

Position Description

Volunteer Role: Educational Outreach Committee Member

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; that nobody else should have 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.

Tragically, most are children and young people, 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 (BMFS) 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 BMFS, 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 exceptionally long journey.

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

Maddie's Vision is leading the fight against BMFS by funding research into better treatments and cures, while also providing vital support and connection for patients and families.

Our Impact

Since Maddie Riewoldt's Vision started in 2015, we have achieved incredible impact in BMFS research and patient and family support, including the acceleration and translation of research through collaboration, critical infrastructure, clinical trials and services to patients and families.

Key achievements include:

- Establishment of the Centre of Research Excellence in Bone Marrow Biology - an Australian first.
- Over \$10M committed to research across 37 cutting edge research projects.
- \$37.9M in additional funding leveraged by MRV-funded researchers to further advance BMFS research.
- Partnership with 26 leading universities, medical research institutes and hospitals around Australia.
- Over 175 patients and families supported through our Tele-Support Service, Peer Support Program and Educational Sessions.
- Investment in critical research infrastructure, including the Aplastic Anaemia and other BMFS Registry and the Australian Marrow Failure Biobank.
- Global dissemination of research outcomes via 226 scientific presentations and 95 journal articles.
- Delivery of four National Symposiums on Bone Marrow Failure Syndromes, bringing together researchers and clinicians from Australia and around the world.
- Design and delivery of the CRE Expert Webinar Series to continue our role as the only provider of tailored BMFS education to the research community.
- Annual co-designed educational programs to update patients and families with latest treatment and research outcomes.
- Peer Support Programs to create a safe and confidential environment for patients and families to share lived experiences and access further support.

The opportunity

MRV is establishing an Educational Outreach Committee to support the development and delivery of a national education program focused on BMFS.

This initiative aims to improve awareness, early recognition, and clinical management of BMFS among healthcare professionals—including GPs, nurses, emergency clinicians, and other community-based healthcare services. By strengthening knowledge of early signs, diagnostic pathways, and treatment options, the program seeks to support earlier diagnosis and referral, timely intervention, and improved patient outcomes, recognising that delayed recognition of BMFS remains a key clinical challenge, particularly outside specialist centres.

A key priority of this program is ensuring reach and impact across regional and rural healthcare settings, where access to specialist knowledge may be limited.

The committee will support the design, development, and dissemination of evidence-based educational resources and activities over a multi-year program (2026–2029).

Role and Responsibilities:

As a member of the committee, you may contribute across a range of areas depending on your interests and availability:

Program & Content Development

- Help shape the focus, priorities, and format of the education program
- Identify key clinical knowledge gaps and priority topics
- Contribute to or review educational content to ensure clinical accuracy, relevance, and usability
- Support adaptation of materials for different healthcare settings and cultural contexts, particularly in regional and remote contexts

Content Delivery & Dissemination

- Participate in educational activities (e.g. webinars, videos, presentations) where relevant
- Support dissemination through professional networks, conferences, and MRV channels
- Identify opportunities to engage with professional colleges, associations, and clinical networks

Evaluation & Impact

- Contribute to the design and interpretation of pre- and post-program evaluation
- Provide input into how we measure reach, relevance, and impact on clinical knowledge and practice
- Support continuous improvement of the program based on feedback and outcomes

Stakeholder Engagement

- Support connections with external organisations (e.g. RACGP, professional colleges, associations)
- Identify opportunities to expand reach, particularly in regional and rural communities

What the Committee will help deliver:

Committee members will contribute to a national program that aims to:

- Develop and deliver a suite of evidence-based educational resources (e.g. written, digital, webinar, and video formats)
- Disseminate resources through MRV platforms, professional networks, and conferences
- Support uptake across a range of healthcare settings, including regional and rural services
- Evaluate program effectiveness, including impact on knowledge, relevance, and practical application
- Support engagement with clinical networks and professional bodies to drive reach and adoption

Who might be interested:

We welcome expressions of interest from individuals with a passion for improving care for people affected by BMFS. This may include:

- Healthcare professionals (e.g. nurses, GPs, specialists, allied health)
- Researchers or educators
- Individuals with experience in program development, evaluation, or stakeholder engagement
- People with relevant lived experience or interest in rare diseases

Time Commitment:

- Participation in regular committee meetings, anticipated to be monthly for the first six months, then quarterly thereafter, or as required.
- Flexible involvement depending on your availability and areas of interest
- Opportunities for both advisory input and active contribution (e.g. content development or presenting)

What you'll gain:

- Opportunity to contribute to a meaningful national initiative improving patient outcomes
- Collaboration with a multidisciplinary network of clinicians, researchers, and advocates
- Experience in education, program development, and knowledge translation
- Connection to MRV's broader work supporting patients and families affected by BMFS

Expression of Interest:

If you are interested in being involved, or if you have any queries regarding the role, please contact Jaya Soma (CRE Project Manager) via email at research@mrsv.org.au.