

Thank you!

Celebrating
our community

Annual Report 2020/2021

Our vision and strategic priorities

Our vision is that Australians diagnosed with Bone Marrow Failure Syndromes get to live long, happy healthy lives.

Our mission is to fund the vital medical research needed to discover improved treatments and cures for Bone Marrow Failure Syndromes.

Maddie's Vision is a galvanising force with a relentless focus on advancing vital research into Bone Marrow Failure Syndromes (BMFS). No single research institute, university or laboratory in Australia is more invested in BMFS research.

Funds raised by our generous community of supporters are allocated by our Scientific Advisory Committee (an exceptional team of paediatric and adult haematologists and oncologists, immunologists, and scientists) to fund those research projects with the greatest potential to deliver improved treatments and cures for BMFS patients.

We partner with many of Australia's pre-eminent research institutions, and we direct our funding to the most promising research, no matter where it is happening.

Our virtual Centre of Research Excellence (CRE) in Bone Marrow Biology is the most effective and impactful model for achieving our mission. Comprising all current and previous researchers, the CRE is a uniquely coordinated and collaborative environment in which a growing cohort of national and international experts are amplifying and accelerating research outcomes.

The reason we operate this way? It means better answers for patients and their families, faster.

Our Strategic Priorities

Priority 1: funding and operation

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.

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Maddie's story

Maddie Riewoldt was just 26 years old when she 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. The purple used in our logo represents the humour and spirit with which Maddie fought. It was Maddie's favourite colour as it represents the cytotoxic waste containers for the agents that were used to treat her disease; it signified getting better. We are determined to find better treatments and cures, so please join us and together we will #FightlikeMaddie

What is Bone Marrow?

Bone marrow is a vital, complex organ; quite literally it's our factory for blood cells. Healthy bone marrow produces new blood cells every single day.

In bone marrow failure the bone marrow stops working, resulting in low blood cell counts and significant health impacts.

What are Bone Marrow Failure Syndromes?

Bone Marrow Failure Syndromes are rare, complex and highly debilitating. In simple terms, the 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. Sadly 50% of people diagnosed will die from the condition.

Approximately 160 Australians are diagnosed with BMFS each year. And distressingly, most of them are children and young adults. 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.

The only curative treatment is a bone marrow transplant which carries inherent risks and complications. Patients often endure multiple blood product transfusions and complex treatments with many side effects.



Chairperson's report

The past year has been one of significant change, challenge, and uncertainty for everyone. As we all continue to navigate this new reality, there have also been opportunities to reflect, learn and assess priorities.

With COVID locking many of us down for months on end, we've been unable to connect with you, our community, at the events which you have so generously supported. We have really missed you and can't wait to get together again!

Our founding CEO, Nicky Long, moved on. Big thanks to Nicky for her contribution over the last 5 years.

In February 2021, we were thrilled to have Elaine Montegriffo join as our new CEO. Elaine's passion and experience in the business and for purpose sectors have been critical in helping us to navigate the changing environment and develop new opportunities.

Thanks to the generosity of Dexus, we established new offices in Melbourne's CBD, and, for a short while, things were almost feeling normal!

Geoff Quirk, a passionate supporter of Maddie's Vision and long-serving member of our Board, moved on; a massive thanks to Geoff for his wisdom and support. We were delighted to welcome Michelle O'Brien who brings with her great financial and commercial experience and expertise.

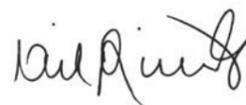
Despite the challenges, we have maintained our momentum with the support of the wonderful Maddie's Vision community – your passion and determination inspire us daily! Some of the highlights include:

- 6th Maddie's Match – Min Pulford announced launch of BioBank
- First ever RideforMaddie was a huge profile-raising success with the CBD turning purple
- Second National Symposium May 2021 – delivered as a fully virtual event with international speakers and 450 attendees
- Delivered two Patient and Family Fora the first in Aug 2020 and another in May 2021.

Looking ahead

We've achieved so much in just 6 years. I know Maddie would be very proud.

But discovering and delivering cures for BMFS will take time. I am excited by the opportunity we have to think about what the next 5 to 10 years will bring and how we can harness the incredible momentum we have generated.



Nicholas Riewoldt
Chair, Maddie Riewoldt's Vision



CEO's report

It's a such an honour and a privilege to have been so warmly welcomed into the amazing community that is Maddie's Vision. Thank you – this report is for you.

Joining in February 2021, it's been a challenge to meet as many of you as I would have liked 'in real life', but those of you I have connected with, albeit virtually, have so inspired and amazed me.

To the incredibly resilient young patients and their families whose determination to overcome the multiple challenges of their conditions and treatments, thank you for your bravery and generosity in sharing your stories – you provide such strength and hope to other families.

To the utterly mind-bogglingly brilliant researchers and clinicians, thank you for your commitment and determination to find those improved treatments and cures.

To our extraordinarily generous and creative supporters who have cut their hair, run marathons, held morning teas and mobilised friends and families to donate precious funds for the vital research that's needed, thank you.

To our wonderful corporate and business partners, thank you for your extraordinary support through fundraising events (yes there have been a couple this year!), sponsorships and pro bono services.

To the Victorian and federal governments, thank you for your insightful and invaluable support in funding vital research in an area of such great unmet need.

And last, but definitely not least, thank you to the wonderful Maddie's Vision team, our volunteers, our Scientific Advisory Committee, our CRE Executive and our Board for your dedication, passion, and support.

During this extraordinary year, that has seen fundraising events cancelled and much disruption and uncertainty, we've nevertheless been able to maintain our momentum:

- Revenue raised of over \$1.5 million
- Research grant funding provided of over \$1.5 million – an increase of 20% on the previous year
- Six new research projects approved with funding of \$1.8 million over the next 2-3 years, bringing our portfolio to a total of 26.

Looking forward, as Teddy Roosevelt said, "believe you can and you're halfway there". Reflecting on how much has been achieved in just 6 years, I cannot wait to see what we can do together next!

A key priority for FY2021/22 will be developing our long-term strategy, assessing strategic opportunities and priorities, and exploring how we galvanise even greater support and action to achieve our mission of discovering better treatments and cures for BMFS.

This is a powerful community driven by passion, love, energy, and commitment and, with your support, we will achieve our bold, ambitious vision so that no one has to go through what Maddie did, and Australians diagnosed with Bone Marrow Failure Syndromes get to live long, happy healthy lives.



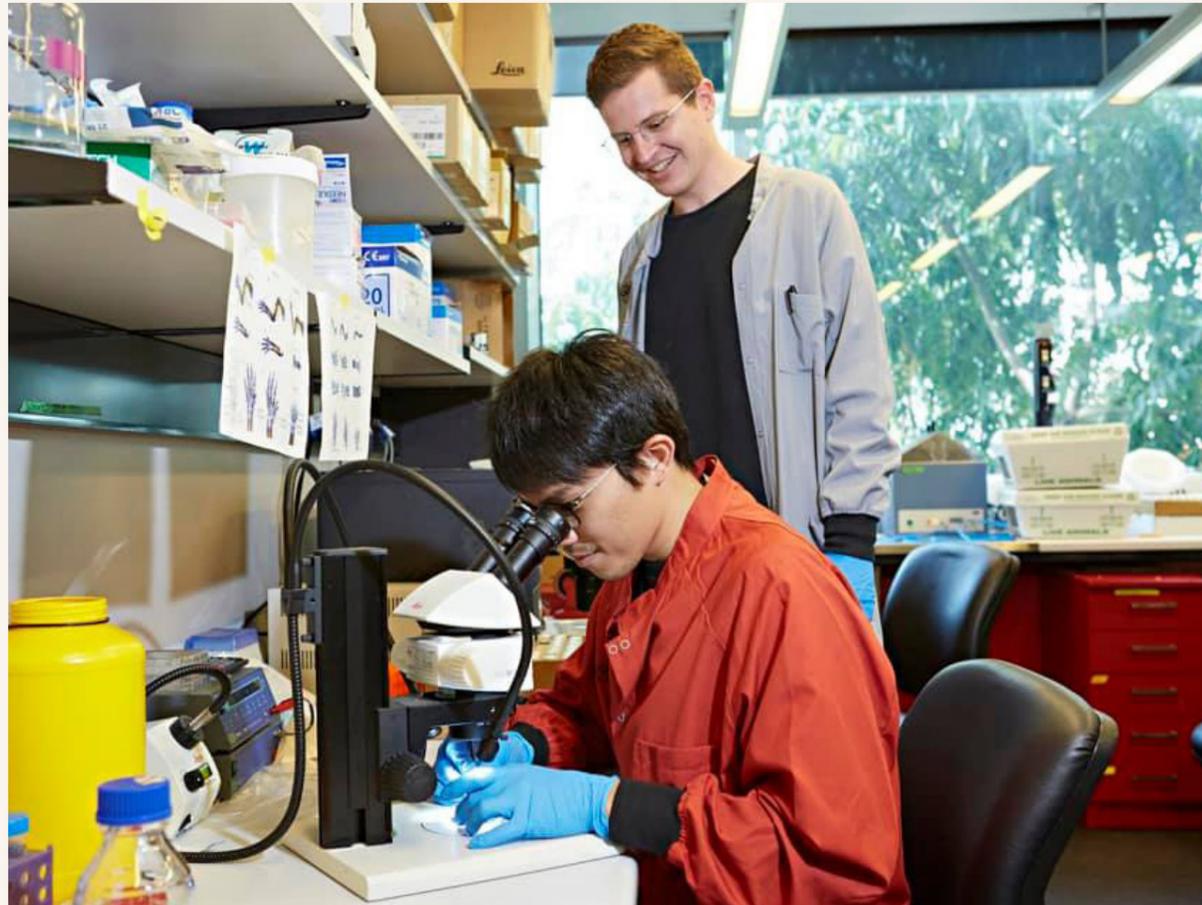
Elaine Montegriffo
CEO, Maddie Riewoldt's Vision



Celebrating our Research Community

Our 5 pillars of research:

1. Comprehensive clinical data and sample collection of current and newly diagnosed patients with BMFS
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



Expanding research

We exist to fund the research that will deliver improved treatments and cures for Australian BMFS patients.

Despite the practical challenges for our researchers to even get access to their labs, this year has been busy, rewarding and super productive; our 'engine room' of research brilliance has continued moving forward, momentum unabated!

We were thrilled to execute 6 new research agreements, bringing our research portfolio to a total of 26! They represent an investment of over \$1.8 million over the next 2-3 years.

- The Alex Gadomski PhD Scholarship in Medical Research, co-funded with the University of Tasmania, awarded to Ariel Simpson for her work in determining genetic and epigenetic drivers of gene expression changes in blood cells at the Menzies Institute for Medical Research, University of Tasmania.
- The RESELECT Trial Program Grant with Principal Investigator Professor David Ritchie at Melbourne Health. The trial will rescue bone marrow function in patients with relapsed Aplastic Anaemia and/or bone marrow failure post allogeneic stem cell transplantation.
- Grant in aid awarded to Dr Piers Blombery at the University of Melbourne, for his work using whole genome sequence analysis to find answers for unsolved cases of inherited bone marrow failure syndrome.
- Grant in aid awarded to Associate Professor Stephen Ting, Monash University, for the curation of the DIAAMOND-based Aplastic Anaemia Biobank.
- Bridging Fellowship awarded to Dr Lucy Fox at the Peter MacCallum Cancer Centre for her work on improving outcomes for Australian patients and families with bone marrow failure-related diseases through comprehensive clinical and genomic care and collaborative research.
- Extension of the Alex Gadomski Fellowship awarded to Dr Kirsten Fairfax at the Menzies Institute for Medical Research, University of Tasmania, for her work in determining genetic and epigenetic drivers of gene expression changes in blood cells.

These outstanding projects have the greatest potential to impact the achievement of our goals of discovering and delivering improved treatments and cures for patients diagnosed with BMFS.

So that nobody has to go through what Maddie did.

Director of CRE report

What inspires us? What motivates us? What moves us, drives us forward, give us courage to try new ideas and then gives us the ability to get up and try again even if we initially fail? The greatest abilities of humanity are those by which we can remember our past and simultaneously imagine the possibilities that our future may hold. In those twin abilities we draw on the inspiration from those who have come before and are motivated by our imagination of what might have been and what may still be possible.

In this annual report, you will read stories of those who have been deeply moved by both joyous and painful memories as they or their families took on the ravages of Bone Marrow Failure with grace and courage. You will also have the chance to read how, through medical research, we can imagine a better future for patients and families who are now affected by Bone Marrow Failure.

Embedded within imagination is the essence of hope. In this report you will find the incredible projects and the wonderful collaborations that have developed within the CRE that are recurrent examples of the realisation of that hope.

Through the CRE of Maddie's Vision we seek to achieve a cure for Bone Marrow Failure by being motivated by the memories of those who have been hurt or lost because of Bone Marrow Failure and inspired by the collective imagination of our wonderfully talented researchers.

The combined voices of patients and families, along with those of clinicians and scientists, represent the strength at the core of our CRE. This critical mix of lived experience and novel research has come together most tangibly in the CRE's inaugural 2020 Patient and Family Forum, and the 2021 edition of the national Scientific Symposium and Patient and Family Forum. This same combined voice is present in every thought and action as we collectively strive for a cure.

While the ongoing success of the CRE can undoubtedly be measured in our continued expansion to 26 research projects, the funding leveraged from support for Maddie's Vision that now totals \$7.4M, and the incredible research achievements and publication output of our CRE members, to me the success of the CRE lies in a collective memory that motivates us to undertake this critical research and a collective, shining imagination of what we can achieve together.



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



Brilliant minds and passionate hearts

We are truly grateful for the passion, expertise and dedication of the many highly talented people who are tirelessly working to help us realise Maddie's Vision of better treatments and ultimately cures for Bone Marrow Failure Syndromes.

Scientific Advisory Committee

Maddie Riewoldt's Vision is extraordinarily fortunate to benefit from the guidance, counsel and wisdom of our Scientific Advisory Committee (SAC).

The SAC willingly volunteers countless hours assessing and reviewing grant applications, monitoring active grants, and providing strategic and scientific direction to the CRE.

We give heartfelt thanks to retiring SAC members Professor David Haylock, Professor Steven Lane and Associate Professor Andrew (Andy) Moore for their important contributions. We also welcome our newest committee members, Professor Kanta Subbarao, Dr Pasquale (Paddy) Barbaro and Dr Andrea Henden who will continue the legacy of our retiring members.

Current SAC members: Professor David Ritchie (Chair), Professor David Haylock, Associate Professor Rachel Conyers, Professor Steven Lane, Associate Professor Ingrid Winkler, Associate Professor Andy Moore, Dr Duncan Purtill, Professor Kanta Subbarao, Dr Pasquale Barbaro and Dr Andrea Henden.

Current researchers in 2020/21

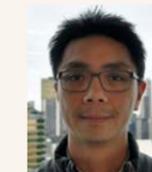
We are very fortunate to have an outstanding group of researchers who are putting their brains and hearts to work to help us realise Maddie's Vision of better treatments and ultimately cures for Bone Marrow Failure Syndromes. Meet the researchers working on projects we funded in 2020/21:



Professor Erica Wood – Aplastic Anaemia and other Bone Marrow Failure Syndromes Registry (AAR), Monash University



Dr Yih-Chih Chan – Genome editing of haematopoietic stem and progenitor cells to uncover novel therapeutics for Aplastic Anaemia and other Bone Marrow Failure Syndromes, the University of Melbourne Sir Peter MacCallum Department of Oncology



Dr Paul Yeh – Influences of clonal haematopoiesis in allogeneic bone marrow transplantation. Dr Paul Yeh and Professor Mark Dawson, the University of Melbourne



Dr Ameer George – Identifying therapeutics which can be repurposed for the treatment of Myelodysplastic Syndromes and other Bone Marrow Failure Disorders, the Australian National University



Professor Graham Lieschke – Discovering new genes and mutations that cause failure of bone marrow neutrophil production. Australian Regenerative Medicine Institute, Monash University



Professor Andrew Elefanty – Using induced pluripotent stem cells to find causes and cures for bone marrow failure in children and young adults, Murdoch Children's Research Institute



Dr Belinda Guo – Gunn Family Women in Haematology Fellowship, co-funded with Snowdome Foundation. Novel blood biomarkers for predicting bone marrow failure in myeloproliferative neoplasms, University of Western Australia



Dr Ashvind Prabakaran – International Travelling Fellowship, co-funded with the Victorian Cancer Agency. Novel immunological assessment of Aplastic Anaemia and post transplant Graft Dysfunction for the purposes of targeted therapeutic intervention, the Royal Melbourne Hospital/Melbourne Health



Dr Parvathy Venugopal – Modelling consequences of cell abundance, heterogeneity and origin for autologous cell therapy in genetic Bone Marrow Failure Syndromes, Centre for Cancer Biology, University of South Australia



Dr Piers Blombery and Dr Lucy Fox – the EMBRACE Trial Evaluating Multidisciplinary Bone Marrow Failure Syndrome Care – a prospective observational clinical trial offering comprehensive diagnostic genomic evaluation, multidisciplinary case review and multidisciplinary clinical care, the University of Melbourne



Professor Tracy Bryan – Establishing an in vivo humanised mouse model for telomere-related Bone Marrow Failure Syndromes, Children’s Medical Research Institute



Dr Rachel Koldej – Microenvironmental determinants of Aplastic Anaemia progression to MDS / AML, ACRF Translational Research Laboratory, Melbourne Health



Professor Melissa Southey – Australian Marrow Failure Biobank, Monash University



Professor David Ritchie – The RESELECT Trial – REscuing bone marrow function in patients with relapsed aplastic anaemia and/or bone marrow failure post allogeneic stem Cell Transplantation, Melbourne Health



Ariel Simpson – The Alex Gadomski PhD Scholarship in Medical Research, co-funded with the University of Tasmania. Determining genetic and epigenetic drivers of gene expression changes in blood cells, Menzies Institute for Medical Research



Associate Professor Stephen Ting – Curation of the DIAAMOND-based Aplastic Anaemia Biobank, Monash University



Dr Piers Blombery – Using whole genome sequence analysis to find answers for unsolved cases of inherited bone marrow failure syndrome, the University of Melbourne



Dr Lucy Fox – Improving outcomes for Australian patients and families with bone marrow failure-related diseases through comprehensive clinicogenomic care and collaborative research, Peter MacCallum Cancer Centre



Dr Kirsten Fairfax – The Alex Gadomski Fellowship – Determining genetic and epigenetic drivers of gene expression changes in blood, Menzies Institute for Medical Research and University of Tasmania.

Centre of Research Excellence in Bone Marrow Biology Executive

Our CRE Executive, comprised of the principal researchers of currently funded and completed projects, also volunteers its time and expertise.

This unique group provides a vibrant and fertile space, enabling conversations that would not otherwise occur to germinate and grow, catalysing collaboration and innovation across specialisations, ideas and projects.

The work of the CRE is wonderfully supported by Dr Simonne Neil and Lou Johns. Members are Professor David Ritchie (Chair), Dr Piers Blombery, Professor Tracy Bryan, Dr Yih-Chih Chan, Dr Lynette Chee, Associate Professor Wayne Crismani, Professor Andrew Elefanty, Dr Kirsten Fairfax, Dr Lucy Fox, Dr Ameer George, Dr Belinda Guo, Dr Rachel Koldej, Professor Graham Lieschke, Dr Ashvind Prabakaran, Ariel Simpson, Professor Melissa Southey, Associate Professor Stephen Ting, Dr Parvathy Venugopal, Professor Erica Wood and Dr Paul Yeh.



Gene and Cellular Therapy Subcommittee

Our Gene and Cellular Therapy Subcommittee, chaired by Associate Professor Wayne Crismani, is focused on opening the very first Australian site for an inherited BMFS Gene Therapy Clinical Trial. With two working groups, 1) the Basic Science/Novel Therapies working group and 2) the Clinical Trials working group, we are simultaneously progressing development of local vector delivery and trial protocol and fast-tracking opportunities to import an existing international clinical trial protocol.

The support of Professor David Williams as our expert advisor from the Boston Children’s Hospital brings vital gene therapy clinical trial experience and builds on international collaborative opportunities. The group is supported by Dr Simonne Neil and Lou Johns. Members are Associate Professor Wayne Crismani (Chair), Professor David Ritchie, Professor Tracy Bryan, Dr Theresa Cole, Associate Professor Rachel Conyers, Associate Professor Andrew Deans, Professor Andrew Elefanty, Dr Kirsten Fairfax, Dr Lucy Fox, Dr Rachel Koldej, Professor Graham Lieschke, Associate Professor Leszek Lisowski, Dr Parvathy Venugopal and Dr Reshma Shakya.

Researcher spotlight – Dr Piers Blombery

The rarity and complexity of BMFS, which can be acquired or inherited, often means that patients and their families have to engage upon a challenging odyssey, searching for a diagnosis of their condition and an understanding of potential risks for other family members.

Dr Piers Blombery, the lead of the Molecular Haematology Laboratory at Peter MacCallum Cancer Hospital, is determined to alleviate this by solving ‘missing heritability’, a term that describes an inability to find the genetic variations that cause disease.

Dr Blombery explains “We are a translational genomics laboratory — we use new technologies to detect alterations in patients’ DNA and RNA that may provide further insight into their condition.”

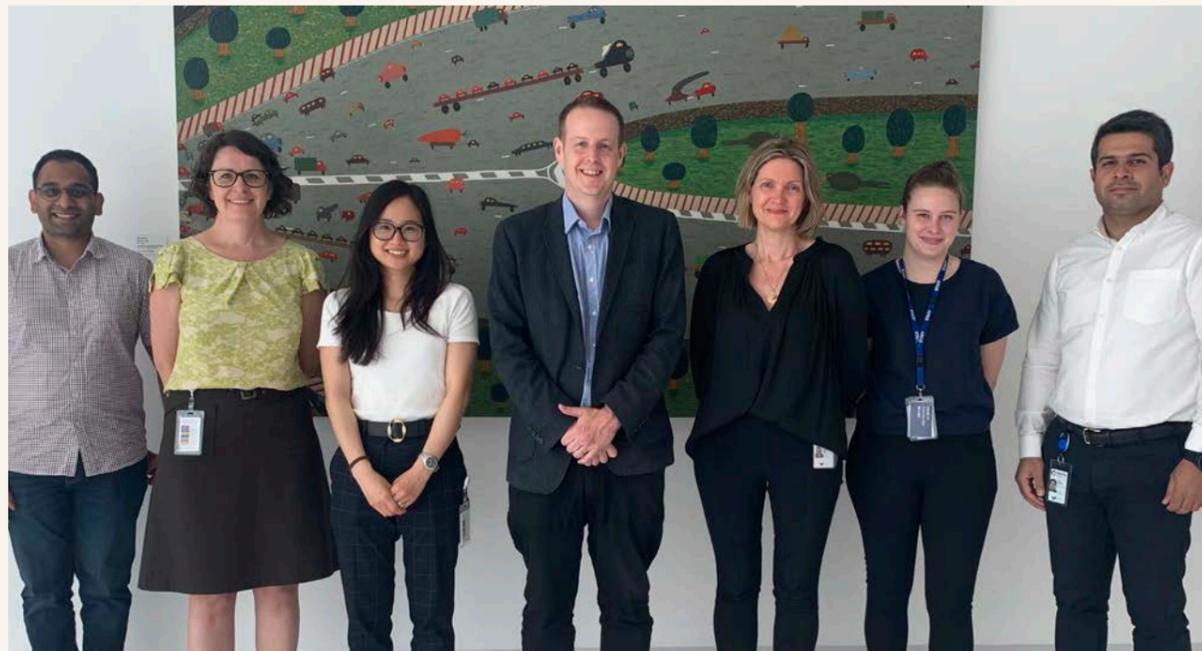
Dr Blombery’s research is using whole genome sequence analysis to find answers for unsolved cases of inherited Bone Marrow Failure Syndromes. His detective work is providing definitive molecular diagnoses for patients who have many features of an inherited BMFS, yet have lived for months, years and even decades without precise diagnosis of the exact genetic variation causing their disease.

There are immense clinical benefits in solving ‘missing heritability’, including ensuring optimal treatment is administered, providing comprehensive understanding of the prognosis of the condition, facilitating testing of family members to detect occult (hidden) disease, facilitating IVF preimplantation genetic diagnosis to prevent passing on the mutation to subsequent generations, and screening potential bone marrow donors for occult disease or carrier status.

The team on this project, comprising Dr Lucy Fox, Dr Pasquale Barbaro, Professor Zornita Stark and Dr Meaghan Wall in collaboration with the Victorian Clinical Genetics Services, is conducting intricate analyses of multiple samples from both the enrolled patient and the patient’s parents, known as a trio analysis.

The project is already delivering results, solving cases by identifying responsible variants in MECOM, MBD4 and RBM8A genes. This has provided direct benefit to Australian patients, in some cases ending a ‘diagnostic odyssey’ that has stretched over decades.

We are thrilled to support Dr Blombery’s project – it is delivering immediate and impactful improvements to the lives of Australians with inherited BMFS.



Left to right: Shравan Yellenki, Dr Nicole den Elzen, Dr Kelsey Man, Dr Piers Blombery, Dr Lucy Fox, Laura Barth, Dr Vahid Pazhakh

National Symposium on Bone Marrow Failure Syndromes

We were thrilled to host the second National Symposium on Bone Marrow Failure Syndromes in May 2021. This event was held entirely virtually with over 430 delegates, including a significant international cohort with clinicians, clinician/scientists, patients and families, allied health professionals and pharmaceutical, hospital and research institution representatives.

We are incredibly appreciative of Mr Frank McGuire, Parliamentary Secretary for Medical Research, attending and officially opening the Scientific Symposium. We featured over 30 local scientific, clinical, allied health and patient speakers and 4 exceptional international guest speakers:



Professor Neal Young Chief, Haematology Branch, National Heart, Blood and Lung Institute, National Institutes of Health (NIH), Bethesda Maryland



Professor Alison Bertuch Department of Paediatrics, Haematology/Oncology Section, Department of Molecular & Human Genetics, Huffington Centre on Aging and Director, Bone Marrow Failure Program, Texas Children’s Cancer and Haematology Centres, Texas Children’s Hospital



Dr Paula Rio Principal Investigator in the Hematopoietic Innovative Therapies Division at CIEMAT/CIBERER/ IIS-FJD, Madrid Spain



Professor Ketan Patel Director MRC Weatherall Institute of Molecular Medicine and MRC Molecular Haematology Unit, University of Oxford.

Huge thanks to all our generous sponsors, including our Platinum sponsor Alexion, Gold sponsors AstraZeneca, MSD and The Royal Melbourne Hospital Foundation.

And a massive thank you to our fabulous Symposium Steering Committee, chaired by the exceptional Dr Lucy Fox, and comprising Professor David Ritchie, Professor Tracy Bryan, Associate Professor Wayne Crismani, Dr Pasquale Barbaro, Dr Anthea Greenway, Dr Piers Blombery, Ms Karen Savage (patient representative/advocate), Mei Ling Yeh, Lou Johns, Dr Simonne Neil and Elaine Montegriffo.

“It’s heartening to know that research into rare bone marrow diseases is taking place. It gives hope to us and to future people suffering similar conditions. Well done to everyone involved in the presentation and research, I’m very grateful.” — BMFS patient’s family



Patient and Family Forum

We were more than delighted to host two Patient and Family forums this year. The Maddie's Vision Inaugural Patient and Family Forum took place on 28 August 2020, attended by over 200 registrants. The forum was a pivotal moment, being the first time a space had been created for our patient and family community to come together with researchers, clinicians, and allied health professionals.

Expertly hosted by Professor David Ritchie, the aim of the forum was to bring people with lived experience of BMFS together with clinicians and experts to increase two-way understanding, explore improvements to patient outcomes, and provide information from clinicians and scientists at the forefront of Bone Marrow Failure Syndrome clinical care and research.

Our second Patient and Family Forum was a virtual event held in May 2021, coinciding with our National Symposium.

We are tremendously grateful to our exceptional panellists, and to the families and patients who so generously shared their experiences.

"I just wanted to pass on my sincere thanks to all involved. It really feels like such a lonely road at times, and it was so nice to hear the advances and hope for the future. MRV are really making a difference and we are really grateful!" — parent of patient

"A great session. From a clinician's perspective, we are not always afforded the time to hear the patient's complete journey. The opportunity to hear the patients' stories in the forum was very special." — clinical haematologist

Enormous appreciation goes to our sponsors, The Royal Melbourne Hospital Foundation and Carman's.

Many thanks to the organising subcommittee, expertly chaired by Dr Lucy Fox, and including Mei Ling Yeh, Dr Jessica Lake, Anna Jarmolowicz, Lou Johns, Nicky Long and Dr Simonne Neil.

Carman's
Real food made with real passion.

Our champions

Bone Marrow Failure Syndromes are complex and debilitating, with current treatments often requiring intricate management of multiple side effects. Distressingly, most of the 160 Australians diagnosed with BMFS each year are children and young adults.

Every single day we are inspired by the bravery and resilience of awesome young Australians and their families who are battling BMFS. We'd like you to meet some of the incredible young people you are helping us to support. This is who we are all fighting for!

Ariana

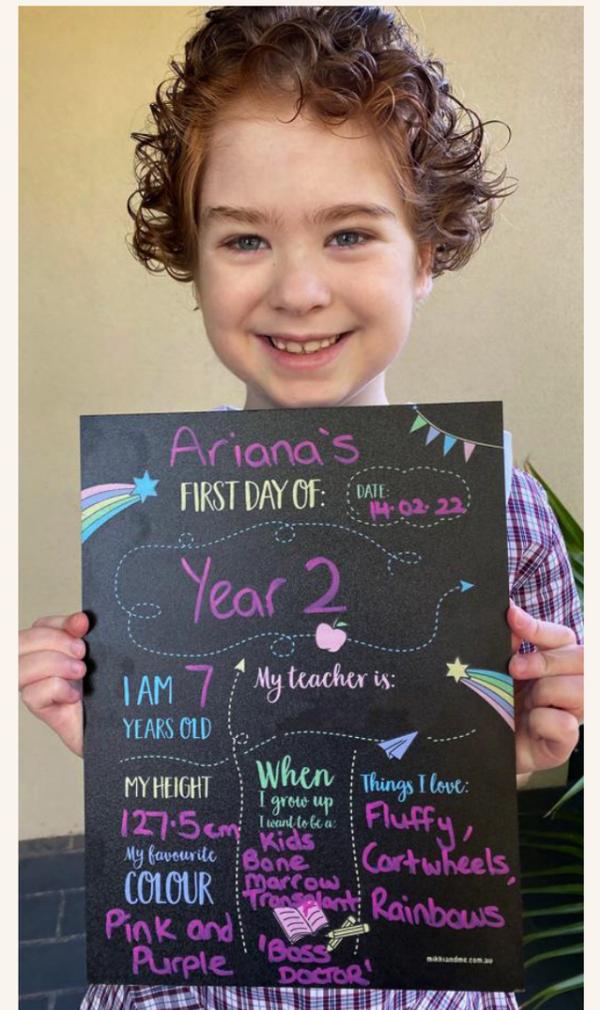
Ariana was first diagnosed with Aplastic Anaemia in 2020, aged 6. Within a couple of months, she was relying on weekly blood transfusions and three platelet transfusions a day. In March 2021, she underwent a matched sibling bone marrow transplant.

While her family is grateful and relieved her bone marrow is now "100% donor", it's been an incredibly tough road, with Ariana suffering multiple life-threatening complications after her transplant. Now she is growing stronger every day and has finally been medically cleared to return home after nearly a year away.

While bone marrow transplants can be lifesaving, people like Ariana need less risky, alternative treatment options. That is the promise research offers.

My wish for the future, says her mum Bec, is that "a predisposition to Bone Marrow Failure Syndromes can be identified, and early treatment given to prevent the need for invasive and risky curative treatments such as a bone marrow transplant.

On a personal level, I wish for Ariana to reach and retain full health and be able to live out her childhood with no limitations."





Matty

11-year-old Matty tossed the coin at Maddie's Match in 2021 and quickly became a crowd favourite!

Born with Fanconi Anaemia, an inherited Bone Marrow Failure Syndrome, Matt had a very stressful start to life.

At the time there was "very limited information" about his condition, says his grandmother Cheryl.

Now, with research firing up in Australia, Cheryl is hopeful that "one day they'll find a magic cure."

It's a vision that seems more real every year.

"It's fantastic" what the Riewoldt family have started, she says.

"We spend quite a bit of time over at St Vincent's in Melbourne. We've been through the labs and had a look at everything over there. It's just phenomenal to watch those very keen minds trying to find a cure."



Seth

9-year-old Seth has Aplastic Anaemia. It's been a whirlwind, anxiety-filled couple of years for his family since his diagnosis.

Seth was first taken to hospital on New Year's Day in 2020 after his mum Jess became worried by his constant nose bleeds and unusual bruising. By mid-January, he'd been diagnosed and in February, his treatment started.

Now – after immunosuppressive therapy, many transfusions, and multiple trips to Melbourne from Tassie – his most recent tests thankfully showed all blood cell counts were stable.

Mum, Jess, is passionate about the need for more medical research. Having a child diagnosed with any medical condition is scary, says Jess, "but having a child diagnosed with such a rare condition is terrifying.

Although we're told that chances of Seth relapsing are slim," she says, "the chance is still always there. The more research that can be done, the better our doctors will be able to help Seth should we have to go down that road again."

Telehealth Consultation Service



Our Telehealth Nurse Consultation service was established in 2019 as part of the Patient Pathways Program, funded by the Australian Department of Health and coordinated by the Centre for Community-Driven Research.

Our telehealth nurse, the wonderfully warm and caring Mei Ling Yeh, also works as a clinical nurse specialist in paediatric haematology/oncology at the Royal Children's Hospital.

We are supporting over 60 patients and their families nationwide, and we currently operate for 2 days a week, with plans to expand to meet the growing demand.

With no established care pathway for BMFS patients, Mei Ling plays a vital role in providing an accessible, highly qualified single point of contact for families and access to practical advice, information and resources to help navigate diagnosis, disease management, treatments and side effects.

Mei Ling fills a critical gap by connecting patients, support groups and medical specialists to improve support for patients and families grappling with the complexities of BMFS.

Mei Ling reflects, "I started 2 weeks prior to the turbulence of COVID impacting Melbourne – a time of immense uncertainty. However, the unpredictability and isolation that overtook our world is a challenge our patients and families experience on a day-to-day basis; it is considered their 'normal life'."

Mei Ling is immensely passionate about her role. "Every single phone call and conversation I have is significant. I am very blessed and so very appreciative to be confidentially trusted. I am touched and moved by the loving stories I hear and the vulnerability I witness. I have been inspired and moved by the emotion expressed by parents, family members and carers as they remain courageous and steadfast in supporting their loved one's struggles. I am determined in my role to be there, to walk the journey with patients and families step by step. I do hope, for the patients and families who have accessed the service, they no longer feel completely alone."

To contact Mei Ling, please email telenurse@mrv.org.au or call 0477 884 955.

Celebrating our Partners and Community

Thank you to all our generous supporters! We simply cannot do it without you!

To all of our generous supporters we want to celebrate you all being part of the Maddie Riewoldt's Vision family.

We are so grateful that you have chosen to join us. If you held a fundraiser through Facebook or your school or donated through one, donated through the website, bought merchandise, donated through Maddie's Match, #RideforMaddie, Bloody Long Run or Jane's Match then you have joined our community. Thank you from the bottom of our hearts for all of your support.

Alex Gadomski Fellowship

Alex was only 21 when he lost his brave battle with Aplastic Anaemia. Since then, his family has worked tirelessly to raise funds and awareness of BMFS, with the support of the Tasmanian community, including the stellar Live Life Gala Ball. The funds raised support the Alex Gadomski Fellowship which, in conjunction with Maddie Riewoldt's Vision, is a Tasmanian research fellowship focused on finding better treatments and cures for BMFS.

While they couldn't hold their main event, the Live Life Gala Ball, this financial year, the amazing Gadomski family nevertheless raised \$96,000 through The Bloody Long Run, the Gadomski/Riewoldt Cup and other fundraising events. A huge thank you goes out to Janet, Paul, Lachlan and Jordan Gadomski for their boundless energy and determination, and to the whole Tasmanian community for assisting us with funding vital BMFS research at the Menzies in Tasmania.

The Gadomski/Riewoldt Match September 2020

The annual Gadomski/Riewoldt Match and lunch was held in September 2020 at the Twin Ovals between Kingborough Tigers and Clarence Football clubs to honour the life of Alex Gadomski. The Tigers took the trophy away this year, with courage medals awarded to Elijah Reardon (Tigers) and Ollie Davis (Clarence). A big thankyou to all who supported the day.



IGA Tasmania are ongoing supporters of the Alex Gadomski Fellowship and Live Life Gala Ball. They generously donated \$20,000 even though the ball was not held – what champions! Your ongoing support is making such a difference to so many people.

Bloody Long Run July 2020

Starting at the Eddystone Point Lighthouse at sunrise, eight young men began a 3-day, 300-kilometre run to the Menzies Centre in Hobart. With courage, determination, some sweat and tears, all 8 successfully completed the run, raising vital funds for BMFS research.

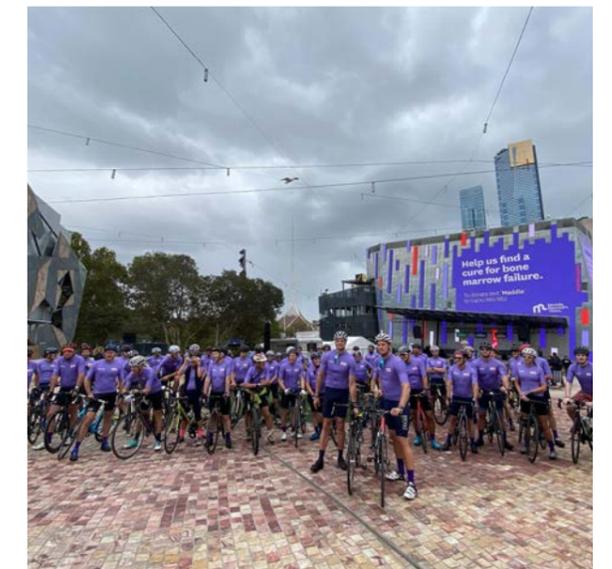


Alex's brothers Lachlan and Jordan and friends

Ride for Maddie - 15 April 2021

After being cancelled last year due to restrictions, and squeezed in between this year's lockdowns, we were so excited to finally hold the inaugural Ride for Maddie in April 2021. Over 50 enthusiastic cyclists donned the purple lycra at RSEA Stadium to ride from Moorabbin to the Melbourne CBD, visiting Federation Square and lapping Marvel Stadium!

Huge thanks to our ride sponsors Adventure Abroad, Coles, Mercedes Benz Brighton, Pedla and RSEA, St Kilda Football Club and Remedy without whom we could not have made such a wonderful event possible. Huge thanks also to Mike Tarr and Maurizio Vasile and team for all the amazing photography and videos.



We are bringing this fabulous ride to you with the generous support of these lovely people.



Maddie's Match #6 – 15 April 2021

Marvel Stadium again turned purple for the 6th celebration of Maddie's Match between AFL greats St Kilda and Richmond. Supported by our awesome community partners St Kilda Football Club, we were excited to be able to host a box for patients and their families to enjoy the match thanks to Marvel Stadium. Our man of the match was undoubtedly the awesome Matty Young who flew over from Tasmania with his grandmother Cheryl and did a fabulous job of tossing the coin to start the match.

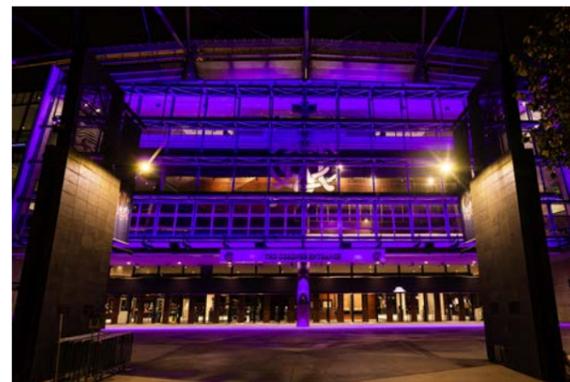
We were delighted to host the Honourable Jaala Pulford, Minister for Employment, Innovation, Medical Research and the Digital Economy to announce the launch of the Australian Marrow Failure Biobank, made possible with the generous support of the Victorian government, and in partnership with Biobanking Victoria. The Biobank will supercharge our research efforts by collecting and storing tissue samples from across Australia for use by researchers in developing new treatments and cures for BMFS.

Marvel Stadium was not the only landmark to turn purple this year! City of Melbourne landmarks including the MCG, AAMI Park, Federation Square, Flinders Street Station, 101 Collins Street, Rod Laver Arena, Spencer Street Station and Spencer Street Outlet all turned bright purple for the night to raise awareness of BMFS.



The success of the Ride and the Match reflects the incredibly generous support of so many and we want to thank you all!

St Kilda Football Club especially the Maddie's Match planning committee: (Calzak Bowen, Mim Waterman, Aisling McCarthy, Bridie Murphy, Bryce Shilton, Chelsea Frawley, Maddi Clarke, Stefan Valerio and Tom Allright, Clair White). Crown Casino for function catering, Holly Hauenstein, Jo Juler, QMS Media for their great billboards, Quest Apartments for accommodating our patient and family, Maurizio Vasile, Mike Tarr, our wonderful team of loyal volunteers, Alysha Crawford, Andrea Owen, Brooke Thomas, Brooke Sinnett, Cat Chinery, Catherine Allen, Chloe Sinnett, Danelle Greenwood, Danny Allen, Donna Chalmers, Jane Cowan, James Lynch, Jasmine Allen, Karen Savage, Kyle Davey, Lynne Williams, Michelle Evans, Paul Owen, Rhonda Myers, Tash Allan, Shannon Slade, Robyn Wootton. The generous sponsors of the Maddie's Challenges, Dare, Pepper Money and RSEA. Finally, to all the wonderful businesses and landmarks that lit up the CBD in purple we thank you for becoming part of the Maddie's Vision family and showing your support.



Maddie's Month # 5 - November 2020

For the fifth year our long-term, very generous partners at Flavorite raised \$100,000 during the month of November – Maddie's Month – through the sale of their yummy glasshouse-grown cherry tomatoes and capsicums at Coles Supermarkets. The strong family connection between Flavorite and Maddie's Vision is at the heart of this special partnership: Flavorite co-founder Mark Millis lost his battle with blood cancer in 2019, and the family is passionate about supporting medical research to improve patient outcomes.

To date, Flavorite has contributed \$500,000 to support Maddie's vision of finding better treatments and cures for BMFS. Heartfelt thanks go to the wonderful team at Flavorite, Chris Millis, Tom Millis, Rruta Narula and Sam Kisvarda.

We are also so grateful to the whole team at Coles that helped to pull Maddie's Month together and make it a successful month.

Maddie's Month Ambassadors: Alice Zalasky, Dee Dee Dunleavy, Emma Inglis, George Calombaris, Laura Henshaw, Megan Huthwaite, Steph Clair Smith and media sponsors NOVA, FOX FM, SMOOTH FM.



Jane's Match # 3 - June 2021

On the 26 June 2021, the St Bede's Mentone Tigers, led by Jane's Army, held the 3rd annual Jane's Match, raising funds in memory of the beautiful Jane Barnes. The hardworking women of SBMT led by Jude Barnes and Jasmine Meehan put together an incredible "Sold Out" pre-match luncheon along with a huge afternoon tea. Guest speaker Brendan Fevola (Maddie's Vision ambassador) created many laughs with stories of his antics in football. The community of SBMT rallied around and raised over \$21,000. Thank you also to the Marine Hotel for holding the after-match function and continuing with the fundraising.





We celebrate our joint fellowship with the Snowdome Foundation. Through the generosity of the Rae and Peter Gunn Family Foundation we continue to support Dr Belinda Guo in the Gunn Family Fellowship – Women in Haematology and her research into “Novel Blood Biomarkers for predicting Bone Marrow Failure in Myeloproliferative Neoplasms”.



For the 4th year in a row, we celebrate the Fox Family Foundation and their support of projects such as “Evaluating Multidisciplinary Bone Marrow Failure Care (EMBRACE) trial in Bone Marrow Failure and Related Disorders” project and the Australian Marrow Failure Biobank launched in April 2021.



Our Telehealth Nurse Consultation service was established in 2019 as part of the Patient Pathways Program, funded by the Australian Department of Health and coordinated by the Centre for Community-Driven Research.



The Victorian Government, through the DJPR, demonstrated immense foresight by funding the establishment of our Centre of Research Excellence (CRE) – an Australian first. The CRE has propelled our research activity from 8 to 29 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 BMFS research outcomes. By partnering with key medical research institutions, we have ignited national and international research initiatives, elevating Victoria’s profile.



We are deeply appreciative of the federal Department of Health’s award of a Medical Research Future Fund grant of \$1,020,000 in 2020, which enabled us to establish an interventional clinical trial for high-risk Bone Marrow Failure Syndrome (BMFS) patients. The RESELECT Trial – REScuing bone marrow function in patients with relapsed acquired Aplastic Anaemia and/or bone marrow failure post aLlogeneic stEm Cell Transplantation – is a long-term project, increasing vital clinical trial capacity building in Australia.

The RESELECT Trial is a multi-site, multi-state and international clinical trials network that will provide patients access to novel therapies and develop a platform for the delivery of innovative treatments, including cutting edge cellular and gene therapies. Maddie’s Vision is the only charity funding clinical trials for Australians with acquired and inherited BMFS.

Thank you to our pro bono partners

A massive thankyou to all our pro bono partners! Your incredibly valuable ongoing support enables us to use more of our precious funds on the vital research that’s needed to find better treatments and cures for BMFS.

In this way, every year you help us make a real difference to the lives of people diagnosed with BMFS.



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 all our financial reporting obligations.

SBA LAW

Richard Moshinsky and Eleanor Weir, we would be lost without all your tireless support in drafting and reviewing the research agreements with our growing numbers of research institute partners.



A massive thankyou 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.



Carman’s generously donated office space for 2 years, and they have patiently continued to store many items for us – we will be rehousing them soon!

TOWN SQUARE

Big thanks to Danielle Moeller, Carly Duckworth and the incredible team at Town Square. Your ongoing creative support of the Bloody Good Dinner is invaluable – and we’re so excited to see it brought to life in 2022!

dexus

We found a fabulous new home with the help of the wonderful Dr Lucy Fox and the generous team at Dexus. We’re delighted to have pro bono office space at 60 Collins Street, Melbourne. Finding a place for the team to work together has been critically important during a year of so much change – not least because it meant new CEO Elaine got to meet with everyone face to face! We are incredibly appreciative to have such fabulous office space in the heart of Melbourne’s CBD and hope that, COVID permitting, it will enable us to connect with you all, our supporters and partners more easily.



Huge thanks to the team at DLA Piper for their advice and support throughout the year on our legal matters. You have been incredibly valuable.

Financial Results to 30 June 2021

The challenging and uncertain conditions resulting from ongoing lockdowns and restrictions since early 2020 prevented many of our fundraising events from taking place this year. However, we have taken this opportunity to explore and develop alternative channels and new ways in which our supporters can engage with us. This, together with government pandemic support, helped sustain revenue during 2020/21.

- While revenue decreased by 30%, we maintained our commitment to funding research and awarded grants of over \$1.5 million, an increase of almost 20% on the previous year.
- Operating expenditure remained stable, with increased CRE costs reflecting the biennial Scientific Symposium.
- The net result for the year, a deficit of \$568,296, was largely due to an accounting adjustment requiring revenue of \$371,329 to be recognised post 30 June 2021. This was due to an extension of the activity period of a federal government grant due to delays caused by COVID-19. The net operating position, absent this adjustment, was a deficit of \$196,967.

- All performance measures were met as follows:
 - revenue of \$1.5 million
 - operational expenses no greater than 20%
 - twice yearly funding commitment for two grant in aid research projects and two research fellowships
- Net equity of \$2,396,181 represents a reduction of under 10%, reflecting a sound and sustainable operating model.

Statement of Surplus or Deficit and Other Comprehensive Income for the year ended 30 June 2021

		30 June 2021	30 June 2020
		\$	\$
Revenue	4(a)	1,436,908	2,063,738
Other income	4(b)	127,643	64,011
		1,564,551	2,127,749
Research grant expenses		1,571,041	1,319,402
Centre of Research Excellence costs		72,043	24,055
Employee expenses – research		120,299	130,464
Employee expenses – administration		259,554	269,128
Fundraising costs		4,623	8,921
Merchandise costs		10,394	12,246
Other expenses		94,893	115,243
Total Expenses		2,132,847	1,879,459
(Deficit)/Surplus before tax		(568,296)	248,290
Income tax expense		–	–
(Deficit)/Surplus		(568,296)	248,290

Celebrating our 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). See [here](#) for details.

Nick Riewoldt
Chair

Professor David Ritchie
Director CRE in Bone Marrow Biology and Chair Scientific Advisory Committee

Jack Riewoldt
Director

Geoff Quirk
Director to May 2021

Kieran O'Brien
Director

Amanda Stevens
Director

Edward Kemp
Director

Michelle O'Brien
Director wef May 2021, Chair FAR committee

Elaine Montegriffo
CEO

Maggie Lynch
Senior Executive Administrator

Annabel Banks
Ambassador Liaison to Dec 2020

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

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

Mei Ling Yeh
Telehealth Nurse

Jane Nethercote
Marketing & Comms Manager



Left to right: Mei Ling Yeh, Maggie Lynch, Elaine Montegriffo, Simonne Neil, Lou Johns



How you can help

It's only with your generous support, our amazing Maddie's Vision community, that we have been able to achieve so much. We look forward to connecting and working with you all in the coming year to make even greater progress on achieving our vision, so that all Australians diagnosed with BMFS get to live long, happy, healthy lives.

Become a Maddie's Vision regular supporter

Regular giving is an incredibly valuable way of providing ongoing support for Maddie's Vision. While we have achieved much in 6 years 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. More research means answers, faster.

[Become a regular donor here.](#)

Hold an event

Whether you're a club, a business, a school or a family, if you'd like to host an event to benefit Maddie's Vision, that would be fabulous! It could be anything from a morning tea, a stroll around the park with friends, or hosting a brekkie to mullet making or a marathon! If you'd like to create your own personal fundraiser, it's quick and easy to set up a page on our website: [find out about fundraising here.](#)

We love seeing how our community mobilises friends and family to join in the action!

Birthday

Why not run a Birthday Fundraiser this year? It's easy to set up on Facebook if that's where you hang out.

[Check out how to set up here.](#)

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. [Set up an In memory page here.](#) You can also make a one-off in memory donation.

Schools

We have been fortunate to have many local schools fundraise for Maddie's Vision with their social service days. If you're looking for ideas, we have a few to get you started ...and we'd love to hear yours!

[To get your school involved go here.](#)

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's Vision – ask your employer about workplace giving! [Find out about Good2Give's Workplace Giving platform here.](#)

We'd love to hear what other ideas you have, and how we can help, so please call Maggie during office hours on 0477 003 940.

Shop at our store

Maddie's Vision Beanies launched this year ...with our community helping choose the design!

[Shop at our store here](#)





Maddie Riewoldt's Vision

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