



MEMORANDUM

TO: MEMBERS, GOVERNANCE SUBCOMMITTEE, CALIFORNIA INSTITUTE FOR REGENERATIVE MEDICINE
FROM: CIRM STAFF
DATE: December 6, 2021
RE: ICOC PATIENT ADVOCATE MEMBER COMPENSATION

Background

Proposition 71 required that Patient Advocate members of CIRM's Governing Board participate as members of CIRM's Working Groups. Because the Working Groups make recommendations to the Board regarding applications for research, facilities funding, and ethical standards to govern CIRM-funded research, service on the Working Groups requires a substantial commitment of time, above and beyond service on the Board and its subcommittees. Proposition 71 created three working groups and stipulated that:

- (1) seven of the ten Patient Advocate members of the Board serve on the Grants Working Group;
- (2) six of the seven Patient Advocate members of the Grants Working Group serve on the Facilities Working Group; and
- (3) five of the ten Patient Advocates serve on the Standards Working Group.

As a result, the Patient Advocate members of the Board are required to devote a substantial amount of time recommending criteria for the review and oversight of applications for funding, reviewing, and making recommendations regarding applications for research and facilities funding, and developing and recommending standards pursuant to which research must be conducted. The service by Patient Advocate members on the Working Groups affects members' ability to serve while simultaneously carrying out their other responsibilities, including their current occupations. However, Proposition 71, as originally drafted, provided only a daily per diem of approximately \$100 for Patient Advocates' service on the Working Groups, even though the scientific, facilities experts, and ethicists who serve on the same Working Groups are entitled to a daily consulting rate that is significantly higher.

In 2011, Senate Bill No. 1064 authorized CIRM to compensate the Patient Advocate members through a daily consulting rate, in lieu of a per diem, for their extraordinary time commitment to CIRM.

In response to SB 1064, the Board amended its bylaws to establish parameters for this compensation. First, the bylaws amendment required the Board to determine on an individual basis that the Patient Advocate member's service on a Working Group requires an extraordinary commitment of time. Second, the bylaws amendment limited the compensation rate to 75 percent of the daily consulting rate established for scientific members of the Grants Working Groups. Third, the bylaws capped the total compensation for Patient Advocate members of the Board for their service on Working Groups at \$15,000 unless the Board approved an exception.¹

Proposition 14 increased the number of members on CIRM's Governing Board from 29 to 35. As part of the Board expansion, Proposition 14 added two additional Patient Advocates to the Board. Proposition 14 also tasked the California State Treasurer and State Controller to each appoint a nurse with experience in clinical trial management or stem cell or genetic therapy delivery. In addition, Proposition 14 created a new Treatments and Cures Accessibility and Affordability Working Group.

Like Proposition 71, Proposition 14 stipulates that the Patient Advocates members and Nurse members of the Board serve on each of the four Working Groups:

- (1) five of the 14 Patient Advocates members or Nurse members serve on the Standards Working Group;
- (2) seven of the 14 Patient Advocates members or Nurse members serve on the Grants Working Group;
- (3) six of the seven Patient Advocate members or Nurse members of the Grants Working Group serve on the Facilities Working Group; and
- (4) five of the 14 Patient Advocates members or Nurse members of the Board serve on the Treatments and Cures Accessibility and Affordability Working Group.

Finally, Proposition 14 required the Board to establish daily consulting rates and expense reimbursement standards for the members of all Working Groups, including the Patient Advocates members and Nurse members who serve on Working Groups. The daily consulting rate is intended to compensate the Patient Advocate and Nurse members for time spent in preparation for, and participation in, CIRM, Working Group, and Board meetings, including compensation and expense reimbursement for caregivers when necessary to facilitate a member's participation in a meeting as a result of the member's medical condition.

Recommendation

In order to implement Proposition 14's statutory mandate, we request that the Board set the daily consulting rate for all Patient Advocate members and Nurse members of the Board at 75% of the daily consulting rate for scientific members of Working Groups. Currently, the daily consulting rate for scientific members of the Grants Working Groups is \$750. Under this proposal, the daily consulting rate for Patient Advocate members or nurse members of Working Groups would be \$562.50 per day for any day that they attend a CIRM, Working Group, or Board meeting.

¹ Because the Chair and the Vice Chair are considered employees of CIRM and are compensated for their service, including on the Working Groups, through a salary, they are not eligible to receive the daily consulting rate.