in the considerations of the Little Hoover Commission?

As you recall, I called up and asked to speak, and was told that there would be room for public comment at the end of the program. I also requested to speak at the next meeting, (there will be at least two) and have not heard back if this will be permitted.

Conflict of interest is something very easy to attest, and very difficult to know for sure.

For instance, the Sacramento Bee has systematically and enthusiastically opposed the California stem cell program, writing literally scores of editorials against it . It is my understanding, Director Drown, that you were an editor of that paper. Is that not at least a perception of conflict of interest?

Additionally, at least one member of the LHC board is a Republican, a party whose official platform calls for criminalization of embryonic stem cell research—is that a conflict of interest, as he/she considers the structure of an organization dedicated to the enhancement of that research?

It is in no way my intent to cast aspersions on the honor and dignity of the Little Hoover Commission, nor any individuals involved: but merely to point out that the perception of conflict of interest can be found everywhere, even here.

As you consider the future of the California stem cell program, which embodies the hopes and dreams of millions of suffering men, women, and children, here and around the world, please remember that there are no perfect structures on this earth. Consider the substance of what is, not the shadows of what might be perceived.

Use your powers carefully.

Thank you,

Don C. Reed

Sponsor, Roman Reed Spinal Cord Injury Research Act  
Founder and Co-Chair, Californians for Cures

*Don Reed is also Vice President of Public Policy for Americans for Cures  
Foundation; opinions voiced here as an individual may or may not reflect those of the  
Foundation.*