In the trenches: lessons for scientists from California's Proposition 71 campaign

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ABSTRACT **I describe a number of valuable lessons I learned from participating in California's Proposition 71 effort about the role that scientists and rigorous scientific advice can play in a public political process. I describe how scientists can provide valuable information and advice and how they can also gain a great deal from the experience that is valuable to a practicing research scientist. Finally, I argue that in the future, building similar broad coalitions to support biomedical and other areas of scientific research will be essential to protect publicly funded science. Thus, a key lesson from the Proposition 71 experience is that engagement of scientists with diverse nonscientific groups can make a big difference and that scientists must actively engage with the public in the future if we are to contribute robustly to the medical and economic health of our communities.**

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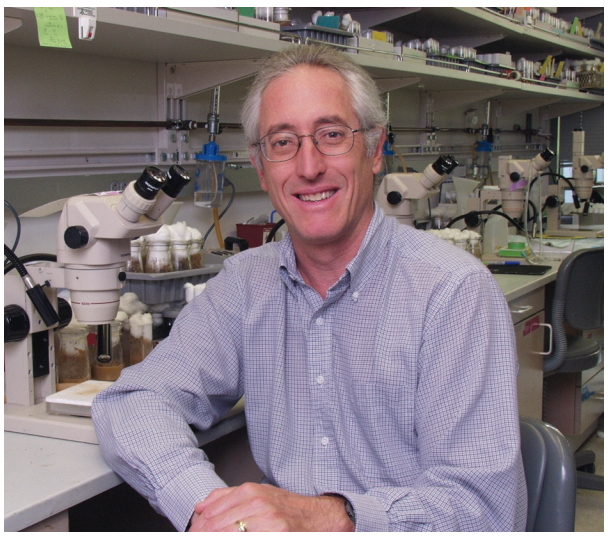
INTRODUCTION

From 2002–2004, I had the privilege of working with a diverse group of patient advocates, communications professionals, political consultants, scientists, and professional politicians to conceive, nurture, design, and secure the passage of California's landmark Proposition 71 ballot initiative, which established the California Institute for Regenerative Medicine (CIRM). CIRM was designed to award $3 billion in competitive, peer-reviewed grant funds to stem cell research running from basic science to clinical application. The Proposition 71 ballot initiative that created CIRM passed with almost 60% of the voters supporting it, primarily because of the medical promise of stem cell research, the unique political pressures and ethical debate surrounding stem cell research in the United States, and the potential and recognized benefit that biomedical research brings to California's biotechnology industry and economy. Much has been said and written about the merits and challenges of this landmark effort and its current function. I want to focus this essay, however, on a number of valuable lessons I learned about the role that scientists and rigorous scientific advice can play in the political process, in discussions with the public and patient advocates, and in the crucible of a high-visibility political and scientific initiative. In particular, I learned that, while the public political process can be messy, practicing research scientists not only can provide valuable information and advice, but can gain a great deal of valuable experience. I also learned that, while the world of science is not the only data-driven group, it nonetheless contributes a much longer-term perspective on issues than do other groups.



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FINDING A HAPPY MEDIUM

"False hope!" "Don't crush our hopes!" "Overhype!" "Too much pessimism!" I heard all of these conflicting statements and more from my patient advocate friends and colleagues during the Proposition 71 campaign. The lesson I learned is that one has to walk a fine line between too much pessimism, which some patient advocates will tell you has a negative impact, because it kills their hope, as

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Abbreviation used: CIRM, California Institute for Regenerative Medicine.

opposed to too much optimism, which contributes to the problem of overhyping or promising more than can be delivered in the time frame that you or someone else imagines. In short, I learned that I should paint a reasonable picture of what success would bring, while describing reasonable expectations and likely obstacles. For example, it is and was clear that success with stem cell approaches for type 1 diabetes will potentially bring complete insulin independence. But a number of important technical and safety problems will have to be solved on the path to achieving that goal, which leads to an uncertain time frame.

THE PROBLEM OF TIME

I have often been asked, both during the Proposition 71 process and since then, how long it will take a particular area of research to reach clinical application or, even harder to answer, "When will my wife's, child's, or parent's disease be cured?" These are difficult, if not impossible, questions to answer, because the point of research is to find answers to unanswered questions, often with little accurate information available at the outset. The answers one gives thus require an explanation, not a number, since one cannot possibly give an accurate number. However, one can note correctly that expanding funding moves research more quickly. I also learned that it is appropriate to describe what success might look like, to talk about past experience with success in generating new therapies or discoveries, and to describe how broad portfolios of parallel opportunities will yield some that will proceed more quickly and some that will go more slowly. I also found analogy to be useful. In many settings, I would describe being a scientist in this (and other) fields as being like an explorer at the edge of a new continent, where I could see mountains and forests in the distance and knew it was likely that there were riches to be had. Thus I could argue it was worth proceeding and there would be great rewards, but predicting exactly how long it would take to yield results would be problematic. But I also learned that it is compelling to note that not starting a long journey leads to no benefit, or adds delay to what will be a long journey, no matter what. Nonetheless, the issue of time is hard and can also be difficult to communicate. Thus I also learned one can talk about short-term and long-term returns and describe what the process will look like. Finally, I learned that telling people that scientists are working as rapidly as possible to find better therapies is helpful. Many people respect this honesty and find it reassuring that the scientific community does care about trying to find therapies for people's diseases, even if success will take time.

MEDIA AND SOUND BITES

The media and the communications industry are essential if scientists are to communicate with the public. In fact, the media is a megaphone that allows us to talk to more than just a few people at a time. In that context, the media is an essential part of how scientists work with other groups in political settings. But I often hear my colleagues say that "reporters never get it right" or that some reporter "didn't quote them accurately" or that they "talked to a reporter for half an hour or more and they only used a one-sentence quote or a 15- to 20-s segment in the final radio or TV report." My perspective and experience are different. First, my experience is that the vast majority of people I interacted with in the media are intelligent, hard-working professionals with little scientific background, who are nonetheless trying very hard to get the facts straight and to be as objective as possible. Second, my experience is that the point of a 20- or 30-min interview is that this is time a scientist can use to educate a reporter about the topic being covered, so the overall story is accurate, including the parts not directly based on the interview. Furthermore, my experience is that the journalist will be more likely to choose the right quote and/or get it right if the scientist has done a good job of providing an understandable explanation of the topic under discussion. To achieve this goal, however, requires that scientists learn to explain complex topics in plain everyday English with a minimum of jargon or Latinate language, which of course, is the same as good teaching. For example, I learned to say "blood-forming" stem cell instead of "hematopoietic stem cell" to nonscientific audiences.

THE PROBLEMS WITH TEAMWORK

Any coordinated action of a group with media and the public will inevitably require teamwork, as well as consolidation and discipline around shared messages. This can get tricky when the shared messages fail to agree with any one scientist's view regarding correctness of information imparted or focus on the proper priorities. There is not an easy solution to this kind of problem. But if every member of a group chooses to broadcast his or her own version of a message, instead of uniting around common themes, what will emerge is cacophony, confusion, and likely failure. The question is how to balance scientific and personal integrity with teamwork, shared goals, and shared messages. My own solution was to work vigorously in private to ensure that the common message themes were rigorously correct, so that I, and my colleagues on the team, were always saying things that to the best of our knowledge were scientifically accurate and defensible. But I also chose to agree to focus on shared message points publicly, even if my own view was that these points were not as important scientifically as other messages. Similarly, I had to accept that the public at large and the scientific community sometimes use the same words differently. A case in point is the word "cure." My personal and scientific view is that few diseases other than infectious diseases are ever truly "cured" and that what we offer are therapies that relieve, reduce, or manage a disease. In the public arena, however, what I regard as short- to medium-term therapies seem to be thought about as cures. In this case, my solution was to speak about therapies in my own interviews and public talks, but not to publicly debate the issues around the word "cure" with my own team. Thus my strategy was to be absolutely honest, while avoiding anarchy and confusion. In this situation, the crucial role of a scientist is to work as hard as possible privately to get the substance of the messages absolutely correct, and then to work with the team on promoting them in a coordinated and agreed-upon way.

APPLYING PROPOSITION 71 LESSONS TO OTHER INITIATIVES?

Building broad coalitions to support biomedical and other fields of scientific research is clearly an area where scientists, politicians, and other interested groups will have to work together more than ever to protect publicly funded science in the coming years. There is increasing scrutiny by politicians and the public, who want to know how the investment of their funds benefits them. Responding to that legitimate concern, and finding ways to continue to expand scientific research that supports healthy vigorous societies, will require scientists to be part of these teams of diverse interest groups. I can virtually guarantee from my experiences that decisions about funding and science policy made in the absence of scientific input will likely be unpalatable to scientists and ultimately not in the best interest of our broader societies. Thus a key lesson from the Proposition 71 experience is that engagement of scientists with diverse nonscientific groups can make a big difference and that scientists must actively engage with the public in the future if we are to contribute robustly to the medical and economic health of our communities.