

**Maddie  
Riewoldt's  
Vision.**

# **Telehealth Nurse Consultation Service**

Bone Marrow Failure Syndromes, including  
Aplastic Anaemia and inherited Bone  
Marrow Failure Syndromes



**We care,  
we listen,  
we understand  
& we can assist**



Maddie Riewoldt's Vision (Maddie's Vision) is Australia's premier Bone Marrow Failure Syndromes (BMFS) charity. We have been fighting to find new treatments, and ultimately cures, since 2015 by raising funds to support innovative scientific research that will help us reach our goal.

We are proud of our partnerships with preeminent collaborative research institutes, hospitals and universities across Australia. We are resolute and unwavering in our commitment to improve the lives of those affected by this group of rare, complicated and chronic conditions.

Our Telehealth Nurse consultation service was established in 2019 and is accessible to anyone affected by Bone Marrow Failure Syndromes (BMFS), including patients newly diagnosed or undergoing long term follow up, carers, families, friends and health professionals. The service is part of a national Patient Pathways pilot program, an initiative funded by the Australian Department of Health, and co-ordinated by the Centre for Community-Driven Research (CCDR).

Our Nurse will listen, support, provide up-to-date information on advances in treatments, encourage and help you. The physical and emotional challenges associated with both acquired and inherited Bone Marrow Failure Syndromes are difficult.

**Let us help you navigate a pathway.  
We are here to provide assistance.**

# A legacy of a determined young woman

Maddie's Vision was established by the Riewoldt family in 2015 in honour of Madeleine Riewoldt, who passed away at the age of 26 from Aplastic Anaemia. Frustrated by the devastating lack of knowledge, treatments and resources devoted to BMFS, Maddie asked her family to make her a promise when her fight was ending - that nobody else went through what she did. Her legacy continues to make a difference to the world of BMFS.

## How our Nurse can help you

Every year, approximately 160 new cases of both acquired and inherited BMFS are diagnosed in Australia, the majority of whom are paediatric and adolescent. Thousands more are living each day with the challenges of these conditions. Our Telehealth Nurse consultation service utilises innovative measures and practical resources to deliver cutting edge care. Our Nurse is able to provide you with understanding, compassion and sympathy whilst simultaneously delivering up to date information about all aspects of BMFS care.

**Please note** that medical advice, doctor referrals, treatment recommendations or laboratory analysis are not included within the telehealth nurse's scope of practice.

## We are here to assist

**Please call 0477 884 955  
or send an email to [telenurse@mrv.org.au](mailto:telenurse@mrv.org.au)**

Our Nurse is available on both Monday and Wednesday business hours or pre-arranged appointment outside this time.

# Quick Facts about BMFS

BMFS are a group of rare diseases which have in common an inability of the bone marrow to produce sufficient red blood cells, white blood cells and platelets to meet normal physiological demands.

BMFS can be broadly divided into two types:

- Acquired Aplastic Anaemia
- Inherited syndromes, including Fanconi Anaemia, Schwachman Diamond Syndrome, Diamond Blackfan Anaemia, Dyskeratosis Congenita, Severe Chronic Neutropenia, Thrombocytopaenia Absent Radii and Congenital Amegakaryocytic Thrombocytopaenia.

In approximately 15% of all BMFS cases, there is a progression to the related conditions of Myelodysplastic Syndrome (MDS), Acute Myeloid Leukaemia (AML) and Paroxysmal Nocturnal Haemoglobinuria (PNH).



## Ways to Get Involved

There are many opportunities for our patient and family community to be involved with Maddie's Vision, including attending our biennial Patient and Family Forum, attending our National Scientific Symposium and participating in fundraising activities. We warmly embrace your interest and presence. Please email [admin@mr.v.org.au](mailto:admin@mr.v.org.au) or visit [mr.v.org.au](http://mr.v.org.au) for further information.

Maddie's Vision values inclusivity and diversity, we welcome all to be part of our big family.