

Science for People

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In 1995, shortly after he was injured and came to New Jersey for rehabilitation, Christopher Reeve asked me if treatments that restore function to people with spinal cord injury were possible. I hesitated and replied yes, saying that scientists believe that the spinal cord can be regenerated and remyelinated, that we don't have to grow and restore more than 10% of the axons to have substantial recovery and several therapies are ready for clinical trials. So Christopher immediately asked the question, how long would it take? Again, I hesitated and said that, if we are lucky (because all scientific success involves luck), we worked hard, and we had the resources, it would take at least seven years. Christopher said, let's make that our goal. He subsequently went on "20/20" and "CBS 48 Hours," and said that it was his goal to cure spinal cord injury in seven years.

Why did I hesitate? Cure is not something that comes to the lips of a scientist without hesitation. We are trained to be conservative and cure is definitely not a conservative word. In fact, it was a word that I was reluctant to use, a word that I went to great lengths to avoid, for fear that it may give false hope, for fear that we would not be able to deliver. The time frame for the cure was also something that gave me the heebie-jeebies. How did I know how long it would take? There are too many variables and we scientists think in terms of three to five year grant periods and specific aims. We have been trained by NIH peer-review not to say what other scientists would question as being feasible. My conversation with Christopher Reeve was the beginning of a transformation for me.

In October, 2004, the night that Christopher Reeve died, I couldn't sleep and wrote a eulogy for him that began, "Christopher taught me how to use two four-letter words: hope and cure." Regarding cure, Christopher asked, why should we aim low? If we aim at all, why not aim at our real goal? These two words were frightening because they represent a commitment. Christopher later talked about this, using the example of John Kennedy and his commitment of the nation to the goal of reaching the moon in the early 1960's. Was it so crazy to set a goal and dedicate oneself to reaching it? If we don't set a goal, we will never reach it. Worse, if we convince ourselves that we may not be able to reach it, we will not reach it. It is better to have tried and failed than not to have tried at all. We should not be afraid of failure. We should be much more afraid of not having tried, of not working hard, and of giving up before we even start.

Those lessons from Christopher not only transformed my science but also expanded my field of endeavor. For nearly 20 years, I labored under the impression that my job was science, that what I had to do was to deliver the science and that somebody would take over from there and bring it to the people. This of course, as we all know, is wishful thinking. If we do not bring our science to the people, who will? That was the insight that Christopher gave me. We cannot be successful if we limit ourselves to the lab. We have to engage in the politics needed to bring our ideas to fruition. Nobody else can do it. If we are playing to win, we must get involved and solve all the problems. It is not enough to have an idea, get the data and sit back while the ideas languish in a journal somewhere, never reaching the people for whom the ideas were intended. To do that would be the ultimate loss. If we are not willing to go all the way, why do it at all?

Scientists are trained to do science for other scientists. From the beginning, as students, we are trained to please our professors. As graduate students, we work to gain the praise of our mentors. As postdoctoral fellows, we work to get our papers published in journals reviewed by scientists. As young professors, we work to achieve the approval of our grants by other scientists. As senior scientists, we work to gain the approval of our peers and judge our performance against the history of science and other scientists' accomplishments. Because of this life-long training, we don't know how to do science for the people. Science for the people? That idea was so foreign to me at the time that I could not even conceive of how to do it. But, isn't that the real goal of science, to benefit people? They are our real constituents, are they not? After all, they are the ones who are paying for the science, for us to pursue the ideas, for us to buy the equipment and supplies, for us to work on their behalf.

In the past several decades, a frightening trend has appeared in public perception of science and scientists. In the 1960's and even the 1970's, we were the "good guys." Nerdy maybe, absent-minded, definitely, but "bad guys?" No. People trusted us to tell the truth. Perhaps the first sign of the fall of science came with the debate on recombinant DNA in the early 1980's. For the first time in the history of science, people said openly what was in the backs of their minds: perhaps scientists are not to be trusted. Perhaps it is a sign of our isolation from the people that we probably did not even realize this was happening until it slapped us in the face, when animal liberation activists vilified us, when every movie that we went to portrayed scientists as villains, when the movement against stem cell research grew to the point that NIH was forced to stop funding or prevented from funding stem cell research.

As scientists, we have not helped reverse the vilification of science. Many of us have engaged in profiteering from our science, starting companies, even leading companies whose intent is to make money from people. Several years ago, no, it was in 1996, there was a movie about a scientist who was kidnapping homeless vagrants from the streets of New York, cutting their spinal cords, and re-growing them, in a place that looked remarkably like Bellevue Hospital. In fact, it was filmed partly at Bellevue Hospital where I was heading the neurosurgery laboratory. More recently, there was another movie, the "Constant Gardener," about a company that was doing unethical clinical trials in Africa, testing dangerous AIDS drugs, killing people, falsifying data, and trying to

profit from ill-begotten data. Heck, why go to movies and fiction. Four months ago, the world was treated to a real-life spectacle of a world-renowned scientist Woo-suk Huang, who claimed to have cloned 11 embryonic stem cell lines, nine of which came from people with spinal cord injury. In 2005 I had lunch with Woo-suk, attended by three people in wheelchairs. He looked them in the eyes, and told them that he was going to cure them. I will not forgive him because he did that knowing that his data was false.

We have lost the trust of the people. That is clear. We don't need to go to the movie or watch the news to know this. As many of you may know, I run a website for the spinal cord injury community called CareCure.org. where thousands of people come everyday to find out the latest in care and cure. A major recurring topic on these websites is the conspiracy theory that scientists already have the cure for spinal cord injury and that we are holding back on the cure so that pharmaceutical companies can continue to make money from the dying and disabled. Every time a news item announces a promising therapy for spinal cord injury, the conspiracy talk subsides. But, it always crops up its ugly head when there is any slackening of the news. Woo-suk Huang has not helped. This going to get worse, not better.

What can we do? The one thing that we cannot do and should not do is duck. Of that, I am convinced. Our tendency in academia is to retreat, to hide in our ivory tower, and to pretend that this situation does not exist. We can no longer hide in our laboratories. The loss of trust in scientists is a challenge to the core of who we are and what we do. The future of science depends on our restoration of public trust in who we are and what we do. It is little surprise that there is little or wavering public support for biomedical research at NIH. Should we be surprised by the inability of Congress to over-ride the actions of a president who has restricted what most scientists believe is the most promising advance in biology, stem cells, since the discovery that DNA is the basis of our genes. Should we be retreating to our laboratories while members of Congress hold hearings proclaiming that adult stem cells are curing hundreds of diseases and that we don't need to do embryonic stem cell research? Should we be ducking and remaining silent when school boards around the nation are deciding that evolution is an unproven theory and that intelligent design should be taught alongside Darwin?

Many of us are speaking out but I believe too half-heartedly. More important, we are not doing enough to restore trust, public trust in science and scientists. In the end, if we don't speak out, who will? Should we let the politicians speak for us? Should we not be speaking for ourselves? Unfortunately, we are often not heard. In my opinion, we are not getting traction because we are no longer trusted. Without that trust, we have become just a crowd of hucksters, each one less trustworthy than the next. Our message, whatever it is, is lost in the din of infomercials that occupy our airwaves and internet and that nobody listens to or looks at anymore. After all, public relations is an equal opportunity beast, willing to work both sides of the fence.

So what should our message be? I propose that this message be **SCIENCE IS FOR PEOPLE**. We should not only give this message, but practice what we preach. Otherwise, we will never re-gain the trust of the people. They have to believe the

scientists are working for them or else they will not, indeed cannot, support us. If science is for people then people will be for science. For too long, we have labored under the impression that we do science only for other scientists, taught our students this, and have failed to address our real constituents, the people who pay for our science and who benefit from our science. To be sure, there is some merit to the argument that there is science for profit and science for science sake and that we cannot pull the wool over people's eyes. They are too smart for that. But that is why we must not only preach it. We must practice what we preach. I submit that if we do not do so, at least in academic science, we should kiss public support of science goodbye and we will condemn future generations of scientists to science for profit only, because only scientists support science for science sake.

How should we deliver this message? Marshall McLuhan said in the 1960's, "The medium is the message." We should heed his words because they are more true today than he could have imagined. Companies spend billions of dollars advertising but we all know, because we ourselves do it, that people just tune out the ads. In fact, the most effective ads are those that don't claim anything overtly but attract attention to the brand. Likewise, the trend on the Internet is away from company sites that look slick and like they are advertising. People are more likely to read and trust other people, rather than ads. That is why blogs and interactive forums are much more effective than ads, or even news articles. News articles have become like blogs.

In short, the only way that we can deliver the message to the people is through direct interaction with the people. In the world of Internet, this has become far more efficient than in Marshall McLuhan's time. Every day, I talk to thousands of people through the Internet. This is more efficient than giving public lectures, giving interviews to reporters, and even going on television, although we must do all of these as well. Direct interactions are important for one other reason. As scientists, we must learn how to talk to our constituents, understand what they need and want, and become one of them. We must step out of our ivory towers. We must not be complacent about this interaction and relegate it to a few scientists. We must not only practice it and become good at it but we must teach our students how to do it because they have to deliver the message, too.

At the W.M. Keck Center for Collaborative Neuroscience, we have developed several programs that have been very effective, in my opinion, and deliver a lot of bang for the buck. First, as I have already mentioned, we have a web site called CareCure.org. This website is an interactive forum, visited by thousands of people every day. Since 2001, I have posted over 25,000 articles or posts in response to questions from people and families with spinal cord injury. The site has accumulated over 500,000 posts in the past five years and is accelerating at the rate of 500 posts per day by over 12,000 members. A team of about 32 community members help moderate and guide the discussion, welcome newbies, and offer their insights to the community. Second, we hold an "Open House" in the Center on the first Friday of every month. As many as 30 families come to hear about the latest in research. They tour the laboratory with our students as their guides. Over 5,000 people have come to visit us in the past five years, many of them coming over and over again, to "re-fuel" as one said.

Third, I give up to 500 lectures per year to people interested in spinal cord injury research and stem cells, often in synagogues and churches, community halls, and high school gymnasiums, but also to legislators and policy makers, venture capitalists, business people, and even to companies whose employees want to hear that their science is doing something for people. You may ask how I find the time to do this. It is not so hard. It is about one talk a week and sometimes you can do two or three in a day. More important, I find that I learn more from these experiences than I could have imagined.

Fourth, we cultivate reporters. They usually come to us with little knowledge and experience on the subject but you work with them over and over again, provide them with contacts and sources, help them with the science, and you eventually have a core group of writers who understand your message and sometimes deliver the message better than you can.

How can I justify these activities as a professor? As research administrators, you know how much time professors spend writing grants. Most scientists that I know spend at least a third of their waking hours either thinking about or writing grants, 80% of which fail to be funded. Well, I donate all my honoraria to research and my student teaching activities. It is not peanuts by the way. Our Center also receives many donations from people, often in \$5 checks. It adds up to much more than an R01 grant from NIH. But even more important than the money (I would do it even if there were no donations, which by the way are not solicited), it is a teaming experience that I bring back to the laboratory, so that we can do SCIENCE FOR THE PEOPLE. We cannot do science for the people unless we know them and communicate with them. That is the most important justification for this work. It makes our science better.

I would be glad to answer any questions. I apologize to those of you who came here expecting a talk about the science of spinal cord injury. But, as I realized that you are the Research Administrators, I thought that this would be of greater interest.