

**Stem Cell Action Network Testimony Before the Little Hoover Commission
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National Advisory Board
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The Stem Cell Action Network is a nationwide grassroots patient advocacy organization.

We support the priority that the California Institute for Regenerative Medicine (CIRM) is giving to advancing stem cell science and moving it from the lab to the bedside in a timely way. We recognize as well the enormity of the task that the Institute has before it -- assuming leadership in a field of biomedical research, due to the failure of the federal government to act responsibly.

Although we are hopeful that, with the election of a new administration in Washington, the federal restrictions of embryonic stem cell research will be lifted, we are realistic in recognizing that federal support for stem cell research is unlikely to even come close to reaching the level that is needed. California we still need you – as much today as in the past!

The main aim of our testimony before you today, however, is to evaluate a particular criticism of CIRM's governing structure that has been made in the past and that will surface again in the testimony today. This criticism is that the CIRM governing board, the Independent Citizens Oversight Committee (ICOC) does not have members on it who represent "the public interest," as these critics choose to define it, and that therefore ICOC governance is fundamentally flawed.

We note first of all that this critique is being advanced by self-appointed guardians of the "public interest" who have attacked Proposition 71 from the very beginning. Their claim that the public interest is not being taken into account by the Institute is without foundation. The ICOC and CIRM have in fact welcomed and continue to welcome public scrutiny, input, and participation. CIRM meetings and policy making are exceptionally public affairs, except in those decision-making areas, such as the evaluation of grant applications, where, even the critics agree, some confidentiality is called for.

Hence the allegation that the ICOC is neglecting the so-called "public interest" is an unwarranted one. The assumption that somehow the "public interest" is an entity separate and distant from the ICOC, and that needs to be imported into the CIRM governing process, is mistaken. Let us note that the members of the ICOC are appointed by California public officials, and that one of the most important criteria for their selection is their track record of public service. Indeed the ICOC members have shown in the openness of their policy-making processes that they are fully aware of the need to keep the public informed and involved

Moreover, the Institute provides for strong representation of the public interest on the ICOC itself, in the form of the ten patient advocate members who sit on the ICOC. These

representatives have only one aim: the responsible development of stem cell science and the application of its discoveries to advance the search for effective medical remedies. This aim is the public interest that Californians voiced when they voted overwhelmingly in favor of Proposition 71 that established the Institute.

Who better to represent the public interest than the ten patient advocacy group representatives on the ICOC? They are not partial to or beholden to any particular scientists or institutions public or private, to any particular research approach or program, to any ideological or religious agenda. And we have seen in practice that they are not, in fact, even biased in favor of translational work over basic research, since they recognize that basic science is essential to the discovery process that will lead to effective therapies.

We in the Stem Cell Action Network encourage members of the Little Hoover Commission to hear from the ten members of the ICOC who represent patient advocacy groups. You will find that they are knowledgeable, well-prepared representatives of the public interest. They are of course informed about scientific research that might lead to remedies for the particular diseases and injuries with which they are most familiar. But it's absurd to assume that they are interested in healing only one illness, and there is not a shred of evidence that they are partisan in this way. You will find in fact that these ICOC members are knowledgeable about all of the CIRM matters that are of importance to the public. These ten individuals are versed in matters of fiscal responsibility and efficient resource allocation, IP issues, conflict of interest issues, and other ethical and political matters that bear on CIRM policy formation and implementation. And what they don't know, they learn! Invite them to Sacramento to appear before you – you'll see just how well-informed, passionate about the cause, and effective these community leaders are.

In short, the patient advocate representatives on the ICOC are perfectly positioned to represent the public interest authentically and thoughtfully.

Thank you for considering our perspective on these matters.