

**POSITION DESCRIPTION:** Communications and Information Officer

**ABOUT THE ORGANISATION**

Rare Voices Australia (RVA) is the national non-profit peak body, representing Australians living with a rare disease. We are dedicated to working with key stakeholders to drive the best outcomes for Australians living with a rare disease. RVA’s work is non-disease specific and is based on the commonalities of rare disease. Our advocacy focuses on rare disease policy, processes and systems.

- 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 and oversee the collaborative implementation of the Australian Government’s [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 key stakeholders in the rare disease sector and facilitating collaboration.
- Our collaborative approach to working with our 100+ RVA Partners (rare disease groups/organisations) and other stakeholders ensures our actions are well considered and well targeted, sustainable and geared towards achieving a high collective impact.
- Our national team is 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. We thrive on achieving progress on the big issues for people living with a rare disease.

<b>Position Title</b>	Communications and Information Officer
<b>Salary</b>	\$83,200 per annum FTE, based on a 38-hour week, pro rata, plus super
<b>Benefits</b>	Not for Profit Salary Packaging Benefits, which reduces your taxable income
<b>Work Location</b>	Flexible. Current staff work from home offices. The successful applicant may be based in or near any Australian capital city or major regional centre.
<b>Hours</b>	Part-time position 32 hours/week – we are willing to negotiate hours with the right applicant. Flexible office hours, with occasional overtime work and some interstate travel are required.

**RESPONSIBILITIES**

RVA is looking to recruit a Communications and Information Officer. Responsibilities are listed below.

**Support RVA’s Communications Manager and other staff across a range of tasks, including contributing to and assisting with:**

- RVA’s monthly e-Newsletter to all stakeholders.

- Content development and dissemination across RVA's social media channels (Facebook, Instagram, Twitter, LinkedIn, YouTube and our closed Facebook group for RVA Partner group/organisation leaders).
- Additional content development as needed to drive maximum engagement.
- Engaging with stakeholders as needed.
- Other related tasks as required.

## **RARE Portal**

The [Rare Awareness Rare Education \(RARE\) Portal](#) contains current, reliable and straightforward information and resources for all rare disease stakeholders customised for the Australian context. It is a living website in ongoing development, with new information added regularly.

**The Communications and Information Officer will support RVA's small RARE Portal team across a range of tasks, including contributing to and assisting with:**

- Researching and developing customised, evidence-based information about rare diseases for a diverse range of stakeholders across the rare disease community for the RARE Portal.
- Collating information from a range of reliable resources and stakeholders to create information and resources about individual rare diseases.
- Writing 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.
- Contributing to RVA's community and stakeholder engagement, including consulting with a broad range of stakeholders for RARE Portal codesign.
- Other related tasks as required.

## **Other duties**

- Actively participate in the planning and facilitation of RVA events, including the biennial National Rare Disease Summit which engages all stakeholders (rare disease groups/organisations, researchers, clinicians, key peak bodies, industry and government).
- Contribute to a positive and effective team focused on improving the lives of Australians living with a rare disease.

## **KEY SELECTION CRITERIA**

1. Appropriate qualifications suited to this role (e.g. science communication, research, health promotion).
2. Strong written and verbal communication skills with demonstrated experience in the provision of health and science information, including the ability to translate complex concepts into simple English. Comprehensive familiarity with medical terminology and concepts.
3. Ability to adopt RVA's existing communication approach and writing style.
4. Demonstrated research skills and data literacy, including literature/reference searching and fact-checking.

5. Analytical skills, including the ability to critically interpret medical research data, health literature and statistics.
6. An understanding of the ethical principles and guidelines that apply to medical communication and publication.
7. Experience using content management systems (CMS) such as WordPress. Key tasks will include uploading and editing content in WordPress.
8. A collaborative and inclusive approach to working with others. This includes learning from RVA's team, being receptive to constructive feedback and the ability to engage effectively in teamwork in a virtual environment (e.g. high level competency across a range of computer systems and applications, including Microsoft Office, Zoom and Microsoft Teams).
9. 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.
10. Organised, detailed and able to manage priorities to deliver outcomes. The ability to multi-task, work to timelines and pivot when necessary to support team-based priorities. Demonstrated ability to work effectively remotely and with appropriate levels of autonomy, transparency and accountability.
11. 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 to decision making.

### **DESIREABLE CRITERIA**

- Experience working in the rare disease sector.
- Experience using Canva for design.
- Video editing skills.
- Experience working in the non-profit sector.
- Experience using a CRM.

### **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:

**Communications Manager:** Sarah Cannata  
**Phone:** 0472 501 237  
**Email:** [communications@rarevoices.org.au](mailto:communications@rarevoices.org.au)

**APPLY FOR THIS JOB**

Forward your application, addressing the Key Selection Criteria, as well as a copy of your CV to [communications@rarevoices.org.au](mailto:communications@rarevoices.org.au) by **5pm AEST Friday, 29 September**.