



**A BRIGHTER
FUTURE**
**FOR PATIENTS LIVING WITH
BONE MARROW FAILURE
SYNDROMES AND THEIR FAMILIES**

Annual Report 2021/2022

 Maddie
Riewoldt's
Vision.

OUR VISION

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

OUR MISSION

Maddie Riewoldt's Vision funds research that accelerates next generation prevention, diagnosis and treatment of Bone Marrow Failure Syndromes while supporting patients and families.

STRATEGIC PRIORITIES



PRIORITY 1: FUNDING AND OPERATION

Continue to build a sustainable funding and operational base.



PRIORITY 2: RESEARCH

Develop and deliver a national research strategy overseen by the independent Scientific Advisory Committee and supported by the Centre of Research Excellence Executive. Fund the most promising bone marrow failure research aligned to our 5 pillars of research.



PRIORITY 3: PARTNERSHIPS

Develop and nurture valuable, long-term partnerships with business, philanthropy, government, and communities.



PRIORITY 4: REPUTATION AND PROFILE

Build a credible and professional national profile leading vital medical research and supporting patients and families across Australia.

CONTENTS

MADDIE'S STORY	4
CHAIR'S REPORT	6
OUR RESEARCH	7
SUPPORTING PATIENTS AND FAMILIES	12
ZAHRA'S JOURNEY	14
OUR VALUED COMMUNITY OF SUPPORTERS	19
GOVERNMENT	
PARTNERSHIPS	
PHILANTHROPY	
COMMUNITY	
THE MADDIE'S VISION TEAM	27
FINANCIAL RESULTS TO 30 JUNE 2022	28
HOW YOU CAN SUPPORT MADDIE'S VISION	31

MADDIE'S STORY

Maddie Riewoldt was just 26 years old when she tragically died of a Bone Marrow Failure Syndrome called Aplastic Anaemia. She was diagnosed at 21 years and for five tough years, she put up a brave fight. She spent those years enduring several bone marrow transplants, hundreds of blood transfusions and ongoing treatments.

Throughout her life and prior to her diagnosis, Maddie was a talented sportswoman, passionate about soccer, cricket, surf lifesaving and AFL. Maddie fought her battle with inspiring determination and courage. 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.

We are determined to find better treatments and cures, so please join us and together we will #FightLikeMaddie

WHAT ARE BONE MARROW FAILURE SYNDROMES?

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 fundamental disruptions to health.

Bone marrow failure can be acquired or inherited. Inherited bone marrow failure can include additional health challenges, including heart, skeletal malformations, kidney, eye and ear issues, and an increased risk of both solid organ and blood cancer.

Approximately 160 Australians are diagnosed with Bone Marrow Failure Syndromes each year. Distressingly, most of them are children and young adults and 50% will not survive. Thousands more are living with ongoing complex health issues. Diagnosis is often slow and difficult due to the complexity of the conditions. Many will develop blood cancer.

While some patients can manage their symptoms with existing therapies, the only established cure is bone marrow transplantation. However, bone marrow transplants don't always work and have a high risk of failure or adverse side effects. When patients don't respond to existing therapies, there aren't many options available.

That's why Maddie's Vision is here - to fund critical research and provide essential support, working towards improved outcomes for patients with Bone Marrow Failure Syndromes.



CHAIR'S REPORT

It was an honour to become the Chair of Maddie Riewoldt's Vision in early 2022, taking the reins from Nick Riewoldt, one of our founders and a driving force behind the extraordinary impact Maddie's Vision is having in the fight against Bone Marrow Failure Syndromes.

I look forward to representing the Riewoldt family, our patients and their families and the broader Maddie's Vision community as we enter an exciting phase in our history. There is much to do and along with the board, our incredible staff and volunteers, I am committed to leading an inclusive, respectful, and focused organisation, driven by our vision to find better treatments and support for our patients and their families.

I would like to acknowledge and thank Nick Riewoldt for his outstanding commitment and contribution during his time as Chair of Maddie's Vision. During this time, Nick's leadership helped navigate the organisation through the challenges of COVID, keeping us focused on our vision through global uncertainty. Whilst Nick has stepped down from the Chair role, he remains a member of the board and an extremely important part of the Maddie's Vision family.

I'd also like to thank Jack Riewoldt for his time as a member of the Maddie's Vision board. Jack has been an amazing support to the team, and we can't wait to see him play in the next Maddie's Match!

We were delighted to welcome Andrew Yeoland to the board in March 2022. Andrew brings

significant experience and expertise in general management, strategy, business transformation, sales, and marketing. In his short time on the board, Andrew has already made a terrific contribution.

The 2021-22 financial year was not without its challenges, as COVID restrictions in 2021 continued to limit our ability to hold events and engage with our community face to face. Amongst the changes in our day to day lives there were signs of hope, especially in early 2022 where we could gather once more. It was wonderful to connect again with our incredible community of patients, families, supporters, and volunteers.

As highlighted in this Annual Report on page 9, our research portfolio continued to expand, with six exciting new projects awarded in 2021-22, bringing our total to 31. Thanks to our Centre of Research Excellence in Bone Marrow Biology, the funds raised for Bone Marrow Failure Syndrome research are going to the most impactful projects. This is a critical aspect of why Maddie's Vision exists.

The Maddie's Vision Telehealth Nurse Consultation Service continued to grow and provide support and guidance to many patients and their families impacted by Bone Marrow Failure Syndromes across Australia. This service is unique. Before Maddie's Vision, this type of support did not exist. We are very proud of the positive impact we are making in helping patients and their families navigate their way through incredibly challenging times, which

is a testament to our nurse Mei Ling Yeh's expertise and empathy.

A sincere thank you to the patients and their families who have once again shared their stories to help others. Bone Marrow Failure Syndromes are rare, and often underfunded and under-supported. But by sharing these stories we will continue to increase awareness of these conditions and help raise vital funds to drive forward our mission.

In closing, I would like to thank my Board colleagues, the passionate Maddie's Vision team and our valued community of researchers, volunteers and supporters who work tirelessly to help us discover improved treatments and cures for Bone Marrow Failure Syndromes and enhance our critical support to patients and families.



A handwritten signature in black ink that reads "Ed Kemp".

Ed Kemp
Chair, Maddie Riewoldt's Vision

OUR RESEARCH

THE STORY SO FAR...

Since Maddie's Vision was founded in 2015, we've made an extraordinary impact into Bone Marrow Failure Syndrome research.

**\$7.7
MILLION
COMMITTED
TO RESEARCH**

**31
CUTTING-EDGE
RESEARCH PROJECTS**



**13
FELLOWSHIPS**



**13
GRANTS-IN-AID**



**2
CLINICAL
TRIALS**



**\$12.3
MILLION
FURTHER RAISED
FOR RESEARCH
THROUGH
LEVERAGING
MADDIE'S VISION
FUNDING BY OUR
GRANTEES AND
FELLOWS**

**3
GRANTS**



**27
JOURNAL
ARTICLES**



**140
SCIENTIFIC
PRESENTATIONS**



OUR 5 PILLARS OF RESEARCH:

- 1.** Comprehensive clinical data and sample collection of current and newly diagnosed patients with Bone Marrow Failure Syndromes
- 2.** Genomic, epigenetic and proteomic control of the haematopoietic stem cell (HSC) survival growth and differentiation
- 3.** The components and control of the HSC niche microenvironment within the bone marrow
- 4.** Abnormalities of immune function
- 5.** Monitoring and predictors (biomarkers) of prognosis, response to treatment and disease evolution

DIRECTOR OF CENTRE OF RESEARCH EXCELLENCE REPORT

In my 2021 annual report I hope that any reader would have been left with the impression that the research efforts and outputs of the Centre of Research Excellence (CRE) members are amplified by a commonality of purpose, a collaborative spirit and deep feeling of community engagement. Those three principles, commonality, cooperation and community, are at the heart of Maddie's Vision, and have never been more evident for the CRE than in 2021-22.

Since my last report, we have welcomed new members including, Ms Rachel Edwards, our inaugural Fiona Riewoldt nursing Fellowship recipient, Dr Lorna McLeman, PhD fellowship, Dr Steven Keogh, grant in aid recipient and Dr Kath Cummins, Gunn family women-in-research recipient.

You will be able to read of their outstanding work in the pages of this year's report. As our scientific community has grown, so too has the opportunities for collaboration. Collaboration starts with a conversation that identifies a commonality of purpose and a realisation that more can be achieved together than separately. It is that togetherness that is the foundation of community. As our CRE community has welcomed more members, they have brought with them their own network of collaborators through which new conversations can start and so the research capacity towards

a cure for Bone Marrow Failure Syndromes grows. Those same principles are demonstrated throughout all aspects of Maddie's Vision's work, from community engagement, patient and family support, donor partnerships and fundraising events, all of which are deeply acknowledged and proudly reflected in the work of the CRE. Examples abound in our scientific projects, where more has been achieved by the formation of a community, than can be achieved by individual researchers alone.

Our strategic process of project support, local collaboration which builds to international collaboration, and leading to better lives for patients with Bone Marrow Failure Syndromes, remains the centrepiece of the CRE. Our international reach has been particularly prominent in 2022 with Dr Ashvind Prabahan starting a 12-month fellowship at the National Institute of Health in the US, and a strong representation of Maddie's Vision-funded work at the European School of Hematology-Bone Marrow Failure Syndromes conference in Paris.

The Centre of Research Excellence prides itself on being a collective made from and supported by the wider Bone Marrow Failure Syndrome community, all linked by the common purpose of better lives for patients.



A handwritten signature in black ink, appearing to read 'D Ritchie'.

Professor David Ritchie
Director, Centre of Research
Excellence in Bone Marrow Biology

OUR GROWING RESEARCH PORTFOLIO

Maddie's Vision's Centre of Research Excellence in Bone Marrow Biology continues to propel innovative efforts to expand its research portfolio across basic, translational and clinical trials research.

Throughout the 2021-2022 financial year, we were thrilled to execute six new research agreements for cutting-edge projects and critical research infrastructure, growing our research portfolio to a total of 31 projects!

The six new projects represent an investment of \$1.31 million over the next two to three years:



Grant agreement executed with Biobanking Victoria for the Australian Marrow Failure Biobank, led by **Professor Melissa Southey**. The Biobank will be a national repository of blood and bone marrow samples for use by researchers in developing new treatments and cures for Bone Marrow Failure Syndromes.



Grant in aid awarded to **Dr Steven Keogh** for his work in reporting outcomes of paediatric stem cell transplantation, on behalf of the Transplant and Cellular Therapy in Children Group of The Australian and New Zealand Children's Haematology/ Oncology Group, in conjunction with the Australasian Bone Marrow Transplant Recipient Registry.



Fellowship awarded to **Dr Rachel Koldej** for her project, 'Dissecting immune dysregulation in acquired bone marrow failure syndromes to identify new therapeutic leads', at the ACRF Translational Research Laboratory, Melbourne Health.



Gunn Family Women in Haematology Fellowship, co-funded with the Snowdome Foundation, awarded to **Dr Katherine Cummins** for her project titled 'Synergising CD47 blockade with chimeric antigen receptor T-cell', at the Peter MacCallum Cancer Centre.



Grant in aid awarded to **Dr Lorna McLeman** for her work in 'Precision gene editing for the treatment of Fanconi Anaemia', at the Genome Stability Unit of St Vincent's Institute for Medical Research.



Inaugural Fiona Riewoldt Fellowship awarded to **Rachel Edwards** at the Queensland Children's Hospital for her project titled, 'Improving capability and capacity of nurses to assess and manage young people with symptoms associated with acquired and inherited bone marrow failure syndromes'.



Pictured: Rachel Edwards and the Bone Marrow Transplant team at Queensland Children's Hospital. From left to right: Ms Jill Shergold, Professor Natalie Bradford, Ms Rachel Edwards, and Ms Rebecca Beardmore.

SUPPORTING OUR YOUNG PATIENTS – THE INAUGURAL FIONA RIEWOLDT FELLOWSHIP

As a clinical nurse consultant in haematology and bone marrow transplantation, Rachel Edwards has seen first-hand the effects the treatment has on young people with Bone Marrow Failure Syndromes.

While bone marrow transplants can be a cure for Bone Marrow Failure Syndromes, children and young people undergoing bone marrow transplant experience distressing symptoms because of their treatment and a long hospital stay.

Rachel was awarded the inaugural Fiona Riewoldt Fellowship, and her project aims to improve symptom management for children and adolescents aged 2-18 who have received a transplant.

The research has two arms: co-designing and implementing nursing education resources to support evidence-based symptom assessment and management and exploring the use of a patient-reported outcome measure (PROM) in clinical practice to support symptom assessment.

This project hopes to improve the capability and capacity of nurses, enabling better assessment and documentation of symptoms, improved communication between the patient, family and the healthcare team, and provision of best practice interventions to manage symptoms.

“Young people receiving bone marrow transplantation for Bone Marrow Failure Syndromes have complex healthcare needs,” Rachel explains. “They are best managed by an interdisciplinary care team including nurses who are competent and capable to both assess and manage symptoms associated with the condition and caused by the treatment.”

There is robust evidence for the use of PROMs in adult clinical practice, but little is known about their use in the paediatric inpatient bone marrow transplant setting, particularly for Bone Marrow Failure Syndromes. Implementing a PROM in this project will help understand and identify the type of symptoms and level of distress experienced by patients receiving a bone marrow transplant and how information from symptom screening can inform nursing care in this treatment setting.

**”
EMPOWERING NURSES WITH THE SKILLS, KNOWLEDGE, AND TOOLS TO SUPPORT SYMPTOM ASSESSMENT AND MANAGEMENT WILL OPTIMISE AN EARLY INTERVENTION FOR DIFFICULT SYMPTOMS, REDUCING DISTRESS ASSOCIATED WITH TREATMENT AND IMPROVING SYMPTOM BURDEN AND QUALITY-OF-LIFE FOR YOUNG PEOPLE WITH BONE MARROW FAILURE SYNDROMES.
”**

Rachel is grateful for the opportunity the Fellowship provides. “The Fiona Riewoldt Fellowship has supported me by providing protected time outside my clinical role to conduct this study and has given me the opportunity to pursue a higher research degree. I am very grateful for the generous sponsorship of Flavorite, who partner with Maddie’s Vision to help make this Fellowship possible.”

OUR SCIENTIFIC ADVISORY COMMITTEE

We are extremely grateful to all Scientific Advisory Committee (SAC) committee members who willingly volunteered countless hours of their time in assessing and reviewing grant applications, monitoring active grants and providing invaluable expertise and direction to the Centre of Research Excellence research strategy.

We gave heartfelt thanks to retiring SAC member **Associate Professor Rachel Conyers** for her outstanding contribution as SAC Deputy Chair and committee member from 2016-2021. We also welcomed our newest committee member **Associate Professor Zoe McQuilten**, consultant haematologist at Monash Health and a NHMRC Emerging Leader Fellow at Monash University. Zoe is also the Deputy-Director of the Transfusion Research Unit at Monash University and a senior research fellow with the Australian and New Zealand Intensive Care Research Centre.

SAC members who served throughout 2021-22 include: **Professor David Ritchie** (Chair), **Dr Pasquale Barbaro**, **Associate Professor Rachel Conyers**, **Dr Andrea Henden**, **Dr Duncan Purtill**, **Associate Professor Zoe McQuilten**, **Professor Kanta Subbarao** and **Associate Professor Ingrid Winkler**.

Thank you to the SAC for your time and outstanding commitment to Maddie’s Vision throughout 2021-22.

We would also like to thank our Centre of Research Excellence in Bone Marrow Biology Executive, Symposium Steering Committee and the Gene and Cellular Therapy Subcommittee and recognise their incredible work and commitment to our research initiatives.

SUPPORTING PATIENTS AND FAMILIES

TELEHEALTH NURSE CONSULTATION SERVICE REPORT

The Maddie's Vision Bone Marrow Failure Syndrome community of supporters has grown bigger and stronger. With common goals, we worked together to fight for the best patient care possible amidst many uncertainties. I would like to say a huge thank you to each of you for your generosity, kindness and understanding to each other and our patients with Bone Marrow Failure Syndromes. A special thanks to the organisations who help ensure our patients and families have access to the best possible support: Koala Kids Foundation, My Room Children's Cancer Charity, Children's Cancer Foundation, Challenge, Arrow Bone Marrow Transplant Foundation, Little Dreamers and many more.

Our Telehealth Service is the only available service for Bone Marrow Failure Syndrome patients in Australia. Thus far, our service has provided holistic support to 72 patients and families Australia-wide. The patients are from a wide range of ages – the youngest is three years old, and the oldest is 71. One-third of our patients are newly diagnosed or currently receiving intense treatments. Others are in maintenance after receiving a bone marrow transplant or immunosuppressant therapy and require long-term clinical follow-up.

Family-centred comprehensive care is the focus of the Telehealth Support Service. We ensure that our patient and family's needs and well-being are understood, evaluated, and fulfilled. This holistic approach and expertise in Bone Marrow Failure Syndromes make our service unique.

With the enormous clinical support from haematologists around Australia, our service has been able to provide up-to-date information and a high standard of care to our Bone Marrow Failure Syndrome patients and families.

By supporting patients and families to acknowledge their worries and articulate their treatment and care-related questions, we empower them to make informed decisions about their management and care.

Finally, I want to acknowledge the Bone Marrow Failure Syndrome patients, families and carers who have trusted us to support them in 2021-2022. It is for you that we advocate and work tirelessly to ensure the best patient care possible.



Mei Ling Yeh
Maddie's Vision Telehealth
Consultation Nurse

”
OUR TELEHEALTH SERVICE IS THE ONLY AVAILABLE SERVICE FOR BONE MARROW FAILURE SYNDROME PATIENTS IN AUSTRALIA. THUS FAR, OUR SERVICE HAS PROVIDED HOLISTIC SUPPORT TO 72 PATIENTS/FAMILIES AUSTRALIA-WIDE.
”

WHAT THE TELEHEALTH NURSE CONSULTATION SERVICE MEANS TO US

When Anna's daughter Zahra was diagnosed with Severe Aplastic Anaemia and then Myelodysplastic Syndrome, she found the support from Mei Ling invaluable.

”

What would we have done without Mei Ling? Once Zahra was diagnosed with Aplastic Anaemia, Mei Ling gave us a call not long after we returned home from her first hospital admission. We began our weekly check-ins with Mei Ling, who was able to provide more detailed information about what the medical team would tell us; particularly the medications and any symptoms or side effects Zahra was having.

As we were new to this world, there was a lot we didn't know. We didn't know what to ask or where to look for trustworthy information online. Mei Ling has a wealth of knowledge, and provided us with more reading material which allowed us to be more informed as we got closer to treatment for Zahra.

Mei Ling also became a friendly voice on the other side who we were able to connect with, as she knew about Zahra's condition and what it meant. It was difficult as a lot of family and friends, whilst extremely supportive, were not able to fully support us in the way that people in the medical world could.

We were lucky enough to meet Mei Ling in person whilst Zahra was in the bone marrow transplant ward, and she looked after not only Zahra, but us as well. She became part of our family.

Post-transplant, Mei Ling has continued to check in. She understood that the journey had not ended, and that the emotional and mental effects of Zahra's diagnosis and treatment had started to rear its head. She has continued to provide further support in dealing with some of the symptoms Zahra developed post-transplant and reassured us during stressful periods when we waited for a call from the hospital.

Mei Ling has been, and continues to be, a big part of the journey.

”

If you or a loved one is impacted by Bone Marrow Failure Syndromes and need support, contact our Telehealth Service via email: telenurse@mrv.org.au.



ZAHRA'S JOURNEY

Zahra is a charming and curious toddler. She is very cheeky, chatty, clever and fiercely independent. Zahra is curious about the world around her and likes to know how things work. She has a sharp mind, and a very good memory - often randomly bringing up little things that happened from months before!

Soon after Zahra started day-care in early 2021, she began to become unwell more frequently. Her mother Anna noticed that she was bruising a lot on her legs and she would get some petechiae on her body. Zahra's fatigue and symptoms increased, and at a family holiday her parents noticed she was lethargic and didn't want to play or eat. Zahra was taken to the Royal Children's Hospital Emergency Department, where they were seen immediately and given blood tests.

"We were told the results may take at least an hour or two, and so we kept Zahra as comfortable as we could. Within half an hour, a haematologist came in and told us that they had come across some irregular results; Zahra's haemoglobin level was seven - the lowest they had ever seen in someone who was still alive." Anna says.

As soon as Zahra was given a blood transfusion, some colour started returning to her face. She was smiling and started making cheeky comments to the nurses. For her parents, this was such a relief to see!

Once Zahra was stable, the haematologist spoke to her parents about the various avenues they were investigating for a diagnosis. Their initial look at her blood work warranted further investigation; a bone marrow biopsy and aspirate.

"This is when we knew things weren't looking good, and Zahra just wasn't low in iron." Anna says. "When we realised that the ward was dedicated to looking after oncology patients, we were filled with dread. Something that still hasn't fully left us."

By the end of the week, Zahra received a diagnosis of Severe Aplastic Anaemia. The following weeks, Zahra had regular outpatient appointments in Day Oncology, receiving blood and platelet transfusions, and dressing changes.

Some things had changed in her bone marrow, Zahra's cells were looking abnormal and now everything was back on the table.

Anna says the feeling of dread returned when Zahra received a new diagnosis of Myelodysplastic Syndrome, a condition that develops from Severe Aplastic Anaemia. "It meant that the only treatment option now was for a bone marrow transplant and Zahra needed to be put on the registry immediately."

” WE WERE TOLD THE RESULTS MAY TAKE AT LEAST AN HOUR OR TWO, AND SO WE KEPT ZAHRA AS COMFORTABLE AS WE COULD. WITHIN HALF AN HOUR, A HAEMATOLOGIST CAME IN AND TOLD US THAT THEY HAD COME ACROSS SOME IRREGULAR RESULTS; ZAHRA'S HAEMOGLOBIN LEVEL WAS SEVEN - THE LOWEST THEY HAD EVER SEEN IN SOMEONE WHO WAS STILL ALIVE. ”





THE GIFT OF A LIFE-SAVING BONE MARROW TRANSPLANT

Zahra's parents received the good news that not one, but two anonymous cord blood donors from overseas were a solid match. Zahra and her family spent Christmas, New Year, and Zahra's 3rd birthday isolated in hospital for the transplant, with hospital staff making the experience as festive as possible.

The bone marrow transplant journey has been long and hard for Zahra. From pre-transplant procedures that resulted in additional admissions and fertility preservation with removal of an ovary. "Zahra continued to be her resilient self, which helped us as her parents be strong for her." Anna says.

While the bone marrow transplant was successful, the road to recovery was difficult. During that time, Zahra also had to learn to walk again after three months. Being so unwell, she was not up for walking and stayed in bed or was carried to the couch. It took some coaxing, but after a few initial difficult sessions with the physiotherapist, Zahra started to build up more strength on her own and was waddling through the ward in no-time.

Zahra was finally discharged exactly three months after her admission, finally coming out of the isolation of the bone marrow transplant ward for the first time.

One long journey ending, with the recovery process just getting started.

LOOKING TO THE FUTURE

Whilst most of Zahra's recovery has been good, it hasn't been without its hiccups. Bone marrow transplants can be a difficult treatment, and Zahra is currently seeing specialists for health concerns as a result of the transplant.

"Whilst a lot of Zahra's treatment went according to plan, it is still quite a scary thing to experience as parents. As new symptoms appear, we always worry about what it could mean." Anna explains.

Zahra's hair has grown back after her chemotherapy, and Anna says her cheeky personality is back too. "She's gotten through the most difficult part of treatment, and now we continue with regular hospital reviews to ensure that her blood work looks good and nothing changes. This will be her new normal for at least another year. We're now looking forward to her Zahra starting kinder in 2023."

”WHILST A LOT OF ZAHRA’S TREATMENT WENT ACCORDING TO PLAN, IT IS STILL QUITE A SCARY THING TO EXPERIENCE AS PARENTS. AS NEW SYMPTOMS APPEAR, WE ALWAYS WORRY ABOUT WHAT IT COULD MEAN.”



E GOT THEM BY THE TA



**THANK YOU TO OUR
AMAZING COMMUNITY
OF SUPPORTERS. WE
ARE DEEPLY GRATEFUL
FOR YOUR COMMITMENT
TO MADDIE'S VISION
AND FOR BEING AN
ESSENTIAL PART OF OUR
IMPORTANT JOURNEY.**

Maddie Riewoldt's Vision
CAPTAIN COACHES FOUNDATION
DATE: 03/04/2022
PAY TO: Maddie Riewoldt's Vision
\$ 310,000
Three hundred and ten thousand dollars
DOLLARS \$

Long TRIATHLON Done!

NO RESERVE
CLARITY HOME AUCTION
PAY: Maddie Riewoldt's vision
THE SUM OF: SEVEN HUNDRED & FIFTY THOUSAND
\$750,000
TOTAL VALUE

OUR VALUED COMMUNITY OF SUPPORTERS

GOVERNMENT



Australian Government
Department of Health



Jobs,
Precincts
and Regions



CENTRE FOR COMMUNITY-DRIVEN RESEARCH

The Australian Government Department of Health generously awarded Maddie's Vision with two Medical Research Future Fund grants in 2019 and 2020. These multi-year clinical trials - EMBRACE and RESELECT - continued throughout 2020/2021 to improve patient care. The EMBRACE study (Evaluating Multidisciplinary Bone maRow failure CarE) has provided approximately 250 patients with complex genomic testing leading to improved diagnosis and therefore more personalised treatment. The RESELECT study (REscuing bone marrow function in patients with relapsed acquired aplaStic anaEmia and/or bone marrow failure post aLlogeneic stEm Cell Transplantation) remains active and of high scientific value. Since opening, 7 patients have been recruited on the trial which aims to test the safety and efficacy of combination N-Acetyl-Cysteine and Atorvastatin in this patient group. In addition, correlative blood and bone marrow samples are being collected and investigated to provide insights into the pathophysiology, diagnosis and treatment of poor graft function and Aplastic Anaemia.

We are deeply grateful to the Victorian Government, through the Department of Jobs, Precincts and Regions, for funding the establishment of our Centre of Research Excellence (CRE) - an Australian first. Since 2018, the CRE has propelled our research activity from 8 to 31 cutting-edge research projects, supporting and nurturing unique multidisciplinary collaborations. This has enabled us to build a critical mass of researchers to accelerate and amplify much-needed Bone Marrow Failure Syndromes research outcomes. By partnering with key medical research institutions, we have ignited national and international research initiatives, further elevating Victoria's profile in the medical research community.

Thank you to the Australian Department of Health and Aged Care and the Centre for Community-Driven Research for being the founding partner of our valued Telehealth Nurse Consultation service. The service has now grown to support 72 patients and families living with Bone Marrow Failure Syndromes.

VICTORIAN
CANCER
AGENCY



The Victorian Cancer Agency (VCA) works to enable cancer research across Victoria. We are thrilled to partner with the VCA via the co-funded VCA/ Maddie's Vision International Travelling Fellowship, awarded to Dr Ashvind Prabharan. Dr Prabharan is currently undertaking studies at the Hematopoiesis and Bone Marrow Failure Laboratory NHLBI, Bethesda MD USA.

PARTNERSHIPS



FAIRHAVEN HOMES AND BALCON GROUP

Home auction for Maddie's Vision is a true labour of love

Fairhaven and Balcon Group held a No Reserve auction at Orana Estate in Clyde to sell the beautiful Mayfield 219 – a fully furnished home with landscaped gardens and state of the art appliances. Proceeds from the auction were donated to Maddie's Vision to fund research into Bone Marrow Failure Syndromes.

The serious bidders were entertained by the Fox FM crew, including ambassadors Fifi Box and Brendan Fevola, while waiting for the auction to start. Real Properties expertly ran the auction and at the fall of the hammer, \$750,000 was raised for Maddie's Vision. Thank you to both teams at Fairhaven and Balcon Group for all their hard work and generosity.



FLAVORITE

Maddie's Month 2021: How tomatoes and capsicums are making a big difference

Australians made a difference to people with Bone Marrow Failure Syndromes by including delicious tomatoes and capsicums in their weekly shop at Coles Supermarkets. Our long-term partners at Flavorite again raised \$100,000 for Bone Marrow Failure Syndromes research in November by donating 10c from every specially marked pack of their tomatoes and capsicums to Maddie's Vision.

The campaign honours two courageous Australians – Mark Millis, one of the founders of Flavorite, who battled blood cancer, and Maddie Riewoldt. Maddie and Mark are sadly no longer with us, but their families proudly continue their legacy.

Funds raised from the campaign supported the inaugural Fiona Riewoldt Nursing and Allied Health Fellowship. Named in honour of Maddie's mum Fiona, this research Fellowship recognises the essential role nurses and allied health staff play in supporting and caring for patients.

Thanks again to our partners at Flavorite for their continued support.



CAPTAIN COURAGEOUS AND MADDIE'S VISION

Joining forces with a shared vision

For ten years, the Captain Courageous Foundation raised money and awareness for Bone Marrow Failure Syndromes. The foundation's mission is to seek a cure for children suffering life-threatening bone marrow failure diseases by funding crucial medical research. It is one that is strongly aligned with Maddie Riewoldt's Vision. We fight the same fight.

This year, Captain Courageous joined forces with Maddie's Vision and by pooling our resources, we'll increase our momentum to find better treatments and cures.

The organisations celebrated the new partnership at this year's Maddie's Match. Jess and Angus Bond from Captain Courageous joined us and presented the Riewoldt family with a cheque for \$310,000 which will fund the Captain Courageous Fellowship, administered by Maddie's Vision through our Centre of Research Excellence in Bone Marrow Biology.





THE ALEX GADOMSKI FELLOWSHIP

Alex's legacy making a powerful impact

Alex Gadomski tragically died at the age of 21 in 2017 after a five-year fight with Aplastic Anaemia, followed by Myelodysplasia. In collaboration with Maddie's Vision, his family (mother Janet, father Paul, and brothers Jordan and Lachlan) created a fellowship position, the Alex Gadomski Fellowship, and a scholarship position, the Alex Gadomski Postgraduate Scholarship, to help find a cure for Bone Marrow Failure Syndromes.

Alex's family have mobilised an incredible community in Tasmania, raising generous funds and ensuring his legacy is harnessed to support innovative medical research towards finding a cure.

Thank you to Janet, Paul, Lachlan and Jordan Gadomski for their incredible work raising funds and awareness so that we can fight Bone Marrow Failure Syndromes.



The Live Life Gala Ball

This is the major annual fundraiser for the Fellowship and was once again a sell out event thanks to the wonderful ongoing support of sponsors and the Tasmanian Community. Guests were treated to fine food and wine, danced the night away to cover band Everburn and enthusiastically bid on live and silent auctions. Thank you to all the organisations that supported this event, including platinum sponsor IGA Tasmania and Wrest Point.



The 7HOFM Bloody Long Triathlon

An extraordinary effort was made by Jordan and Lachlan Gadomski and the crew in Tasmania, who took on the Bloody Long Triathlon in December 2021. The group cycled 400km, ran 100km, and swam 15km to raise funds for the Alex Gadomski Fellowship, driving bone marrow failure research at the Menzies Institute for Medical Research. Thanks to the incredible sponsors, including 7HOFM and IGA Tasmania.



The Gadomski/Riewoldt Trophy

Kingborough Tigers Football Club and Clarence Football Club played the annual Gadomski/Riewoldt trophy match in honour of the courage that both Alex Gadomski and Maddie Riewoldt displayed in their personal battles with Bone Marrow Failure Syndrome. At the end of the match the Tigers won, ensuring the trophy remains proudly in Tigerland with courage medals presented to worthy recipients Sam Green of Clarence and Ben Donnelly of the Tigers. Congratulations to both teams on an outstanding game.



NICK RIEWOLDT WINS CELEBRITY MASTERCHEF FOR MADDIE

Where passion for purpose is a vital ingredient

After an exciting season filled with great food and competition, Nick Riewoldt was crowned the winner of Celebrity MasterChef 2021!

Nick told viewers that his sister Maddie was “A big part of the motivation for coming on MasterChef, because she passed away in 2015 from bone marrow failure. She was 26. She was a huge advocate for change in that space and we’ve picked up that challenge in her name. MasterChef was right up her alley. I’m so determined to do her proud on this show.” Nick absolutely did Maddie and the whole Maddie Riewoldt’s Vision community proud.

By winning the coveted Celebrity MasterChef trophy, Nick raised a total of \$100,000 for Maddie Riewoldt’s Vision, his chosen charity. The prize money will power our fight for better outcomes for patients with Bone Marrow Failure Syndromes.



ST KILDA FOOTBALL CLUB

Maddie’s Match lights up the city in support of patients and families

Maddie was a passionate Saints supporter and loved to watch her big brother Nick Riewoldt and cousin Jack Riewoldt fighting it out on the footy oval. To honour Maddie’s memory, St Kilda hosts Maddie’s Match during their home game against Richmond. The first Maddie’s Match in 2015 funded our first medical research project, and with the incredible support of the Saints and many others it’s become a regular fixture and a massive highlight for fans.

This year the 7th Maddie’s Match was held at Marvel Stadium during Round 3, Sunday, 3 April. Fans flocked to Marvel in their best purple outfits to support Bone Marrow Failure Syndromes patients. This year, fans enjoyed a special luncheon held at the St Kilda Premier Lounge, with lunch and afternoon tea designed by Merrywell, Crown.



After Maddie’s Match, icons across Melbourne lit up purple in support of people living with Bone Marrow Failure Syndromes and the fight for new treatments and cures. Some locations included Melbourne Cricket Ground (MCG), Rod Laver Arena, AAMI Park Flinders Street Station, and 101 Collins Street.

Thank you to everyone who made Maddie’s Match so special this year, including the Richmond Football Club, QMS Billboards, Mike Tarr photography and more. We couldn’t do Maddie’s Match without the support of our founding partners, the St Kilda Football Club. Thank you for your continued commitment to Maddie’s Vision.



PHILANTHROPY



Thank you to the Fox Family Foundation for their support of projects such as “Evaluating Multidisciplinary Bone Marrow Failure Care (EMBRACE) trial in Bone Marrow Failure and Related Disorders” project, the DIAAMOND trial biobank sub-study and the Australian Marrow Failure Biobank, launched in April 2021.

GUNN FAMILY FOUNDATION

Through the generosity of the Rae and Peter Gunn Family Foundation we celebrate our joint fellowship with the Snowdome Foundation. Thanks to the Foundation, we are able to support Dr Belinda Guo and Dr Katherine Cummins in undertaking their Gunn Family – Women in Haematology Fellowships.

COMMUNITY



JANE'S ARMY

A dedicated community comes together for Jane's Match

The St Bede's Mentone Tigers with Jane's Army held the 4th annual Jane's Match in memory of Jane Barnes, who tragically passed away from leukaemia in 2018. On the day players, supporters and the community came together to pay tribute to Jane and raise funds and awareness for Maddie Vision. Guests included Maddie's Vision ambassadors Brendan and Alex Fevola, and Joe Riewoldt. It was an event enjoyed by all, with \$30,000 raised for Bone Marrow Failure Research in honour of Jane. Thank you to the always dedicated and inspiring Jane's Army and the St Bede's Mentone Tigers for your support.



THANK YOU TO OUR COMMUNITY OF SUPPORTERS

We would also like to recognise the generosity and support of the **Sandringham Zebras, Vic Rajah Lawyers, Dark Horse Capital** and **Otway Junction** for their fundraising activities which helped us work towards our mission. Thank you so much.



COLLABORATIVE RESEARCH INSTITUTIONS

Thanks to our collaborative research institutions which form a critical part of the Maddie's Vision community and our Centre of Research Excellence:



PRO BONO

Thank you to all our pro bono partners, whose valuable ongoing support enables us to use more of our funds on the important research that's needed to find better treatments and cures for Bone Marrow Failure Syndromes.



Thank you to Anthony Willis and Victoria Rowe for your financial accounting expertise and management services that ensure we're always up to date and compliant with our financial reporting obligations.



Thank you to DLA Piper for your ongoing legal support and expertise.

SBA LAW

Thank you to Richard Moshinsky and Eleanor Weir for your tireless support in drafting and reviewing the research agreements with our growing numbers of research institute partners.



A massive thank you to Adrian Nathanielsz and his team for undertaking our annual audit, ensuring that we comply with the relevant accounting standards, that our financial reports are accurate and transparent and that we meet our regulatory obligations.

TOWN SQUARE

Heartfelt thanks to the incredible team at Town Square for your ongoing creative support of the Bloody Good Dinner.

dexus

Thank you to Dexus for providing the team at Maddie's Vision with pro bono office space. This office space in the heart of Melbourne's CBD has enabled us to connect with our supporters, partners and researchers face to face and is a valued home for the Maddie's Vision team.

THANK YOU TO ALL OUR DONORS AND VOLUNTEERS

Thank you to all the committed and generous people who supported us this year. Whatever you did, and however much you were able to donate, your invaluable support is making such a difference. You are helping to realise our mission of finding improved treatments and cures for Bone Marrow Failure Syndromes.

THE MADDIE'S VISION TEAM

M Riewoldt Holdings is registered with the Australian Charities and Not-for-profits Commission (ACNC) as a DGR Type 1 organisation (Health promotion charity). [acnc.gov.au/charity/charities/f5742f11-cb01-e911-a96e-0003ado64bd/profile](https://www.acnc.gov.au/charity/charities/f5742f11-cb01-e911-a96e-0003ado64bd/profile)

Edward Kemp
Chair

Kieran O'Brien
Director

Michelle O'Brien
Director

Jack Riewoldt
Director to September 2021

Nick Riewoldt
Director

Professor David Ritchie
Director, Centre of Research Excellence in Bone Marrow Biology and Chair Scientific Advisory Committee

Amanda Stevens
Director

Andrew Yeoland
Director from March 2022

Elaine Montegriffo
CEO

Lou Johns
Projects Administrator,
Centre of Research Excellence
in Bone Marrow Biology

Maggie Lynch
Senior Executive Administrator

Dr Simonne Neil
Director of Operations, Centre
of Research Excellence in Bone
Marrow Biology to February 2022

Jane Nethercote
Marketing and Communications
Manager to April 2022

Jaya Soma
Project Manager, Centre of Research
Excellence in Bone Marrow Biology
from June 2022

Mei Ling Yeh
Telehealth Nurse Consultant

FINANCIAL RESULTS TO 30 JUNE 2022

STATEMENT OF FINANCIAL POSITION AS AT 30 JUNE 2022

	Note	30 June 2022	30 June 2021
		\$	\$
Current assets			
Cash and cash equivalents	5	4,540,858	3,942,035
Receivables	6	97,977	114,619
Inventories		17,609	12,439
Total current assets		4,656,444	4,069,093
Non-current assets			
Plant and equipment	7	4,224	6,303
Intangible assets	8	474	592
Total non-current assets		4,698	6,895
Total assets		4,661,142	4,075,988
Current liabilities			
Payables	9	60,840	158,112
Employee entitlements	10	23,880	24,769
Deferred grant revenue		848,946	1,321,225
Total current liabilities		993,666	1,504,106
Non-current liabilities			
Employee entitlements	10	10,443	9,442
Deferred grant revenue		249,797	166,259
Total non-current liabilities		260,240	175,701
Total liabilities		1,193,906	1,679,807
Net assets		3,467,236	2,396,181
Equity			
Retained earnings		3,467,236	2,396,181
Total equity		3,467,236	2,396,181

**STATEMENT OF SURPLUS OR DEFICIT AND OTHER COMPREHENSIVE INCOME
FOR THE YEAR ENDED 30 JUNE 2022**

	Note	30 June 2022	30 June 2021
		\$	\$
Revenue	4(a)	2,945,555	1,436,908
Other income	4(b)	20,000	127,643
Total income		2,965,555	1,564,551
Research grant expenses		1,351,234	1,571,041
Centre of Research Excellence costs		13,518	72,043
Employee expenses – research		130,922	120,299
Employee expenses – administration		329,374	259,554
Fundraising costs		7,769	4,623
Merchandise costs		9,414	10,394
Other expenses		52,269	94,893
Total Expenses		1,894,500	2,132,847
Surplus/(Deficit) before tax		1,071,055	(568,296)
Income tax expense		–	–
Surplus/(Deficit)		1,071,055	(568,296)
Other comprehensive income			
Total other comprehensive income		–	–
Total comprehensive income		1,071,055	(568,296)

STATEMENT OF CASH FLOWS FOR THE YEAR ENDED 30 JUNE 2022

	Note	30 June 2022	30 June 2021
		\$	\$
Cash flows from operating activities			
Receipts from customers and donors		2,716,876	1,609,771
Receipts from government grants (AASB 1058)		20,000	127,643
Payments to suppliers and employees		(2,138,053)	(2,240,024)
Net cash from/(used in) operating activities	11	598,823	(502,610)
Cash flows from investing activities			
Payments for property, plant & equipment	7	-	(3,430)
Net cash used in financing activities		-	(3,430)
Net increase/(decrease) in cash and cash equivalents		598,823	(506,040)
Cash at the beginning of the financial year		3,942,035	4,448,075
Cash at the beginning of the financial year		4,540,858	3,942,035

STATEMENT OF CHANGES IN EQUITY FOR THE YEAR ENDED 30 JUNE 2022

	Note	Retained earnings	Total equity
		\$	\$
Balance at 1 July 2020		2,964,477	2,964,477
Deficit		(568,296)	(568,296)
Total comprehensive income		(568,296)	(568,296)
Balance at 30 June 2021		2,396,181	2,396,181
Balance at 1 July 2021		2,396,181	2,396,181
Surplus		1,071,055	1,071,055
Total comprehensive income		1,071,055	1,071,055
Balance at 30 June 2022		3,467,236	3,467,236

ABRIDGED FINANCIAL STATEMENTS AND AUDITED ACCOUNTS

The financial statements that form part of this Report are abridged. The complete Annual Accounts and Audit Report of Maddie Riewoldt's Vision can be found online at www.acnc.gov.au/charity/charities/f5742f11-cb01-e911-a96e-000d3ado64bd/documents. These statements should be read in conjunction with the accompanying Notes to the Financial Statements.

HOW YOU CAN SUPPORT MADDIE'S VISION

BECOME A MADDIE'S VISION REGULAR DONOR

Regular giving is an incredibly valuable way of providing ongoing support for Maddie's Vision. Whilst we have achieved so much, there is still much more to be done to find those cures, and we'd love your help! Knowing we have dependable, ongoing sources of funding means that we can confidently commit to more research and support for patients and families.

FUNDRAISE

Whether you're a club, a business, a school or a family, starting your own fundraiser is a fun way to raise awareness and funds for Bone Marrow Failure Syndromes. If you'd like to create your own personal fundraiser, it's quick and easy to set up a page on our website.

IN MEMORY

Many families approach us who would like people to make donations instead of sending flowers in memory of someone they love. You can create an 'In loving memory' page on our website. You can also make a one-off in memory donation.

WORKPLACES

Your workplace is a great place to begin your fundraising efforts. Raise funds and workplace morale at the same time! Employers can also facilitate tax effective regular workplace giving as a simple, efficient and ethical way for businesses and their employees to support causes such as Maddie Vision – ask your employer about workplace giving!

Visit mrv.org.au to find out how you can donate or start your own fundraiser today!



MADDIE RIEWOLDT'S VISION

ABN 20 613 016 765

Postal: PO BOX 18029, Collins St East VIC 8003

Phone: 0477 003 940
Website: www.mrv.org.au
Email: admin@mrv.org.au

Facebook: Maddie Riewoldt's Vision
Twitter: @MaddiesVision
Instagram: MaddiesVision

