

RVA ROUND TABLE OF COMPANIES MEMBERSHIP Terms of Reference 2021

1 Purpose and role

1.1 *Establishment*

The RVA Round Table of Companies (RTC) is a group of pharmaceutical companies who share a common interest in rare diseases and orphan drug development. RVA RTC members provide financial support to RVA and in return, their company benefits from the constructive dialogue being developed between industry, patient organisations and relevant key stakeholders. All RVA RTC members support RVA's mission as the unified voice working with all key stakeholders to drive the best outcomes for Australians living with a rare disease.

Since forming, RVA has gained expertise in dealing with the various stakeholders involved in the rare disease and orphan drug fields.

1.2 *Purpose*

Pharmaceutical companies interested in rare diseases are confronted with very specific hurdles that lie in the path of product development for rare diseases in Australia. These are not the same as in the US where a specific rare disease policy has existed since 1983. In Australia, there is no specific rare disease policy and this adds to the difficulty for drug developers.

RVA understands the inefficiencies and time delays involved with developing new therapies and treatments for rare diseases in Australia. RVA promotes best practice with the TGA's Orphan Drug Regulation and sits on many Federal Committees that inform and advise best practice.

RVA RTC members have adopted a policy 'Working with the Pharmaceutical Industry Policy' adopted in 2013. This policy complies with the Medicines Australia Code of Conduct.

2 Members

2.1 *Membership Benefits and Requirements*

Participation in 4 Round Table of Companies' Workshop meetings per year focusing on relevant issues to members. Each company can nominate up to 3 representatives to join the RTC meetings. These representatives must be nominated ahead of time as per RVA's RTC representative form and should hold roles within the company that suitably reflect the RTC meeting interests:

- Company patient advocacy
- Market access for treatments and reimbursement
- Government relations



rare voices
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Each representative must attend a minimum of 2 out of 4 workshop meetings each year in-person or via teleconference. Please contact RVA in the event of any extenuating circumstances that prevents attendance as outlined here.

The workshop meetings aim to accelerate the development as well as availability of treatments and health services in Australia. They also seek to build relationships with the patient community in a collaborative atmosphere that facilitates discussion on rare diseases. Benefits include:

- Opportunities for direct exchange of views with leaders of the rare disease community
- Opportunities to develop partnerships and collaborations
- All member company logos are listed on the RVA website
- Timely reports, surveys and analysis relevant to the field of rare diseases from different sources

2.2 *Membership Application*

All membership and RVA Round Table of Companies enquiries may be directed to the RVA office at admin@rarevoices.org.au during business hours.