

Position Description

Project Coordinator, Centre of Research Excellence in Bone Marrow Biology

About Maddie Riewoldt's Vision

Maddie Riewoldt was just 26 years old when she tragically died of a Bone Marrow Failure Syndrome called Aplastic Anaemia.

Maddie was diagnosed at 21 years, and for five tough years she put up an incredibly brave fight. She spent those years enduring several bone marrow transplants, hundreds of blood transfusions and ongoing treatments.

When her fight was ending in February 2015, she asked her family to make her a promise; Maddie wanted nobody else to go through what she did.

Maddie Riewoldt's Vision is her legacy.

Every 3 days an Australian is diagnosed with a Bone Marrow Failure Syndrome.

Distressingly, most are children and young adults, and 50% will not survive. Thousands more are living with complex medical issues and ongoing risks to their health, including a significantly higher risk of developing cancer.

Bone Marrow Failure Syndromes are rare, complex and highly debilitating. When our bone marrow fails, our body is unable to produce healthy blood cells, causing life threatening disruptions to our health. Sadly, treatments are inadequate, and the only potential cure is a bone marrow transplantation which has serious risks.

Additionally, patients diagnosed with Bone Marrow Failure Syndromes and their families find there are limited resources and support options available. As a result, they often experience fear, confusion and isolation as they try to navigate this very long journey.

That's why Maddie Riewoldt's Vision is here.

Maddie's Vision is leading the fight against Bone Marrow Failure Syndromes by funding research into better treatments and cures, and providing patients and families with vital support they so desperately need.

Our Vision is that Bone Marrow Failure Syndromes are prevented, diagnosed and treated with the best available medical treatments in Australia and patients and families receive the support that they need.

Our Mission is to fund research that accelerates next generation prevention, diagnosis and treatment of Bone Marrow Failure Syndromes, while supporting patients and families.

The opportunity

Since Maddie's Vision was founded in 2015, we've made an extraordinary impact:

- Establishment of the Centre of Research Excellence in Bone Marrow Biology - an Australian first.
- \$8.8M funded across 36 cutting edge research projects - including two clinical trials which have seen more than 400 patients participate.
- \$24.3M raised by Maddie's Vision funded researchers towards more Bone Marrow Failure Syndrome research through leveraging the outcomes of our funding.

- Partnership with 23 leading universities, medical research institutes and hospitals around Australia.
- 93 patients and families supported through our Telehealth Nurse service.
- Acceleration and facilitation of research through funding critical infrastructure, including the Aplastic Anaemia and other Bone Marrow Failure Syndromes Registry and the new Australian Marrow Failure Biobank.
- Global dissemination of research outcomes via 55 publications and 164 scientific presentations.
- Delivery of three National Symposiums on Bone Marrow Failure Syndromes to drive collaboration and innovation amongst the scientific community.
- Co-ordination of three patient and family forums to provide connection and updates on BMFS research outcomes.
- Launch of our new Peer Support Program to create a safe and confidential environment for patients and families to share lived experiences and access further support.

Our Centre of Research Excellence (CRE) in Bone Marrow Biology is the 'engine room' of our research efforts. This key administrative role supports the delivery and growth of our research project portfolio in partnership with local and international preeminent research institutions. Working closely with our CRE Executive, our independent Scientific Advisory Committee (SAC), our researchers, and our partner research institutions, you will be instrumental to the delivery of our research strategy and goals.

As CRE Project Coordinator, you will ensure the smooth operation of our research activities by engaging with key stakeholders in our research community and facilitating grant rounds, milestone reporting, financial tracking and other administrative tasks. You will develop collaborative and supportive relationships with grantees, research institutions and partners and support the CRE Project Manager with the vital work of the CRE Executive, SAC and other committees.

This role is a 0.4 FTE (2 days/week) role reporting to the CRE Project Manager. One of the work days must be a Monday with the option for the second work day to be a Tuesday or Thursday.

Key responsibilities

Centre of Research Excellence:

- Assist the CRE Project Manager in supporting, communicating and engaging with all key stakeholders to achieve research goals, including researchers, clinicians, fellows, institutions, committees and organisations, maintaining collaborative relationships.
- Provide administrative support for CRE activities, including organisation of meetings, setting of agendas, writing minutes and following-up actions.
- Perform administrative tasks in relation to research projects including timely request and tracking of milestone reports and payments/invoices, tracking project outputs, and drafting other research project related documents.
- Drafting and reviewing research content for the website, annual report, social media and other publications.
- Assist in the renewal and update of CRE and SAC policy documents.
- Provide administrative support to the Telehealth Nurse Service as required.

Event support:

- Provide administrative support for the CRE research and patient/family event steering committees, including setting of agendas, meetings, writing minutes and following-up actions.
- Coordinate venue identification and booking, including AV requirements, catering and accommodation, if required.
- Manage international and domestic travel arrangements for guest speakers as needed, including itineraries, flights, accommodation and transfers.

- Liaise with all speakers in regard to the event program, presentations and related documents.
- Provide administrative support towards the successful execution of symposium and patient/family events including assistance with registrations, communications and post-event surveys.
- Identification of and engagement with event sponsors, ensuring fulfillment of sponsor commitments.

Support to CRE Project Manager:

- Assist the CRE Project Manager with fundraising opportunities and funder reporting, including drafting grant applications, reports and other documents to demonstrate impact.
- Prepare regular key grant information and other activity reports as required for the CRE Project Manager and CEO.
- Work collaboratively to identify development and promotional opportunities to achieve research objectives.

Key Selection Criteria:

- Minimum 1-2 years' experience working in office administration.
- Excellent verbal and written communication skills; able to articulate information accurately and clearly.
- Strong organisational skills to manage multiple meetings, milestones and deadlines with high attention to detail.
- Outstanding interpersonal skills with proven ability to build long-term, collaborative relationships with diverse stakeholders, including internal teams, researchers, clinicians and partners.
- Resourceful and flexible; comfortable working in a small cross functional team.
- Strong alignment with and commitment to our mission and values.
- Sound knowledge of Word, Excel and Microsoft 365 applications.
- Event co-ordination experience (advantageous but not essential).

Additional duties:

From time to time, you may be required to work outside of business hours to support the delivery of key Maddie's Vision events - time in lieu will be provided.

Salary:

\$65,000 (pro rata - 0.4 FTE) plus 11% superannuation and access to not-for-profit salary packaging.

How to apply:

If you want to be part of a small, but high impact, passionate and driven team, please send a copy of your resume and cover letter addressing the Key Selection Criteria (no more than 3 pages) by 5pm **Tuesday 12th March** to research@mr.v.org.au.

Applications which do not address the key selection criteria will not be considered. Only applicants with relevant experience will be contacted. Applicants must have valid working rights in Australia before applying. The successful applicant will be required to provide a valid working with children check and police check. Any enquiries regarding the position can be directed to:

Jaya Soma, Project Manager, CRE

Email: research@mr.v.org.au