

POSITION DESCRIPTION: RARE Helpline Manager

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.

Position Title	RARE Helpline Manager
Salary	\$83,200 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 any Australian capital city or major regional centre.
Hours	Full-time position 38 hours/week – we are willing to negotiate hours with the right applicant. Flexible office hours. Occasional overtime work and some interstate travel are required.
Length	3-year fixed term contract with the potential for renewal

RVA is looking to recruit a RARE Helpline Manager who will report to the Project Manager for The Navigator Project, which was the recipient of the Rare and Complex Disease Telehealth Nurse Program Commonwealth Department of Health and Aged Care grant in June 2023. The establishment of the RARE Helpline is one component of The Navigator Project. An interim RARE Helpline has been operating since July 2023.

The Navigator Project will support the estimated two million Australians living with a rare disease to navigate the health system, including via the assistance of telehealth nurses. This activity is scheduled to run over three years from mid-2023 and RVA is the lead consortium partner. [Read more about The Navigator Project in this article on RVA's website.](#)

RESPONSIBILITIES

- Manage and supervise the day-to-day operations of the newly established RARE Helpline, ensuring smooth functioning and timely responses to enquiries.
- Directly respond to RARE Helpline enquiries. It is anticipated the RARE Helpline Manager will respond to the majority of enquiries initially, but this will decrease over time as volunteer staff are recruited and trained.
- Provide emotional support and guidance to RARE Helpline callers, ensuring their needs are addressed sensitively and appropriately.
- Provide leadership, guidance and support to the RARE Helpline team, which will include RVA staff and trained volunteers.
- Ensure a safe and supportive work environment, including appropriate supervision of staff and volunteers working on the RARE Helpline.
- Develop training processes and materials for volunteer staff.
- Work with the Project Manager of The Navigator Project to develop and implement policies, procedures and training programs for the RARE Helpline to ensure consistent and effective service delivery.
- Collaborate with internal and external stakeholders to expand the RARE Helpline's reach and enhance its impact on the rare disease community.
- Maintain a current understanding about information relevant to Australians living with a rare disease, including regarding the latest research, treatment options and available support services.
- Work with relevant RVA staff to remain updated with relevant legislation, policies and guidelines related to rare diseases and ensure compliance within the RARE Helpline operations.
- Alongside the Project Manager for The Navigator Project, analyse RARE Helpline data and generate reports to evaluate service effectiveness and identify areas for improvement.
- Foster partnerships and collaborations with health care professionals, advocacy groups/organisations and other relevant groups/organisations to strengthen the RARE Helpline's network.
- Participate in rare disease awareness campaigns, conferences and events to promote the RARE Helpline, and raise awareness and education about rare diseases.
- Ensure the RARE Helpline leverages work already being undertaken on the [Rare Awareness Rare Education \(RARE\) Portal](#) for rare diseases and that the RARE Helpline informs the RARE Portal and assists in highlighting gaps moving forward.
- Liaise with RVA staff to ensure the RARE Helpline leverages other key RVA initiatives (e.g. RVA's Education Program, RVA's Online Education Portal etc).

OTHER DUTIES

- Actively participate in the planning and facilitation of RVA events, including the biennial National Rare Disease Summit which engages all stakeholders in the rare disease sector (rare disease groups/organisations, researchers, clinicians, key peak bodies, government and industry).

- Contribute to a positive and effective team focused on improving the lives of Australians living with a rare disease.

KEY SELECTION CRITERIA

1. Proven experience in managing a health-related helpline service or similar support programs.
2. Bachelor's degree in a relevant field such as genetic counselling, social work, nursing, or public health.
3. Knowledge of rare and/or complex diseases, and their impact on people and families.
4. Strong leadership and team management skills, with the ability to motivate and inspire a diverse team of staff and volunteers.
5. Excellent interpersonal and communication skills, both written and verbal, with the ability to engage effectively with individuals from diverse backgrounds.
6. Empathy and sensitivity when dealing with people living with a rare disease, demonstrating a person-centred approach.
7. Ability to handle emotionally challenging situations with professionalism and compassion.
8. Strong organisational, problem-solving and time management skills, with the ability to prioritise tasks and meet deadlines.
9. Proficiency in using helpline management software and other relevant technology platforms.
10. Knowledge of relevant legislation, policies and ethical considerations in the healthcare and non-profit sectors.
11. Experience in data analysis and reporting to measure service impact and identify opportunities for improvement.
12. Demonstrated commitment to person-centred advocacy and a passion for improving the lives of Australians living with a rare disease.
13. 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.

DESIRABLE CRITERIA

1. Experience working in the rare disease sector.
2. Experience working in the non-profit sector.
3. Working with Children Check.

OTHER RELEVANT INFORMATION

- The appointee will be subject to a probation period of six months.
- The position will 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, addressing the Key Selection Criteria, as well as a copy of your CV to nicole.millis@rarevoices.org.au by **5pm AEDT Sunday, 5 November**.