

POSITION DESCRIPTION: Resources and Information Officer

ABOUT THE ORGANISATION:

Rare Voices Australia (RVA) is Australia's national non-profit peak body, representing Australians who live with a rare disease. RVA is dedicated to working with all key stakeholders in the rare disease sector to drive the best outcomes for Australians living with a rare disease.

- We provide a strong unified voice to advocate for rare disease policy reform, as this is essential to improving the lives of the estimated two million Australians living with a rare disease.
- We progress the collaborative implementation of the National Strategic Action Plan for Rare Diseases (the Action Plan). RVA led the collaborative development of the Action Plan, which was launched in February 2020 by the Australian Government with strong bipartisan support. Developed 'by the rare disease sector, for the rare disease sector,' the Action Plan is the first nationally coordinated effort to address rare diseases in Australia.
- We provide leadership and advocacy, raise awareness of issues and influence policy by engaging with all key stakeholders in the rare disease sector and facilitating collaboration.
- Our collaborative approach to working with our RVA Partners (rare disease organisations) and stakeholders ensures our actions are well considered and well targeted, sustainable and geared towards achieving a high collective impact.
- Our growing national team is small, collaborative and strategic. We are innovative thinkers who are nimble and proactive. We are comfortable working remotely as our team members are located across Australia. We all pitch in when needed, and act with the highest level of integrity and respect for our RVA Partners and stakeholders. We thrive on achieving progress on the big issues for people living with a rare disease.

Position Title	Resources and Information Officer
Salary	\$80,000 per annum FTE, based on a 38-hour week, pro rata, plus super
Benefits	Not for Profit Salary Packaging Benefits which reduces your taxable income.
Work location	Flexible. Current staff work from home offices. The successful applicant may be based in or near a major regional centre.
Hours	Part time position 32 hours/week – we are willing to negotiate hours with the right applicant. Flexible office hours, with occasional overtime work required. Some interstate travel will be required.
Length of the role	2 year fixed term contract with the potential for renewal.

RESPONSIBILITIES

- Research and develop customised, evidence-based information about rare diseases for all stakeholders across the rare disease community for the Rare Awareness Rare Education (RARE) Portal. Key stakeholders include people living with a rare disease, advocates, key peak bodies, clinicians, researchers, governments and industry.
 - Identify reliable resources (peer reviewed journal articles and grey literature) and expertise to generate accurate and relevant content for the RARE Portal.

- Engage with rare disease stakeholders to gather relevant information and resources that meet the needs of all rare disease stakeholders, including people living with a rare disease, carers, researchers, clinicians and allied health professionals.
- Collate information from a range of reliable resources and stakeholders to create information and resources about individual rare diseases that captures all viewpoints.
- Write simple, concise, engaging, customised and evidence-based information for the RARE Portal that is tailored to Australians living with a rare disease and all rare disease stakeholders.
- Evaluate and review information and resources housed on the RARE Portal.
- Contribute to RVA's community and stakeholder engagement.
- Contribute to identifying unmet needs of Australians living with a rare disease and priority setting.
- Work with RVA staff to contribute to the full range of RVA's work which includes advocacy and policy, education, research, communications and RVA events (e.g. the National Rare Disease Summit and Parliamentary Events).

KEY SELECTION CRITERIA

1. Appropriate qualifications suited to this role and experience working in the non-profit sector.
2. Strong written communication skills with demonstrated experience in medical writing/science communication, including the ability to translate complex concepts into simple English. Comprehensive familiarity with medical terminology and concepts.
3. Strong research skills and data literacy, including literature/reference searching and fact-checking.
4. Analytical skills, including the ability to critically interpret medical research data, health literature and statistics. Strong data presentation skills.
5. An understanding of the ethical principles and guidelines that apply to medical communication and publication.
6. Understanding of the rare disease and/or health sector and commitment to improving the lives of Australians living with a rare disease.
7. Collaborative and inclusive approach to working with others. Ability to engage effectively in teamwork.
8. Relationship-building and engagement skills and experience with a diverse range of stakeholders including people living with a rare disease, advocates, clinicians, researchers, government, key peak bodies and industry.
9. Organised, detailed and able to manage priorities to deliver outcomes. The ability to multi-task and work to timelines. Demonstrated ability to work effectively remotely and with appropriate levels of autonomy, transparency and accountability.
10. Fits the culture and values of the organisation: respect and care for others, supporting people to succeed, recognising and valuing different strengths and capabilities of team members, collaboration and co-operation, and a person-centred approach in decision making.

DESIRABLE CRITERIA

1. PhD in the medical sciences.
2. Data visualisation experience.

OTHER RELEVANT INFORMATION:

- The appointee will be subject to a probation period of six months.
- The position may be subject to a National Police Records Check.
- Applicants must be an Australian citizen, permanent resident or hold a valid work permit or visa.
- RVA is an equal opportunity employer and welcomes applicants from a diverse range of backgrounds.

For details concerning this role, please contact:

Chief Executive Officer: Nicole Millis

Phone: 0459 021 204

Email: nicole.millis@rarevoices.org.au

APPLY FOR THIS JOB

Forward your application by addressing the Selection Criteria, with a copy of your CV to Nicole Millis by COB 7th January 2022.