

## Rare Voices Australia Scientific and Medical Advisory Committee (RVA SMAC)

### TERMS OF REFERENCE (amended Feb 2018)

1. The Committee will provide support, facilitation, advice and expert opinion to the Board of RVA in the following areas:
  - I. the progression of a National Rare Disease Framework;
  - II. issues and opportunities related to RVA's vision, mission, aims, objectives and work plan;
  - III. the development of linkages and networks among RVA stakeholders; and
  - IV. initiatives and emerging issues that are important to achieving RVA's vision and mission.

### MEMBERSHIP

1. The Committee will have between 8 and 12 Members.
2. Committee membership will reflect the diversity of people involved in health services and medical research that serve people living with rare diseases. These include:
  - a. Biomedical, clinical, public health, allied health, health systems policy and programs;
  - b. Genetic services;
  - c. Medical devices, therapeutics, diagnostics;
  - d. 'Omics' – genomics, phenomics, proteomics, metabolomics;
  - e. Bioinformatics and health information systems;
  - f. Clinical service models and continuity of care;
  - g. Adult health and child health;
  - h. Paediatric and familial cancer.
3. Committee Members will be committed to improving the lives of people living with rare diseases, will have a deep knowledge of and respect for patient perspectives, and a track record of translating research into improved patient care and/or joined up health services.

### APPOINTMENT OF THE COMMITTEE CHAIR AND MEMBERS

1. A Chair will be appointed by the RVA Board on the recommendation of the RVA Executive Officer.
2. The primary role of the Chair will be to promote and inform the broader priorities of RVA.
3. The Chair will appoint Members and, if required, a Deputy Chair, in consultation with the RVA Board.
4. The Chair, in consultation with the Chair of the RVA Board and the RVA Executive Officer, will exercise judgement to achieve a diverse membership, while not constraining the ability to appoint outstanding individual candidates. Appointments will give consideration to gender, organisation and geographic balance, and linkages to bodies such as Orphanet Australia, IRDIRC, and the Global Alliance on Genomics and Health.
5. The RVA Board has the right to remove a Committee Member under certain conditions after consultation with the Chair of the Committee.

## MEETING AND REPORTING ARRANGEMENTS

1. The Committee will:
  - a. Meet quarterly by teleconference;
  - b. limit the duration meetings to one hour; and
  - c. determine meeting times from among its members.RVA will incur the costs associated with hosting and facilitating such meetings.
2. At the discretion of the Committee, Sub-committees and Working Parties may be established for finite periods to undertake specific task/activities, and may co-opt additional people and expert bodies as required. The size and membership of these groups will be prescribed by their operational requirements.
3. The RVA Executive Officer will be an observer at Committee meetings with the right to participate in discussions.
4. A quorum shall comprise five (5) members including the Chair. In the absence of a quorum, any discussion or decisions will require ratification by the Committee members, either via circular resolution or by being held over for discussion and voting at the next meeting.
5. The Committee will provide advice to the RVA Board through the RVA Executive Officer. In addition, the SMAC Chair will be invited to participate in bi-monthly RVA Board meetings on an ex-officio basis. This will facilitate two-way direct communication between the RVA Board and SMAC.
6. The SMAC Chair will provide a report of SMAC activity at each RVA Board meetings.
7. The Committee will evaluate its activities annually. The SMAC Chair will report on this during RVA's Strategic Planning.
8. As appropriate, additional face-to-face Committee meetings may be arranged.

## TERM

1. The Committee Members' positions will be time-limited. It is anticipated that the initial maximum terms will be 3-4 years, but this tenure will be regularly reviewed by and at the discretion of the Executive Officer and SMAC Chair. Retiring Members may apply for a second term.
2. To enable continuity of membership, where possible changes in Committee membership will be staggered and planned. Incoming Committee Members help to revitalise and re-energise the Committee but this should not be done at the expense of group development and momentum.
3. In coordination with the Executive Officer, the Committee will participate in an annual review of its ongoing operational role and coordinating functions.

## MEMBER OBLIGATIONS

1. Members will be required to pre-read meeting documents and, as required, may be consulted by the Chair on an *ad hoc* basis, between meetings.
2. Absence from three (3) consecutive Committee meetings without prior arrangements made with the SMAC Chair/Executive Officer will normally be grounds for retiring a Member and appointing a replacement to the resulting Committee vacancy.



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A U S T R A L I A

3. Members will reflect on their discussions at each meeting to assess their quality of participation and the decisions taken, and to ensure the underlying motivations of discussions support the RVA vision and mission.
4. Members, while they are free to make any comments publicly about matters to do with rare diseases, may not speak on behalf of RVA or the Committee. Only the Chair, after consultation with the Executive Officer, may make media comments on behalf of the Committee. In general, this should be the exception rather than the rule, with most media focused through the Executive Officer.

#### **SUPPORT**

1. RVA will provide executive support and secretariat duties for the Committee.
2. All paperwork relating to the Committee meetings will be provided in an appropriate and timely manner, usually at least one week prior to the Committee meeting.

With Compliments

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The unified voice for all Australians living with a rare disease